

# **HEALTH CARE WITH LIMITED RESOURCES: ETHICS, EPIDEMIOLOGY AND PUBLIC POLICY**

A thesis submitted for the degree of Doctor of Philosophy  
at the Australian National University.

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This thesis is solely the work of its author. No part of it has been submitted for any degree or is currently being submitted for any other degree. To the best of my knowledge, any help received in preparing this thesis, and all sources used, have been duly acknowledged.

*Susan Penning*

*For my parents*

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## Abstract

All modern societies have a shortage of health care resources, which means that we need to have principles to allocate health care resources fairly when not everyone's needs can be met. In this thesis, I argue that health care prioritisation decisions should be largely made on the basis of two factors: to what extent is health care likely to improve a patient's subjective well-being, and to what extent is health care likely to improve a patient's morally relevant capabilities. I argue for my view through critically engaging with alternative theories about how to allocate health care resources fairly in conditions of scarcity.

In Part 1 of this thesis, I consider luck egalitarian principles, which, as I describe in Chapter 1, provide a philosophically nuanced formulation of responsibility-sensitive principles for the allocation of health care resources. Many luck egalitarians argue that those patients who deliberately engage in reasonably avoidable, health-damaging behaviours (such as smoking) should receive lower priority for scarce health care resources than those who do not engage in these behaviours. I reject this view, arguing in Chapter 2 that luck egalitarian principles are too harsh to be a plausible moral way of regulating health care resources. In Chapter 3, I argue that to the extent that luck egalitarian principles are intended to be used in public policy as a way of regulating health care resources, they should be rejected as they would be impractical to implement.

In Part 2 of this thesis, I consider other principles (which do not make use of individual responsibility for health behaviours as a rationing criterion) for allocating health care resources fairly in conditions of scarcity. In Chapter 4, I reject the view that health care rationing should be primarily determined by market forces, as due to the structural features of health insurance and health care, health care rationing requires some level of government intervention. In Chapter 5, I explain the problems with two metrics, Disability Adjusted Life Years (DALYs) and Quality Adjusted Life Years (QALYs) arguing that they are problematic because they conflate two questions which should often be considered separately: how to evaluate interventions which improve people's quality of life, and how to evaluate interventions which extend people's lifespan.

In the final two chapters of this thesis, I argue for my own view of how to fairly allocate health care resources in conditions of scarcity. In Chapter 6, I argue that much of what makes health care morally valuable is the effect that it can have on improving people's capabilities, however, focusing on improving morally valuable capabilities alone cannot provide a *full* account of how we can make fair health care allocation decisions. This is because capability-based accounts focus on objectively

measurable effects of health care, but many effects of health care, such as relieving chronic pain have an inherently subjective component. Thus, these theories do not provide plausible priority to caring for the needs of those in chronic pain and the terminally ill. In Chapter 7, I argue for the importance of including measures of subjective well-being, in addition to capabilities, in considering which health care interventions to prioritise in situations of scarce resources.

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## Introduction

1. The problem of scarcity and rationing in health care
2. Philosophical approaches to medical resource scarcity
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### 1. The problem of scarcity and rationing in health care

Imagine that you start to feel an uncomfortable pressure on the centre of your chest. You think that it's nothing, that it will go away, but instead it gets worse. It feels like a rope tied around your chest, squeezing tightly. You notice that you are also short of breath – you are puffing as though you had just run a marathon, though in fact you have been sitting down. While considering what you should do, you also start to feel nauseous and lightheaded. As these symptoms continue and worsen, you become concerned that this may be something serious. You get a friend to drive you to the nearest hospital. As you and your friend walk into the emergency room, people are sitting on every chair waiting for treatment, sitting on the floor, lying on the floor, sitting propped up against the wall. You go to the nurses' station to tell them about your symptoms. A doctor bursts out into the waiting room and says to you 'I'm really sorry, we can't treat you, we don't have the resources, we don't have the staff. We can't treat most of the people waiting here, we're overwhelmed.' You begin to protest, but it's clear that they're serious and they're not going to treat you here. You and your friend walk out of the waiting room, and as you breathe in the cold morning air, you collapse with a heart attack.<sup>1</sup>

While this may be a particularly dramatic example, scarcity is an omnipresent problem in the provision of health care. Every society and every health care system needs to cope with shortages of resources and must constantly make decisions about which patients will receive care, and which patients will miss out. Scarcity refers to the gap between the demand for health care and the supply of health care. To put it more precisely, it is the shortfall between the demand for treatments that patients expect to be of net benefit<sup>2</sup> to them, and the supply of resources<sup>3</sup> which are available to

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<sup>1</sup> These symptoms are taken from the American Heart Association's guide to heart attack symptoms in women. 1. American Heart Association. Heart Attack Symptoms in Women. 2015. <<https://www.heart.org/en/health-topics/heart-attack/warning-signs-of-a-heart-attack/heart-attack-symptoms-in-women>> (accessed 1 Jul 2019).

<sup>2</sup> By net benefit, I mean that the expected benefits of the treatment are considered by the patient to outweigh any negative side effects.

<sup>3</sup> Resources in this context includes money, physical resources such as transplantable organs, and the opportunity cost of time spent on health care.

meet these demands.<sup>2</sup> Scarcity in health care would not exist if everyone believed that there were no treatments available for health problems of net benefit for the patient, or if the universal reaction to health problems was to simply accept them, without looking for treatments. In these cases, there would be no scarcity in health care because there was no demand for health care. Likewise, scarcity in health care would not exist if resources were limitless, such that all people were supplied with every treatment that they believed to have even a small net expected benefit to them. In this case, the supply of health care resources would always be able to meet demand. The contrast between the real world and these hypothetical cases illustrates the extent of scarcity in health care that currently exists.

Many people react to scarcity in health care with a sense of outrage and injustice, especially when the people turned away are in severe need. The inability to access health care offends people's sense of justice with an intensity that they do not feel about being denied other goods and services. There are a number of factors that may explain this. One factor is that access to health care can affect all aspects of a person's life to an extent that is not true of many other goods or services. I may prefer to be able to buy a luxury car, but the fact that I cannot afford one does not affect many other areas of my life. In contrast, for many people, being unable to access health care can mean ongoing pain and impairment, with a profound effect on their employment, education, family and social life, overall well-being and life expectancy. Scarcity in health care is troubling because it requires making decisions which will result in some people being unable to access health care and missing out on this health care will have far-reaching effects on all aspects of their lives. At the same time, decisions about how to allocate health care in conditions of scarcity can be extremely complicated. These decisions rely on the interaction of medical conditions, epidemiological patterns, economic systems and ethical theories, all of which are themselves diverse and complex areas of knowledge. It is not surprising that many people would prefer to deny or ignore scarcity in health care, and instead insist that their health care systems are able to avoid difficult prioritisation decisions.

Even though there have been some very cost-effective successes in health care in the last hundred years, such as the increased availability of vaccines, oral rehydration treatment for diarrhoea and the development of antibiotics, scarcity in health care is only increasing. There are a number of reasons for this. One reason is that most countries are currently going through or have gone through demographic transition and have ageing populations. For example, in Japan, people aged 65 years or over made up about 7% of the population in 1970, which has risen to 25% of the population in 2013. In Germany over the same time period, the proportion of people aged over 65 has risen from 13% to 21%.<sup>3</sup> Older people tend to have more health problems and require more health interventions. For

example, the Australian Institute of Health and Welfare has found that per person expenditure on health care increases progressively each year after a person reaches the age of 40, remaining at a relatively high level of expenditure for ages over 80.<sup>4</sup> In OECD countries, the average health expenditures (per capita) for people who are 65 years or older are two to eight times greater than those for the working-age population and steadily increase with age.<sup>5</sup>

Another reason is that many societies, including in the developing world, are going through what has been called 'epidemiological transition'.<sup>6</sup> This means that there is a transition from the main health care problems being communicable diseases (such as measles or malaria) to being non-communicable and chronic diseases (such as cardiovascular diseases, mental illnesses and Type 2 diabetes). Unlike diseases such as measles, these chronic illnesses cannot be prevented with cheap vaccinations, and need to be managed over a long period of time, perhaps for life, and this management can be expensive. Societies are experiencing this epidemiological transition partly due to the increasing success over the twentieth century in treating many communicable diseases. This success has led to greater longevity, and so a greater proportion of people are surviving to ages at which non-communicable diseases are more common. Epidemiological transition is also occurring because certain risk factors, such as lack of exercise and diets high in unhealthy fats and sugars, have become more prevalent across many different countries.<sup>6</sup>

Furthermore, technological and scientific advances have increased the number of treatments that patients expect to provide a net benefit to them. This has increased demand for health care and has contributed to scarcity in health care. In response to this increased demand, countries across the OECD are spending substantially higher proportions of resources on health care over time. For example, health expenditure rose in the United States from 5.1% of GDP in 1960 to 15.3% in 2004 and is continuing to grow. In Japan, expenditures rose from 3.0 to 8.0% of GDP over the same period and in France from 3.8% to 10.5% of GDP.<sup>6</sup>

Scarcity in health care leads to the need for health care rationing. Health care rationing is the process by which individuals and social institutions set priorities; choosing which resources and treatments should be provided, and which patients should receive them. In this thesis, I define *rationing* as any principle or procedure used to make allocations of resources under scarcity. The word 'rationing' to some people implies a single central planning agency making decisions about resources, such as was done in the Soviet Union. Although Soviet central planning is clearly an instance of rationing, I do not want to use the term in a restrictive way to imply that it *must* involve central planning. Rationing can occur even when no person, group or institution, is in charge of deciding on the distribution of

resources. For example, allocations made by the equilibrium of supply and demand in a free market can be regarded as a form of rationing, yet no party involved is planning or determining the distribution on their own. In this case, rationing occurs through the interaction of the incentive structures, preferences and actions of everyone involved in the market transaction.

Much of the rationing that currently occurs in health care is not recognised as such, and yet involves mechanisms for managing scarcity of resources. For example, a number of 'best practice' medical guidelines provide advice not to offer certain treatments to particular types of patients, or require physicians to prescribe or administer medications in a particular order. The guidelines may recommend only offering a particularly expensive drug to patients for whom no other treatment has worked. For example, in Australia, Humira, an expensive, on-patent, immunosuppressant medication used in the treatment of ulcerative colitis and Crohn's Disease,<sup>4</sup> is only recommended for use in patients with moderate to severe symptoms who have had an inadequate response to conventional therapy or who are intolerant to or have medical contraindications for such therapies.<sup>7</sup> This is the case even though other patients with milder symptoms may also benefit from this medication.

Other treatments, such as some vaccinations, may be recommended or subsidised for high-risk groups only, such as children or the elderly. For example, only women over the age of 40 in Australia are eligible for free mammograms to screen for breast cancer<sup>8</sup> even though breast cancer can also occur in much younger women. The state of New South Wales only provides free influenza vaccines for people who are pregnant, or who are over 65 years of age, are Aboriginal, or have medical conditions such as diabetes and heart problems,<sup>9</sup> even though the vaccine provides protection against influenza for other population groups as well. While the explicit motivation of doctors in following medical guidelines may be to use the accumulated advice of other doctors and researchers to do what is best for their patients, many current guidelines are devised at least partially with attention to the distribution of resources in mind.

Rationing in the Australian health care system occurs in many ways. People make decisions based on the cost of a treatment on an individual level. They may decide to forgo a visit to the doctor or choose to consult one doctor and not another based on the size of the gap between the doctor's fee and the government rebate. People sometimes choose not to fill prescriptions for medication based on the cost. Governments choose which medications should be eligible for subsidisation on the Pharmaceutical Benefits Scheme, and the conditions for the sale of other medications which are not

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<sup>4</sup> Humira can also be used in the treatment of a number of other conditions, including rheumatoid arthritis. I will only focus on the prescription guidelines for Crohn's and ulcerative colitis.

subsidised. Students decide whether or not to study medicine as opposed to other subjects, and governments decide how many medical school places to fund, affecting the supply of doctors and the fees that they are able to charge. Pharmaceutical companies decide, given the structure of government rules and subsidies, whether it will be profitable to release a medication for the Australian market. Health insurance companies decide which plans to offer, what premiums to set, and what limits for each category of treatment. All of these actions, incentives and structures together interact to ration health care in the Australian context.

## **2. Philosophical approaches to medical resource scarcity**

Prior to the twentieth century, while there were many discussions about the ethical duties of medical practitioners to their patients, few philosophers considered the issue of how medical resources should be distributed throughout a whole population. During the twentieth century, breakthroughs in medical research made more effective health care available. For example, the production of artificial insulin dramatically increased the lifespan of many diabetic patients. Vaccines for many deadly diseases were developed, including vaccines for diphtheria, poliomyelitis, measles and hepatitis B, preventing millions of early deaths.<sup>10</sup> Researchers discovered antibiotics which had the ability to prevent or cure otherwise untreatable infections.<sup>11</sup> Better prenatal health care and treatment during delivery has reduced both maternal and infant mortality around the world. The extent of the impact of these interventions on people's life expectancy, health status and well-being has raised awareness of the value of health care. It has also raised philosophical questions about who should be able to receive these interventions, and which treatments should be prioritised when there are not enough resources to meet everyone's needs.

The most common way for philosophers to think about the problem of scarce health care resources is as an application of theories of distributive justice. Each society has economic, social and political frameworks which result in patterns of benefits and burdens for members of that society.<sup>12</sup> Theories of distributive justice provide moral guidance for the processes and frameworks which result in these distributions.<sup>12</sup> Historically, theories of distributive justice have focused on the patterns of income and wealth throughout society, the processes of how income and wealth are generated and transferred, and what moral principles should regulate the distribution of income and wealth in a just society.

Modern discussions of distributive justice have been enormously influenced by the philosophy of John Rawls. In the 1970s, Rawls developed a detailed account of distributive justice. In his book *A Theory of Justice*. Rawls recognised the importance of health and health care to people's quality of

life. However, Rawls explicitly excluded the issue of how to consider the allocation of health care from his theory of distributive justice. In designating the bounds of his theory of justice, Rawls specified that

‘I shall assume that everyone has physical needs and psychological capacities within the normal range, so that the questions of health care and mental capacity do not arise. Besides prematurely introducing matters that may take us beyond the theory of justice, the consideration of these hard cases can distract our moral perception by leading us to think of persons distant from us whose fate arouses pity and anxiety. The first problem of justice concerns the relations among those who in the everyday course of things are full and active participants in society and directly or indirectly associated together over the whole span of their life. Thus the difference principle is to apply to citizens engaged in social cooperation; if the principle fails for this case, it would seem to fail in general’.<sup>13</sup>

There are a number of things to note here. One is that Rawls explicitly makes simplifying assumptions in his theory of how people should share the benefits and burdens of social cooperation, by including only cooperation between ‘full and active participants in society ... over the whole span of their life’. This excludes people with severe chronic illnesses and disabilities, as well as people with any condition which would result in a shortened lifespan. Another notable factor is that Rawls seems to have believed that the moral intuitions invoked by questions about the provision of health care were not essential to his theory of justice, that they are instead ‘hard cases [that] can distract our moral perception’.

Rawls also writes that:

‘Other primary goods such as health and vigor, intelligence and imagination, are natural goods; although their possession is influenced by the basic structure, they are not so directly under its control.’<sup>13</sup>

In this way, although Rawls agrees that patterns of health and illness, and the availability of health care are affected by social factors, he classifies them as primarily governed by natural contingencies. This, to Rawls, puts them in a different category from other distributions, such as the distribution of income and wealth across society, which Rawls sees as more directly governed by the basic structure and thus a more appropriate and central focus for his theory of justice.

Since the 1970s, many philosophical discussions about the principles of distributive justice and how these principles should be applied in practice have responded to Rawls, and have defended, extended, or criticised Rawls’ account. A range of philosophical accounts which address the question of scarcity in health care arose in response to Rawls. For example, Norman Daniels’ work is strongly



influenced not only by Rawls but by epidemiological literature about the social determinants of health, especially empirical studies exploring the causal mechanisms by which patterns of income, wealth and social status can affect people's health status and life expectancy. Daniels disagrees with Rawls about the distinction between natural and social goods, arguing that:

‘Understanding the breadth of the social factors that affect levels of population health and its distribution, however, undermines much of the force of this contrast. In whatever sense health is a natural good, its distribution is to a large extent socially determined, as is the aggregate level of health in a population.’<sup>14</sup>

Daniels has attempted to integrate questions about the distribution of health and health care into an extension of Rawls' theory. Daniels' account argues that for a society to have fair equality of opportunity, it must first regulate the social determinants of health fairly and provide a just distribution of health care resources.<sup>5</sup>

A different (and largely critical) philosophical response to Rawls' work has been provided by the Capability Approach. Philosophers who adopt the Capability Approach argue that Rawls' focus on the distribution of resources in a just society is misguided. They instead focus on the distribution of 'capabilities', which are things that people can do and be, such as having the ability to be well-nourished or the ability to be literate. Many Capability theorists, such as Martha Nussbaum, argue that a just society is one in which everyone has more than a threshold level of morally important capabilities. Capability theorists tend to see questions about the distribution of scarce health care resources through the lens of how this health care is likely to affect people's morally important capabilities.<sup>6</sup>

Luck egalitarian philosophers have also been influenced by Rawls and have attempted to integrate individual responsibility into principles for setting priorities for health care. Rawls, in *A Theory of Justice*, thought carefully about the many ways in which luck can affect the distribution of benefits and burdens of social cooperation, and about how a consideration of luck should affect our theories about to what extent social inequalities are justified. Luck egalitarian philosophers tend to emphasise a distinction between outcomes which are the result of chance or unchosen factors (such as being born into poverty or having a genetic predisposition to a disease) as compared to outcomes which are the result of individual choice. Many luck egalitarians argue that inequalities between two people are only morally justified when the inequalities stem from factors under those people's control. As an application of this principle, many luck egalitarians would give higher priority for health care to

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<sup>5</sup> I discuss Daniels' substantial contribution to the philosophical literature in more detail in chapter 6.

<sup>6</sup> I consider Capability theorists' approaches to the problem of medical resource scarcity in chapter 6.

people whose medical condition was a result of unchosen bad luck, and lower priority to people whose health condition was the result of reasonably avoidable choices.<sup>7</sup>

The increasing effectiveness of medical care and preventative health interventions throughout the twentieth and twenty-first centuries has raised the question of how to allocate health care resources fairly in conditions of scarcity. Philosophers have applied more general principles of distributive justice to the specific question of medical resource scarcity. Many of these accounts defend, extend, criticise or otherwise respond to Rawls' principles of distributive justice.

### **3. Thesis scope**

Before going on to describe my approach to the problem of scarcity in health care, and to outline the how I argue for this in my thesis, I first need to make some clarifications and caveats.

The first of these clarifications concerns how I use the terms 'health' and 'health care'. What counts as health, or as health care, is a contested term, with different definitions in different contexts. I define *health care* broadly, as an intervention intended to prevent, ameliorate or cure a health problem. This is not limited to the services of doctors, nurses or pharmacists, but includes a wide variety of other types of services, such as physiotherapy, psychological counselling, soft tissue therapy, nutritional advice, and acupuncture. Paid and unpaid caring roles are also an important part of health care, as are actions or interventions intended to prevent the development of health conditions in the future.

In this thesis I will restrict myself to discussing justice and health care rationing between the citizens of a country, and not internationally or globally. There are many important and difficult philosophical issues to do with how national governments should relate to each other, as well as what forms of health care citizens of wealthier countries ought to provide to those of poorer countries. There are also many ways in which it is important to empirically study health and health care within an international context. Often, epidemics do not stay within national borders. Many aspects of the social determinants of health are properly described with reference to multiple countries, such as those involving climate change, the conditions of migration and international conflict, and the effects of these changes on health and health care. However, these issues are beyond the scope of this thesis. Also, although health care rationing is certainly a problem in developing countries, my primary

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<sup>7</sup> I discuss luck egalitarian versions of responsibility-sensitive theories in Part 1.

focus in this thesis will be on modern developed industrialised countries, as that is the focus of much of the health economics, epidemiology, political theory and social sciences academic literature.

There are a number of different possible approaches to discussing the scarcity of medical resources. My approach is to see this problem as on the intersection of moral philosophy, political theory, economics, epidemiology and public policy. This interdisciplinary approach to the problem means that I try to integrate evidence and insights from all of these areas of research in my thesis.

My primary interest in this thesis is in developing an argument for principles that could assist with making health care priority decisions, given people's actually existing patterns of health and illness. In discussing these topics, I also assume that people's moral psychology, levels of compliance with moral and legal rules and social norms, and responses to incentives are roughly the way that they are in the real world. There are many types of other theories about scarcity of medical resources that could start from different assumptions. For example, philosophers might consider the appropriate distribution of medical resources in a society where everyone was completely compliant with medical advice, or in a world where infectious diseases did not exist, or where there was perfect epidemiological knowledge, or where the pattern of economic incentives in society was extremely different. These theories based on different assumptions may be of considerable philosophical interest. But I mention them here to differentiate them from the focus of my thesis, which is to consider principles for allocating medical resources in conditions of scarcity that can be applied in practice.

#### **4. Thesis plan**

The overall argument of this thesis is that health care prioritisation decisions should be largely made on the basis of two factors: to what extent is health care likely to improve a patient's subjective well-being, and to what extent is health care likely to improve a patient's morally relevant capabilities. I argue for my view through engaging with a range of interdisciplinary literature about how to allocate health care resources in conditions of scarcity.

Part 1 of this thesis (which consists of Chapters 1, 2 and 3) considers *responsibility-sensitive health care*. The purpose of Part 1 is to argue that a person's responsibility for causing their health condition should not play a part in deciding the strength of their claim to health care resources.

In Chapter 1, I describe and explain the concepts and distinctions involved in responsibility-sensitive health care. Health-damaging behaviours (such as smoking, excessive alcohol consumption, and

overconsumption of calorie-dense, nutritionally poor foods) are causally linked to a large and growing proportion of health care costs. In modern Western societies, it is widely known that these behaviours pose a significant risk of causing health conditions. Many people, both philosophers and non-philosophers, believe that it is fair and reasonable to take into account the extent to which a person is responsible for causing their own health condition in deciding their priority for health care. One of the most philosophically sophisticated formulations of responsibility-sensitive health care principles is that of luck egalitarianism, and I focus on luck egalitarian versions of responsibility-sensitive health care in Part 1. Many luck egalitarians argue that people who deliberately engage in reasonably avoidable, health-damaging behaviours (such as smoking) should receive lower priority for scarce health care resources than those who do not engage in these behaviours.

In Chapters 2 and 3, I provide arguments for rejecting the luck egalitarian principles of health care allocation which I have described and explained in Chapter 1. In Chapter 2 I reject luck egalitarian principles as applied to health care rationing on normative grounds. One of the main objections to luck egalitarian principles in the philosophical literature is known as the 'Abandonment Objection'. This objection argues that luck egalitarian principles allow or require denying assistance to people who are victims of their own imprudent or reckless choices (in this case people who need health care as a result of engaging in reasonably avoidable health-damaging behaviours) and argues that this harshness means that luck egalitarianism cannot provide plausible moral guidance about distributive justice in general, or in problems of rationing health care specifically. I consider some responses to the Abandonment Objection provided by luck egalitarian writers and argue that none of them can suitably answer the objection within the confines of luck egalitarian principles.

In Chapter 3 I argue that it would be infeasible to use luck egalitarian principles to regulate health care resources in practice. While not all luck egalitarian philosophers intend their principles to be used in real-world public policy, I argue that those luck egalitarian philosophers who do intend this face a dilemma. A policy could focus on making the rationing of health care sensitive to people's *behaviours*, which would require directly monitoring to what extent a person smokes, drinks too much alcohol, or overeats. In this case, the implementation of the policy would result in the compounding of existing social disadvantages and be unacceptably intrusive. On the other hand, public policy attempting to implement responsibility-sensitive health care could focus on *measurable outcomes as a proxy for behaviours*, such as penalising some people with a high body mass index due to their assumed imprudent food consumption behaviours. In this case, due to lack of information, the policy will not be able to accurately implement sensitivity to health behaviours. Regardless of whether the policy focuses on health behaviours or measurable proxies for behaviour, these

problems render the implementation of responsibility-sensitive health care in public policy impractical.

In Part 2 of this thesis (which consists of Chapters 4, 5, 6, and 7) I consider responsibility-*insensitive* accounts of how to allocate health care resources in conditions of scarcity, and develop my own view.

In Chapter 4, I argue that the allocation of scarce health care resources should involve some level of government involvement. Some people believe that the best way to allocate health care resources is to rely on individual consumer and supplier decisions in the context of a free market, without government intervention. I reject this view, arguing that (even assuming a hypothetical fair distribution of income and wealth) the structure of risks and incentives in health care insurance market mean that without government intervention many people will be unable to buy health insurance. Given the consequences of not providing health insurance or health care, I argue that this is not a plausible moral way of meeting the challenge of rationing health care.

In Chapter 5, I reject the use of two metrics that are currently used by health economists and policymakers to make health care allocation decisions: Disability Adjusted Life Years (DALYs) and Quality Adjusted Life Years (QALYs). I argue that QALY and DALY methodologies are problematic because they conflate two questions which should be considered separately: how to evaluate interventions which improve people's quality of life, and how to evaluate interventions which extend people's lifespan. QALYs and DALYs also use inaccurate and disrespectful information about the lives of people with disabilities and obscure issues of distributive justice.

In Chapters 6 and 7, I develop my own view about how to set priorities and allocate scarce health care resources. In Chapter 6, I describe two well-developed philosophical accounts: Norman Daniels' theory and the Capability Approach. These theories are similar in that they both emphasise that the value of health care lies in its role in improving people's morally important capabilities and functionings. While I agree that this is a large part of what makes health care valuable, I argue that these theories can't be a *full* account of how we can make fair health care allocation decisions. This is because they cannot justify providing plausible priority for caring for the needs of the terminally ill and patients in chronic pain. Capability and functioning-based accounts focus on objectively measurable effects of health care, but many effects of health care, such as relieving chronic pain, have an inherently subjective component.

If a focus on improving objective capabilities and functionings is not enough for a plausible theory of health care resource allocation, what would such a theory look like? In Chapter 7, I argue for the importance of including measures of subjective well-being (in addition to capabilities) in considering how to prioritise health care interventions. I discuss the different ways in which subjective well-being can be measured on a population level and explain the empirical research which indicates how subjective well-being is often affected by different health conditions. I suggest a number of ways in which subjective well-being could be incorporated into health policy. Among other effects, these policies would be likely to prioritise addressing ongoing major depression and chronic pain conditions to a greater extent than health care policy currently does.

# Part 1: Responsibility-Sensitive Health Care

## Chapter 1: Luck, Choice and Responsibility-Sensitive Health Care

1. Responsibility-sensitive health care
  - 1.1 What is responsibility-sensitive health care?
  - 1.2 Harmful health behaviours and health care costs
  - 1.3 Harmful health behaviours and voluntary, informed choices
  - 1.4 Responsibility-sensitive health care in the real world
2. Luck egalitarianism
  - 2.1 What is luck egalitarianism?
  - 2.2 Luck egalitarian principles as applied to health care rationing
  - 2.3 Luck egalitarian principles and the pervasiveness of luck
3. Conclusion

In this chapter, I will describe one set of principles that could be used to guide the allocation of scarce health resources. This set is based on individual responsibility, such that a person's share of health care resources is at least partly dependent on their choice of health-related behaviours. I aim to show why some people are motivated to support responsibility-sensitive principles as a way of allocating health care resources in conditions of scarcity. Far from being an obscure and irrelevant approach, many people (both in the general public and among philosophers) think that responsibility-sensitive principles are a fair and effective way to allocate health care resources fairly.

The purpose of this chapter is also to describe the key distinctions and concepts involved in one type of responsibility-sensitive view: that of luck egalitarianism. Luck egalitarianism is a well-developed family of philosophical theories which attempt to explain what personal responsibility is and how it should affect people's distributive shares. I will describe some prominent accounts of luck egalitarianism and explain how we could apply luck egalitarian principles to the problem of rationing in health care. I will then go on to critique these luck egalitarian principles in chapters 2 and 3 on normative and practical grounds.

### 1. Responsibility-sensitive health care

In this section, I will define responsibility-sensitive health care, and discuss why many people believe responsibility-sensitive principles should be used to ration scarce health care resources.

### 1.1 What is responsibility-sensitive health care?

The first three chapters of this thesis will focus on what I call *responsibility-sensitive health care*.<sup>8</sup> By this I mean any system of health care resource allocation in which the strength of a person's claim to health care depends on whether (and to what extent) that person damaged their own health and was morally responsible for doing so. In my discussion of health behaviours, I will use the terms 'health-damaging' behaviours and 'imprudent' or 'reckless' behaviours interchangeably.

Systems of responsibility-sensitive health care assume that people have some moral responsibility to act in ways that do not damage their own health. However, different systems of responsibility-sensitive health care may disagree about how strong this obligation is, and which particular behaviours people should engage in or avoid so that they do not damage their health.

A system of responsibility-sensitive health care does not necessarily require that a person who damages their own health (such as a person who smokes and is morally responsible for doing so) is then denied all health care *entirely*. However, it does require that a person who smokes and is morally responsible for doing so has a weaker claim to health care than a person who is otherwise identical in all respects but who does not smoke. Having a weaker claim to health care than others could mean a variety of things in practice. It could mean that the person with a weaker claim has to wait longer than others to receive health care, to pay higher insurance premiums, or to receive less extensive treatment than those who are not responsible for causing their health condition.

### 1.2 Harmful health behaviours and health care costs

One precondition for believing that individual responsibility is a useful and effective principle to ration health care is that health-damaging behaviours contribute to a large proportion of health care costs. This means that focusing on these behaviours has broad applicability to priority-setting for health care. To see why broad applicability is important, imagine a principle for setting priorities in health care which only applied to people with one rare illness who live in one specific village. While this principle may or may not be fair, it would certainly not be very useful for setting health care priorities within a whole country, and among many different health conditions.

In contrast, health-damaging behaviours such as excessive alcohol consumption, tobacco smoking and the overconsumption of calorie-dense nutritionally poor foods are causally linked to a

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<sup>8</sup> I take this term from Shlomi Segall. See 15. Segall S. *Health, Luck and Justice*. Princeton: Princeton University Press; 2009.



substantial and growing proportion of health care expenditure.<sup>9</sup> The Australian Institute of Health and Welfare estimated that in 2011, tobacco use contributed to over 13% of all deaths in Australia and is calculated to cause around 15 000 deaths annually.<sup>16,17</sup> Tobacco use has been found to be responsible for more than 9% of the overall burden of disease, especially contributing to cardiovascular diseases, cancers and respiratory illnesses. The Center for Disease Control notes that approximately one in five deaths in the United States are attributable to tobacco smoking, and that smoking causes more deaths each year than HIV, illegal drug use, alcohol use, motor vehicle accidents and gun deaths combined.<sup>18</sup>

Over recent decades, there has been a dramatic increase in certain health behaviours leading to a rise in the prevalence of obesity around the world. In 2014-15, only 5% of Australian adults met guidelines for consuming enough fruit and vegetables to meet dietary guidelines,<sup>19</sup> and it is likely that the shortfall in fruit and vegetable consumption is being made up with more calorie-dense, nutritionally poor foods. In Australia, obesity has also risen from 19% to 28% of the adult population between 1995 and 2014–15.<sup>20</sup> Obesity is a major risk factor for many serious and chronic health conditions, including cardiovascular disease, strokes, gallbladder disease, Type 2 diabetes, and cancers<sup>21</sup>. Obesity is also believed to raise the risk of ongoing psychological conditions, such as major depression and clinical anxiety, and to increase the prevalence of sleep apnoea and other breathing disorders.<sup>22</sup> The prevalence of being overweight or obese was estimated in 2005 to cost Australia \$21 billion in added health care costs alone.<sup>23</sup> The total costs of health care attributable to obesity and being overweight are expected to double every decade, and are projected to account for 16–18% of total US health-care expenditure by 2030.<sup>24</sup>

High alcohol consumption has been implicated in the development of chronic diseases such as liver disease, some cancers, oral health problems and cardiovascular disease.<sup>20</sup> The National Institute of

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<sup>9</sup> As a caveat here, there is a contentious debate among health economists and epidemiologists about the net effect that various health-related behaviours have on health care expenditure. For example, some researchers argue that on net, cigarette smokers *save* health care systems money. They argue that as smokers die at significantly younger ages than non-smokers, the added health care expenditure from smoking-related conditions is outweighed by the age-related health care expenditure that the system would have incurred if they had continued to live into their 80s and 90s. This debate is likely to be difficult to resolve on an empirical level, given varying health care systems, data availability and behavioural patterns internationally. For the purposes of this thesis, arguments about harmful health-related behaviours in the context of health care rationing should be read as *to the extent that they add to health care needs and expenditure* without committing to empirical claims on this matter. Furthermore, this debate does not make a significant difference to the plausibility of luck egalitarian theories. Luck egalitarians can note when particular medical treatments (such as treatment for lung cancer) are the result of health damaging behaviours and give patients who freely chose to engage in these behaviours lower priority for health care. Whether these same patients have lower health costs at the end of their life than the rest of the population (due to a lower life expectancy) is not something that needs to be relevant to a luck egalitarian account of justice in health care.

Health in the United States notes the substantial impact of excessive alcohol consumption on health, writing that:

‘Alcohol problems, both those of individuals and those that affect society at large, continue to impose staggering social and economic burdens... An estimated 20 to 40 percent of patients in large urban hospitals are there because of illnesses that have been caused or made worse by their drinking.’<sup>25</sup>

The Centre for Disease Control estimates that excessive alcohol use led to approximately 88,000 deaths each year in the United States from 2006 to 2010, and these deaths shortened the lives of those who died by an average of 30 years.<sup>26</sup> In Australia, 5,785 people aged over 15 died of alcohol-attributable disease and injury in 2015, while there were more than 144,000 hospitalisations due to alcohol consumption in 2012-13.<sup>27</sup> Women who drink alcohol while pregnant also run the risk of the foetus developing Foetal Alcohol Syndrome Disorder, a condition causing lifelong and severe cognitive, behavioural, health and learning difficulties, including problems with memory, language, attention, and impulsivity.<sup>28</sup>

Health-damaging behaviours such as smoking, excessive alcohol consumption, and overeating contribute to a large variety of health conditions and a substantial proportion of health care costs. For this reason, principles which focus on these health behaviours have broad applicability to the project of setting priorities in health care.

### **1.3 Harmful health behaviours and voluntary, informed choices**

An important reason why people may support responsibility-sensitive health care is that the choice to engage in health-damaging behaviours can be plausibly considered to be a voluntary and informed individual decision. For example, compared to historical standards, individuals in modern societies tend to have considerable choice about whether to drink large quantities of alcohol, whether or not to smoke, and what and how much food to eat. People in modern Western societies usually have access to a range of fresh fruit and vegetables all year round, to an extent that would have been considered astonishing a century ago. They have access to clean running drinking water, making it unnecessary to consume alcohol as an alternative to unsafe water, and the caloric value of alcohol is not an important part of many people’s diets.<sup>29</sup> People in modern Western societies are increasingly unlikely to work at jobs requiring difficult physical labour, reducing the pressure to smoke cigarettes as a stimulant. To the extent that the activities of formal institutions, such as government regulations or taxation, affect these behaviours, they commonly aim to encourage people to make healthier choices, for example by imposing extra taxes on or restricting the sale of cigarettes or alcohol. These

factors lead many people to argue that individuals are not compelled to engage in these health-damaging behaviours and that these behaviours are best described as a voluntary choice.

It would be possible to object here that it is hard to know which behaviours damage people's health and so health-damaging behaviours are not the result of informed choices. Many behaviours have both positive and negative possible health consequences. For example, imagine a person who makes regular car trips in order to visit their family and friends. On one hand, car accidents are a significant cause of accidental death (and injuries) even in countries with a well-maintained road system and consistently enforced road rules. On the other hand, maintaining social contact with family and friends reduces social isolation, and social isolation has been shown to have significant effects on mortality, similar to the size of the effect for cigarette smoking.<sup>30</sup> Another example is playing a team sport such as soccer, which has the effect of creating social connections and also the benefit of improving cardiovascular health and bone strength.<sup>31</sup> However, soccer playing also foreseeably produces injuries in the knees and ankles, even when best practices for avoiding injuries are followed. One study looking at Danish soccer players over a range of ability levels found that as many as 89 players out of 123 experienced a soccer-related injury over the course of a year.<sup>32</sup> Medical advice has also changed substantially over time. For example, for decades, the best medical advice claimed that saturated fat was the primary cause of obesity and cardiovascular disease.<sup>33</sup> Due to this consensus, many people made an effort to eat a low-fat diet. Many packaged foods substituted high fructose corn syrup or other highly refined carbohydrates in order to make their products low fat and therefore 'healthy'. However, current research has found that there is little evidence for a connection between fat intake and heart disease, and that the increasing intake of carbohydrates stimulates a hormonal response causing the body to store the calories as fat rather than burning them off.<sup>33</sup> Is it reasonable to expect people to avoid health-damaging behaviours when even accepted medical orthodoxy for decades can prove not just ineffective, but actively harmful?

However, this objection overemphasises the level of uncertainty about health behaviours. Many health behaviours have been recognised as damaging for decades or centuries and continue to be so regarded now. For example, it has been widely known since the 1970s that smoking cigarettes significantly raises the risk of cancer, even if the substantial effects that smoking has on other aspects of chronic disease were less well known. The widely-reported US Surgeon-General's report on smoking as a major cause of lung cancer was released in 1964, and this report represented the scientific consensus on the topic.<sup>34</sup> The UK government ran its first anti-smoking campaign in 1969,<sup>35</sup> and anti-smoking messages began in Australia in the early 1970s.<sup>36</sup> To take a different example, the negative health effects of excessive and binge drinking have been known for centuries, not just

because drunk people are more likely to get into accidents, but also because of alcohol's other effects on health. It has been known since at least 1813 that excessive alcohol consumption raises the risk of liver disease.<sup>29</sup> While there may have been past ambiguity about the relative value of added sugar compared to fat content in foods, it has long been uncontroversial that a diet of vegetables, pulses, wholegrains and lean protein is healthier than a diet high in sugar and saturated fat. For example, George Orwell wrote in the 1930s about the tendency for middle class people to complain that the working class could, even on their low incomes, choose healthier foods than they actually did.<sup>37</sup> There appears to be little disagreement, even at this time, that eating carrots and wholemeal brown bread were better health behaviours than eating ice cream and hot chips (in Orwell's examples). The relevant disagreement in Orwell's discussion is solely about the psychological and motivational background behind these choices.<sup>37</sup> While there may be legitimate disagreement about the health effects of some behaviours, there is widespread agreement among researchers about the substantial risks of smoking, excessive drinking and eating calorie-dense food of low nutritional value. This scientific consensus extends back to at least the 1970s (and in many cases much earlier). Therefore, arguments about whether it is reasonable to expect people to know about health risks cannot be said to apply to at least these three very common health-damaging behaviours.

The role that health behaviours can play in causing and worsening health conditions is well known on a general level. In most modern Western countries, there have been numerous public health campaigns about the harmfulness of cigarette smoking. In Australia, for example, there have been decades of television advertisements showing in graphic detail the harms that nicotine is likely to do to different parts of the body. In Australia, cigarettes are required to be sold in 'plain packaging' which means that, unlike other goods, the producer must substitute their preferred packaging design and logo for confronting images of how tobacco can destroy lungs, teeth and eyes, among other body parts. The damage that excessive consumption of alcohol can cause is also widely known. Legislation restricts to whom, where and how much alcohol can be sold, and imposes penalties for doing any activity after drinking for which alcohol could raise the risk of accidents, such as driving a car, flying a plane or operating machinery. The link between excessive alcohol consumption and liver damage is part of social common knowledge.

Health-damaging behaviours such as smoking, excessive alcohol consumption and overeating can plausibly be regarded to be the result of voluntary, informed choices. This leads many people to argue that it is reasonable to make health care resource allocation sensitive to individual responsibility for these behaviours.

#### **1.4 Responsibility-sensitive health care in the real world**

A variety of responsibility-sensitive health policies have been applied by organisations and governments. For example, the World Health Organization has a policy of refusing to employ any person who uses tobacco products, even when they do this privately away from the workplace.<sup>38</sup> Employers in Australia, even those not directly involved in health care, increasingly specify that they will not employ smokers. Reasons for this include protecting the employer's public image, concerns about second hand smoke, and concerns that smokers will be more likely to be absent due to illness and to be less productive than non-smokers.<sup>39</sup>

Governments have also experimented with including responsibility-sensitive practices directly into health care service delivery. For example, Medicaid (a US government program providing health care for people in poverty) has in the past provided two benefit packages in West Virginia. The first is a basic 'restricted' benefit package with no terms and conditions on recipients. The second is an 'enhanced' benefit package including greater coverage of vision, dental, prescription drugs, cardiac and diabetes care and mental health benefits, among others. The condition for receiving the enhanced package is that participants need to sign an agreement that they will show up to appointments, take medicines correctly, and follow their doctor's advice. In Florida, Medicaid patients have been given the opportunity to earn cash credits of approximately \$150 (which can be used to buy items at pharmacies) in return for behaviours such as getting a pap smear test, getting a vision exam, showing up to all appointments, or participating in a program to quit smoking. In Germany, a system of patient payments and other financial incentives has been introduced to move some of the cost of medical procedures onto patients to try to encourage health-promoting behaviour.<sup>40</sup> These three types of public health programs are different from each other, but all attempt to make the provision of health care more sensitive to individual responsibility.

Many of these policies are intended to provide incentives to reduce the incidence of health-damaging behaviours. Unlike some other policies, which may distort people's incentives to engage in socially beneficial behaviour, responsibility-sensitive health care seems likely to have incentive effects which are in the long-term interest of both the individual and society.

Responsibility-sensitive health care policies are popular with the general public and this can be seen through social survey data. For example, survey research<sup>41</sup> indicates that the majority of Australians, when asked about health care rationing, believe that smokers, the significantly overweight and alcoholics should be given lower priority in the healthcare system than other patients.

Health behaviours such as smoking, excessive drinking, and eating high-calorie, nutritionally poor foods make a substantial contribution to the prevalence of illness and the need for health care. These behaviours are widely known to be harmful and appear to be based on an individual's decision as to whether or not to engage in them. Given this background, many people, organisations and governments argue that it is reasonable to use individual health behaviours as part of the process for deciding who should get priority for receiving health care resources.

## 2. Luck egalitarianism

For the rest of the thesis, when I discuss responsibility-sensitive principles for health care rationing, I will be focusing on one particular set of principles: those of luck egalitarian theories of distributive justice. There are many people who support responsibility-sensitive health care rationing for reasons which have nothing to do with luck egalitarianism.<sup>10</sup> However, I will focus my discussion on luck egalitarian versions of responsibility-sensitive health care because the luck egalitarian literature is a thoughtful and philosophically rigorous attempt to take responsibility seriously in accounts of distributive justice. The luck egalitarian literature is extensive, and increasingly nuanced and reflective about what luck egalitarian principles may entail in practice. For example, luck egalitarian thinkers such as John Roemer<sup>42</sup> and Zofia Stemplowska<sup>43</sup> have grappled with the problem about the relationship between supposedly autonomous individual choices and unchosen socioeconomic status in a variety of social contexts. For these reasons, when I discuss principles of responsibility-sensitive healthcare, I have luck egalitarian versions of this in mind.

In this section, I will describe the key distinctions and concepts involved in luck egalitarianism, explain how luck egalitarianism could be applied to priority-setting in health care, and clarify how luck egalitarian philosophers respond to the problem of the pervasiveness of luck.

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<sup>10</sup> There are a number of philosophers who are not luck egalitarians but also present a case for responsibility-sensitive health care. For example, Thomas Pogge argues that in the literature on health, distributional factors have overshadowed important process and causal considerations. Pogge's account is intended to be an extension of Rawls' theory of justice and argues that social institutions should consider medical conditions caused by natural, social and personal causes separately. He argues that in the case of 'natural' health conditions, society is required to provide a form of health insurance which benefits the worst-off, though it is not unjust if all medical needs from naturally caused health conditions are not met. In contrast, social institutions must carry the burden of health costs from socially caused health conditions, as they form part of people's distributive share of the benefits and burdens of social cooperation. For personally caused health conditions, social institutions may only pay for health costs in so far as they indirectly pay for themselves, such as through increased productivity of beneficiaries. I do not address Pogge's account in detail due to lack of space. However, many of the criticisms of luck egalitarian accounts, such as concerns about objectionable abandonment (Chapter 2) and concerns about intrusiveness and lack of epidemiological knowledge (Chapter 3) also apply to Pogge's account.

## 2.1 What is luck egalitarianism?

Luck egalitarianism is a family of theories about distributive justice. Luck egalitarians believe that people are entitled by principles of justice to be equal in something (whether this is identified as welfare, opportunities, resources, or something else), but argue that this distribution should also be sensitive to individual responsibility and choices. There are a variety of luck egalitarian accounts. However, luck egalitarian philosophers agree that people should not be disadvantaged or advantaged due to factors which are unchosen, out of their control and for which they are not morally responsible.

For example, the luck egalitarian philosopher Shlomi Segall writes that:

‘The defining feature of luck egalitarianism is no doubt the distinction it draws between eventualities for which we are responsible and ones for which we are not... Luck egalitarianism is essentially the idea that it is unfair for one person to be worse off than another due to reasons beyond her control.’<sup>15</sup>

In a related formulation, Kok-Chor Tan writes that:

‘however different luck egalitarians work out its implication, the intuitive idea that they all share is that persons should not be disadvantaged or advantaged simply on account of bad or good luck.’<sup>44</sup>

As the early luck egalitarian G.A. Cohen put it

‘the purpose [of egalitarianism] is to eliminate involuntary disadvantage, by which I ... mean disadvantage for which the sufferer cannot be held responsible, since it does not appropriately reflect choices that he has made or is making or would make.’<sup>45</sup>

In explaining the difference between factors that do and do not stem from individual choices, many luck egalitarians draw a distinction between brute luck and option luck. Outcomes that result from calculated gambles, such as freely chosen investments or business deals, can be regarded as option luck. Brute luck refers to outcomes that are not the result of these deliberate choices.<sup>46</sup> For example, having a health condition such as autism can be regarded as a result of brute luck, whereas losing money after freely choosing to gamble can be regarded as the result of option luck. In general, luck egalitarians prioritise neutralising the disadvantages that people face as a result of bad brute luck, over disadvantages caused by bad option luck.

One of the strengths of luck egalitarianism is its integration of personal responsibility into a theory of distributive justice in a way that appears to fit well with deeply held moral intuitions. For example,

John Roemer<sup>47</sup> notes that everyone agrees on the importance of holding individuals accountable for their own lives, at least to some extent. Richard Arneson<sup>48</sup> illustrates the intuitive nature of the basis of luck egalitarianism by arguing that assumptions about personal responsibility are embedded in our views about distributive justice. For example, Marx's moral criticism of nineteenth century capitalism was powerful because the proletariat, through no choice or fault of their own, had to work long hours of exhausting physical work in order to maintain a bare subsistence existence. Our moral intuitions, Arneson argues, would be very different for a situation which he calls *proletarian\**, where a group of people begin their lives with inherited wealth, good childhood experiences, and fortunate genetic inheritance, yet waste all these advantages and have to work hard, unrewarding jobs to stay alive. Even, Arneson argues, if people are owed second and third chances, the case of the *proletarian\** lacks the strong and intuitive moral appeal of Marx's original critique. Arneson thinks that there is something intuitively wrong with a theory of justice that bundles those who exhibit blameworthy conduct with morally upstanding people who are unlucky in their social and economic circumstances as if there were no significant differences between them.

Another attractive element of luck egalitarianism is that it provides a single overarching principle to account for a range of moral intuitions. For example, it unifies people's moral intuitions that some people experiencing a lower quality of life than others due to genetic disease, disability or intergenerational poverty is unjust and should be remedied by social institutions, whereas people experiencing a lower standard of living due to freely chosen gambling should at least have lower priority to redress from social institutions. Luck egalitarianism provides a set of principles that enables people to reconcile their moral intuitions about the responsibility of individuals for their personal behaviour as compared to their unchosen circumstances in a variety of areas of life. One benefit of this apparent simplicity and breadth of luck egalitarian principles is the ability to use the same set of principles for discussing health and other domains. By this, I mean that there is no need to have a separate set of principles about justice in health, as opposed to justice in regard to income, wealth, housing or the environment. This is important as decades of epidemiological research has shown the profound effects that housing, the environment, employment conditions and economic inequality can have on people's health status, even where free and high-quality health care is equally available to everyone.<sup>49-51</sup> Rather than drawing artificial distinctions between different domains of people's lives, luck egalitarianism is able to use the same set of principles to analyse the conditions which cause health problems to arise, and to discuss ways to allocate health care fairly.

## **2.2 Luck egalitarian principles as applied to health care rationing**



As applied to the problem of health care rationing, most luck egalitarians would agree that people who freely and avoidably choose to engage in damaging health behaviours should receive lower priority for health care given conditions of scarcity. One type of reasoning that luck egalitarians can use to argue for this rationing criterion is that choices to smoke or drink excessively are types of 'expensive tastes'. The problem of expensive tastes refers to the fact some people will be more unhappy than others with the same bundle of goods due to their particular preferences. For example, some people have a preference for smoking, excessive drinking and calorie-dense food, whereas other people prefer to exercise, drink moderately, and eat a balanced diet. The former set of preferences can be regarded as expensive tastes to the extent that they affect the development of future health conditions and are likely to require additional spending on health care. A commonly held intuition is that it is unfair to allow people with these preferences to impose extra costs on the rest of society in the form of extra health spending. It is argued that this results in distributional inequity, as the people with expensive tastes then receive an unjustified additional share of scarce resources from social institutions. These intuitions provide support for luck egalitarian reasoning about making health care rationing sensitive to individual choices.

Another reason why luck egalitarians can argue that people's health choices should affect their health care is that, in general, people have moral intuitions that people's choices, preferences and behaviours can legitimately affect their distributive share of resources. For example, Will Kymlicka presents a case of a gardener and a tennis player who start with equal shares of resources, but, due to different preferences, choose to use these in different ways.

'To take the simplest case, imagine two people of equal natural talent who share the same social background. One wants to play tennis all day, and so only works long enough at a nearby farm to earn enough money to buy a tennis court, and to sustain his desired lifestyle (i.e. food, clothing, equipment). The other person wants a similar amount of land to plant a garden, in order to produce and sell vegetables for herself and others. Furthermore, let's imagine, with Rawls, that we have started with an equal distribution of resources, which is enough for each person to get their desired land, and start their tennis and gardening. The gardener will quickly come to have more resources than the tennis-player, if we allow the market to work freely. While they began with equal shares of resources, he will rapidly use up his initial share, and his occasional farm work only brings in enough to sustain his tennis-playing. The gardener, however, uses her initial share in such a way as to generate a larger income through longer hours of work... But there is something peculiar about saying that such a tax is needed to enforce equality, where that is understood to mean treating both people as equals. Remember that the tennis-player has the same talents as the gardener, the

same social background, and started with the same equal allotment of resources. As a result, he could have chosen income-producing gardening if he wished, just as she could have chosen non-income-producing tennis. They both faced a range of options which offered varying amounts and kinds of work, leisure, and income. Both chose that option which they preferred.<sup>52</sup>

To many people, it seems strange and counterintuitive to insist on restoring the tennis player to a situation of equal resources with the gardener. In a similar way, for luck egalitarians, it may also seem strange to prioritise making resources available to people with imprudent health behaviours if this is at the expense of people with prudent health behaviours. To choose to drink alcohol excessively and to smoke is predictably likely to lead to health problems, just as the choice to play tennis rather than cultivate a garden is likely to lead to lower income. Taking income from people who engaged in prudent health behaviours to pay for the health care of people who engaged in imprudent health behaviours could be argued to be similar to giving the imprudent an additional share of resources. Within luck egalitarian principles of distributive justice, if people come from equal initial starting points and their different shares are a result of their own choices, it is difficult to justify redistributing resources from the gardener to the tennis player in Kymlicka's example, or from prudent to imprudent citizens in the case of health.

In a luck egalitarian view, what sort of personal choices would result in a person receiving lower priority for health care? Clearly it would not refer to all individual choices that result in some negative outcome. For example, if I choose to go for a walk outside on a clear fine day, and then am caught in an unexpected thunderstorm which causes pneumonia, it would be strange to say that I am responsible for contracting pneumonia because I chose to go for a walk. Luck egalitarians such as Nicholas Barry would not describe this example as being of personal responsibility, as the thunderstorm and subsequent pneumonia could not be 'reasonably foreseen'.<sup>53</sup> It would also not meet Zofia Stemplowska's criteria, as she describes the behaviours that should result in lower priority as 'recklessness, negligence, absentmindedness, [or] deliberate pursuit of danger' which she describes collectively as 'imprudence'.<sup>43</sup>

Luck egalitarians are also likely to argue that they are interested in responsibility in the sense of some pattern of behaviour being under the *autonomous control* of the agent. The details of this would depend on the account of autonomy or agency which is being appealed to. For example, Harry Frankfurt<sup>54</sup> presents an account where to really be the author of one's actions, it is necessary to have and identify with certain second-order volitions. In explaining this concept, Frankfurt distinguishes between two drug addicts, both of which have an overpowering first-order desire to take the drug.

The difference between them is in their second-order volitions – one drug addict strongly wants to be free of the desire to take the drug, whereas the other identifies himself with the desire to take the drug. In Frankfurt's account, only the latter addict is truly the author of his actions. Michael Bratman<sup>55</sup> and Gary Watson's<sup>56</sup> accounts of agency differ, but they both specify acting with some sort of consistency with longer-term plans as being part of what it means to be the author of one's actions.

The details of a particular luck egalitarian view would depend on the account of autonomy or agency which is being appealed to, however, there is reason to think that most health behaviours of interest to luck egalitarians are likely to meet criteria for autonomous agency. For example, there is evidence that very heavy drinkers adjust their type, quantity and purchasing of alcohol according to price<sup>57</sup> in ways that requires consistent planning, not simply acting on a desire on the spur of the moment. In Australia, smokers go to some lengths to buy loose tobacco rather than buying cigarettes, as cigarettes are almost always more expensive.<sup>58,59</sup> These strategic behaviours do not seem to be examples of unendorsed first-order desires or isolated actions without reference to any of the agent's plans.

Many luck egalitarians believe that inequalities in health are unjust when they are not caused by *reasonably avoidable* personal behaviour. Some philosophers may argue that whether an action was 'reasonably avoidable' is a somewhat vague criterion on which to determine whether a person should bear distributive costs. However, Shlomi Segall notes that this is actually a strength of this formulation, as it means that it is sensitive to contextual factors in a way that is consistent with our moral intuitions. For example, under one reading of what it means to be responsible for an action, many people who live in some parts of California are responsible for living on a geological fault line. They would be counted as responsible for choosing to live there because the existence of the fault line was common knowledge, it would have been possible for them to live in other parts of California or of the United States and their choice to live in these parts of California were under their autonomous control. However, a luck egalitarian account of distributive justice would not deny these people disaster assistance and health care if they were injured from an earthquake. This is because it would be unreasonable for society to expect people to avoid living in large parts of California because of the very small chance that they would be caught in an earthquake. In a sense these people may be responsible for their decisions to live near the fault line but would not be made to suffer distributive costs as a result of it in a luck egalitarian society.

However, in contrast, consider thrill-seekers who choose to camp and go hiking on the side of a volcano, despite repeated and explicit warnings that the volcano is due to erupt any day now. It would not have been unreasonable to expect the people to avoid camping and hiking so close to the volcano. Many luck egalitarians would argue that in this case, if the volcano does erupt and the campers are injured, it *would* be acceptable for social institutions to demand that the campers pay at least part of the cost of their rescue and health care. Whether it would be unreasonable to expect someone to avoid an action may seem to be a vague criterion for deciding questions of distributive justice. However, it is a useful criterion in explaining the difference in common moral intuitions about the people living on a geological fault line as compared to people camping on the volcano. The criterion helps explain why despite the superficial similarity between the cases, the people living on the fault line should not be liable for extra costs in the case of disaster, whereas those on the volcano could be liable for extra costs.<sup>15</sup>

Engaging in reasonably avoidable health-damaging behaviours could be grounds within a luck egalitarian account for receiving lower priority for health care, given conditions of rationing and scarcity.

### **2.3 Luck egalitarian principles and the pervasiveness of luck**

One objection to luck egalitarian principles could be to appeal to the pervasiveness of luck – to argue that in fact *all* outcomes are determined by factors outside any individual's control and thus it is not useful to discuss whether health-damaging behaviours were reasonably avoidable. However, luck egalitarians argue that concerns about the pervasiveness of luck do not challenge the coherence or plausibility of luck egalitarian principles.

Many people think that a necessary (but not sufficient) condition for holding people responsible is that the person was able to control the behaviour or outcome for which they are being held responsible. It seems strange and arbitrary to hold people for events unrelated to their agency, like holding an individual in 2018 responsible for the fact that Canberra is geographically closer to Sydney than it is to Melbourne or that the French revolution began in 1789.

However, what does it mean for a factor to be outside a person's control? After all, in one sense, *all* human outcomes and actions could be regarded as the result of factors beyond people's control.

This issue raises a complex and extensive arena of philosophical debate about the implications of determinism for the possibility of moral responsibility. A standard definition of determinism stipulates that it is:

‘the metaphysical thesis that *the facts of the past, in conjunction with the laws of nature, entail every truth about the future*. According to this characterization, if determinism is true, then, given the actual past, and holding fixed the laws of nature, only one future is possible at any moment in time. Notice that an implication of determinism as it applies to a person's conduct is that, if determinism is true, there are (causal) conditions for that person's actions located in the remote past, prior to her birth, that are sufficient for each of her actions.’<sup>60</sup>

Given a deterministic universe, the causal processes which affect all our circumstances, psychological processes and behaviours are not under our control. Even if the universe is not completely deterministic (if, say, random events on the level of quantum physics are able to affect human actions) then even these events will be experienced as good or bad luck from the perspective of human agents.<sup>61</sup>

Is it the case that determinism means that nothing is really under people's control and thus no one is really morally responsible for any of their actions? If true, this would be a radical conclusion with implications far broader than questions about setting priorities in health care. At a minimum it would undermine the luck egalitarian distinction between chosen and unchosen behaviours and the distinction between behaviours for which people are and are not responsible. If the pervasiveness of luck undermines choice and responsibility in this way, then it would mean that all behaviours would be considered equally a result of luck and thus it would not be appropriate to hold people responsible for any of them. It would also provide no guidance about how to ethically ration health care.

One common interpretation of what it means to have control over an outcome is to have some sense of alternative possibility - that the agent could have performed a different action from the one that they actually did. This is also an intuitive interpretation of what it might mean for an action to be ‘reasonably avoidable’ in the sense in which luck egalitarians would say makes a person responsible for their choice. However, our moral intuitions do not actually support this interpretation. Take Harry Frankfurt's famous example:

‘Suppose someone— Black, let us say— wants Jones to perform a certain action. Black is prepared to go to considerable lengths to get his way, but he prefers to avoid showing his hand unnecessarily. So he waits until Jones is about to make up his mind what to do, and he does nothing unless it is clear to him (Black is an excellent judge of such things) that Jones is

going to decide to do something other than what he wants him to do. If it does become clear that Jones is going to decide to do something else, Black takes effective steps to ensure that Jones decides to do, and that he does do, what he wants him to do. Whatever Jones's initial preferences and inclinations, then, Black will have his way.<sup>62</sup>

The vast majority of people have the moral intuition in this scenario that what matters for moral responsibility in this case is whether Black *actually* intervenes. If Jones' action is consistent with his mental processes in the right kind of way then we still hold him responsible, even if he could not have done otherwise.

Many luck egalitarian philosophers, in addressing the pervasiveness of luck and chance, argue that the type of responsibility that they have in mind has nothing to do with whether the agent had the ability to do otherwise and do not depend on metaphysical arguments about determinism. What they appeal to is that people are responsible for the choices that they make as long as they are connected to their mental processes in the right kind of way, regardless of whether the agent could do or choose otherwise or not. Many luck egalitarian philosophers specify that their theory is agnostic as to which theory of choice and responsibility is used. For example, Zofia Stemplowska argues that:

'So, to clarify, when I say that one has chosen a disadvantage or is responsible for it or the disadvantage is avoidable—terms I use interchangeably—I mean that one is to be thought of as the author of the disadvantage according to whichever plausible account of authorship/choice we adopt.'<sup>63</sup>

In a similar way, Richard Arneson argues that:

'luck egalitarianism is fully compatible either with compatibilism or free will libertarianism and has no stake in the debates between these rivals.'<sup>63</sup>

Arneson, Stemplowska and other philosophers argue that these questions of free will and moral responsibility are not relevant to discussions of the plausibility of luck egalitarianism, as a luck egalitarian theory would follow from whichever account of moral responsibility was adopted.<sup>64</sup> Luck egalitarian philosophers argue that luck egalitarianism has fair and reasonable implications for distributive justice whichever metaphysical theory turns out to be true, and thus the pervasiveness of luck does not undermine luck egalitarian principles of distributive justice.

### 3 Conclusion

In this chapter, I have noted that people's health behaviours (in particular smoking, excessive alcohol consumption, and consumption of large amounts of calorie-dense, nutrient-poor foods) have a very substantial effect on the demand for and cost of health care. These health-damaging behaviours are widely known to be harmful and can be plausibly seen as being the result of voluntary and informed choices. These factors motivate many people to argue that responsibility-sensitive principles for rationing health care are useful and fair. Luck egalitarians provide a philosophically nuanced set of views about how it is appropriate to use and apply the concept of personal responsibility in a theory of distributive justice. Luck egalitarian philosophers draw a strong distinction between outcomes which are the result of people's autonomous choices and those caused by factors outside people's control. Many luck egalitarian philosophers argue that it is appropriate to use criteria for allocating health care which are sensitive to people's freely chosen health-related behaviours.

Having described how luck egalitarian views can be applied to the problem of rationing scarce health care resources, in the following two chapters I will critique these applied luck egalitarian principles on both normative and practical grounds. In Chapter 2, I will discuss one of the more common objections to luck egalitarian principles. This is called the 'Abandonment Objection' and refers to the criticism that luck egalitarian principles are implausibly harsh to people who suffer as a result of their own bad choices or imprudence. This discussion is particularly relevant to people's health care behaviours, given the previously discussed shortages of health care, the impact of imprudent behaviours on need for health care, and the suffering which many health conditions can cause. In Chapters 2 and 3, I will argue that the luck egalitarian approaches to health care allocation that I have described in Chapter 1 have difficulty in responding to the Abandonment Objection and would be impractical to apply to real world public policy.

## Chapter 2: The Abandonment Objection and Responsibility-Sensitive Health Care

1. The Abandonment Objection and health care
2. The Basic Needs response to the Abandonment Objection
  - 2.1 Problems with the Basic Needs response: The vagueness of the concept of basic health needs
  - 2.2 Problems with the Basic Needs response: The scopes of distributive justice and basic needs
  - 2.3 Problems with the Basic Needs response: Basic needs and objectionable abandonment
  - 2.4 Problems with the Basic Needs response: Abandoning the innocent
3. The Solidarity response to the Abandonment Objection
4. The All-luck-egalitarianism response to the Abandonment Objection
5. The Social Value of Jobs response to the Abandonment Objection
6. Conclusion

In the previous chapter I discussed reasons why people support using responsibility-sensitive principles to ration health resources fairly in conditions of scarcity. The purpose of this chapter is to explore one of the most serious objections to luck egalitarian approaches to health care resource allocation – the Abandonment Objection. The most basic form of the Abandonment Objection is that luck egalitarianism permits and may require refusing medical treatment to people whose health condition is a result of their own reasonably avoidable behaviour, and that this outcome is so harsh and objectionable as to mean that luck egalitarian principles cannot be a plausible account of distributive justice. Luck egalitarians have provided a variety of responses to the Abandonment Objection, such as arguing that luck egalitarian principles of justice were never intended to apply to people's basic needs, or that the value of solidarity within a luck egalitarian view may outweigh penalising the imprudent. Other philosophers have provided a revised version of luck egalitarian principles which they claim is not subject to the Abandonment Objection or argued that luck egalitarian principles would not penalise people who make altruistic life choices, such as the choice to become a carer.

While there is an enormous volume of philosophical literature discussing the Abandonment Objection, and no single chapter can hope to provide definitive conclusions from a literature of this



size, I aim to show in this chapter that serious questions remain as to whether luck egalitarians can adequately respond to the Abandonment Objection. Another purpose of critically engaging with the luck egalitarian literature is for its implications on what kind of qualities a theory of allocating scarce health care resources should have. I suggest that luck egalitarianism does not have the internal resources to reject the challenge of the Abandonment Objection and that this provides a significant challenge to the moral plausibility of responsibility-sensitive health care. This provides a reason for thinking that a theory of health care justice should not be sensitive to individual responsibility for health behaviours.

### **1. The Abandonment Objection and health care**

One of the most prominent objections to luck egalitarianism was originally posed by Elizabeth Anderson and is called the 'Abandonment Objection'.<sup>65</sup> The crux of the objection is that luck egalitarianism permits and may require excessively harsh policies or attitudes towards victims of bad option luck. This outcome is not just a counterintuitive implication of luck egalitarianism but, in Anderson's view, undermines the goals of egalitarianism. This is because luck egalitarians, like other egalitarians, believe that the state should treat all citizens with equal respect and concern, and this equal respect and concern is undermined by excessive harshness of the policies that Anderson claims that luck egalitarianism would entail.

In describing her objection about the implausibly harsh consequences of luck egalitarianism, Anderson provides an example of an uninsured driver who negligently makes an illegal turn and crashes into another car. Anderson argues that in this situation, luck egalitarian principles do not require society to send an ambulance to provide medical care to the driver at fault, even if this means that the driver subsequently dies on the side of the road. Furthermore, if the driver survives the crash but becomes disabled, the state is under no obligation to accommodate his disability or provide disability services to him. One aspect to notice is that the alleged luck egalitarian response can be disproportionately severe. In Anderson's example, less than a minute's inattention while driving results in dying by the side of the road. Anderson notes that while there may be efficiency or procedural reasons for a luck egalitarian society not to deny medical treatment to the at-fault driver, these are not reasons of *justice*. While these other principles may mitigate the harsh implications of luck egalitarianism in practice, Anderson alleges that the fact that luck egalitarian policies would have these harsh implications at all renders them implausible.

Anderson also argues that luck egalitarianism would license giving lower priority, or may refuse help altogether, to people whose disadvantage is due to a freely chosen, altruistically motivated decision,

such as to become a carer for someone who is ill or elderly. To support this objection, Anderson quotes Roemer, who says that: 'Society should not compensate people for their choice of [a more altruistic, self-sacrificing] path because it owes people no compensation on account of their moral views.'<sup>65</sup> This objection could also be applied in regard to those who are injured as a result of taking up employment in freely chosen dangerous jobs, such as those in the logging or mining industries, or jobs in the armed services. Anderson argues that luck egalitarian theories lead to the conclusion that people who chose these occupations with foreknowledge of their potential dangers are thereby accepting the risk of potential injury or disability. Consequently, social institutions do not owe them medical care or disability payments in the event of accident or injury at work.

According to the Abandonment Objection, luck egalitarianism justifies policies that would allow serious harm to come to people if their misfortune was the result of their own reasonably avoidable choices. Anderson argues that:

'Luck egalitarians tell the victims of very bad option luck that, having chosen to run their risks, they deserve their misfortune, so society need not secure them against destitution and exploitation. Yet a society that permits its members to sink to such depths, due to entirely reasonable (and, for dependent caretakers, even obligatory) choices, hardly treats them with respect. Even the imprudent don't deserve such fates.'<sup>65</sup>

Anderson concedes that some luck egalitarian policies may limit the damage suffered by imprudent people who suffer bad luck. However, she argues that even these schemes, such as requiring people to take out mandatory insurance, are justified in paternalistic ways which also do not meet the egalitarian goal of expressing equal respect and concern for all citizens. Paternalism is inconsistent with equal respect in Anderson's view because it implies a negative judgement about a person's capacities, such as that they are inherently unable to make properly autonomous choices. Anderson argues that:

'Luck egalitarians do entertain modifications of their harsh system, but only on paternalistic grounds. In adopting mandatory social insurance schemes for the reasons they offer, luck egalitarians are effectively telling citizens that they are too stupid to run their lives, so Big Brother will have to tell them what to do. It is hard to see how citizens could be expected to accept such reasoning and still retain their self-respect'.<sup>65</sup>

In this quote, Anderson argues that paternalistic social institutions send the message that there are two types of people with two different levels of autonomy that are appropriate to them. There are the people with the capacities to make prudent decisions for both themselves and others. These are the people who can be decision-makers within social institutions. Then there are people who require

others to make decisions for them, citizens who are not properly autonomous because they 'are too stupid to run their lives'. In Anderson's view, social institutions which express that some people are less able to make properly autonomous choices than others are not social institutions which are fulfilling their moral duty to treat all citizens with equal respect and concern.

Samuel Scheffler<sup>66</sup> is another philosopher who argues that the Abandonment Objection is a serious challenge to luck egalitarian principles. Scheffler writes that 'the fact that a person's urgent medical needs can be traced to his own negligence or foolishness or high-risk behaviour is not normally seen as making it legitimate to deny him the care he needs.'<sup>66</sup> According to Scheffler, in our ordinary ethical intuitions, the fact that a disadvantage or injury is in some sense a result of a person's choices is not a deciding factor as to whether that person should receive assistance from social institutions or not.

The Abandonment Objection argues that luck egalitarian theories permit or require denying social assistance to people whose imprudent or risky choices result in them requiring health care. To the extent that it is implausible that justice requires or permits this denial of treatment and 'abandonment' of the imprudent, the Abandonment Objection provides a reason to reject luck egalitarian principles for the purpose of allocating health care resources in conditions of scarcity.

The Abandonment Objection has generated a substantial philosophical literature in the last twenty years. I do not have the space in this chapter to address all luck egalitarian responses to the Abandonment Objection. Given this limitation, I have chosen to address what I take to be the most promising luck egalitarian responses to the Abandonment Objection for the purposes of luck egalitarian health care. For example, Carl Knight provides a detailed discussion of the metaphysics of luck in his response to the Abandonment Objection, but this abstract metaphysical discussion is less directly relevant to my specific applied question of how to allocate health care resources fairly.<sup>64</sup> The most common luck egalitarian response to the Abandonment Objection appears to be a version of what I call the 'Basic Needs' response, arguing that luck egalitarian principles were never intended to cover situations of dire need, such as the situations that Anderson uses as examples. I have addressed this 'Basic Needs' response at the most length, as health care is often regarded to be a basic need and so this response is the most directly relevant to my question of how to allocate health care resources fairly. Other types of luck egalitarian responses which are relevant to the question of how to allocate health care resources include appeals to the importance of other luck egalitarian values (such as Anca Gheus' response discussed in section 3) and attempts to reformulate luck egalitarian principles (such as the All-luck-egalitarian version discussed in section 4). The way luck

egalitarian theories treat the altruistic (those who knowingly damage their health for the sake of other people) as compared to the ‘imprudent’ (those who knowingly damage their health without reference to other people’s interests) has received less attention in the philosophical literature than other responses to the Abandonment Objection. However, I address it in this chapter, as many people who damage their own health as a result of altruistic motives are carers for people with illnesses or disabilities. Caregiving is an important (and often overlooked) type of health care and the stressfulness of being a caregiver can be damaging to the carer’s own health. I discuss Carl Knight’s responses to this issue in more detail in section 5.

One response that luck egalitarians<sup>11</sup> have occasionally made is to agree that luck egalitarian principles require the abandonment of the imprudent but to deny that this is unjust. The force of the Abandonment Objection is to claim that luck egalitarianism necessarily leads to *objectionable* abandonment. These philosophers agree that if a person ‘recklessly’ damages their own health then this behaviour may cause them to have a weaker claim to health care than others and perhaps miss out on receiving health care altogether. However, they argue that this result is in fact morally acceptable and does not constitute *objectionable* abandonment. While this is may be a coherent response to the Abandonment Objection, it is also a ‘high-cost’ response, that is, a response that comes at the cost of making luck egalitarianism significantly less attractive and plausible to many people. Furthermore, as Carl Knight notes, many luck egalitarian philosophers are committed to other views (such as views about about basic rights), which mean that they cannot make this response consistently.<sup>68</sup> Most luck egalitarian philosophers<sup>12</sup> take the Abandonment Objection to be a serious challenge which cannot be responded to in this way.

Many luck egalitarian theorists agree with Anderson to the extent that if luck egalitarian theories necessarily required excessively harsh ‘abandonment’ of the imprudent, that this would be an important argument against accepting their view. However, luck egalitarian theorists argue that in fact, their theories do not require this.

## 2. The Basic Needs response to the Abandonment Objection

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<sup>11</sup> The philosophers who have come the closest to making this argument are probably John Roemer and Eric Rakowski. See 42. Roemer JE. A Pragmatic Theory of Responsibility for the Egalitarian Planner. *Philosophy & Public Affairs* 1993; **22**(2): 146-66.and 67. Rakowski E. Equal justice: OUP Oxford; 1991.

<sup>12</sup> For overviews of the range of luck egalitarian responses to the Abandonment Objection, see 68.

Knight C. Abandoning the Abandonment Objection: Luck Egalitarian Arguments for Public Insurance. *Res Publica* 2015; **21**(2): 119-35. Also see 69. Voigt K. The Harshness Objection: Is Luck Egalitarianism Too Harsh on the Victims of Option Luck? *Ethical Theory and Moral Practice* 2007; **10**(4): 389-407.

One of the more common responses to the Abandonment Objection is to argue that scope of luck egalitarian principles is narrower than many of its critics suggest – meaning that luck egalitarian principles should only be applied to a certain subset of problems involving resource allocation. This scope restriction and the importance of other values mean that luck egalitarian theories do not require refusing health care or assistance to those whose condition is due to their own choices. These luck egalitarian philosophers argue that luck egalitarian theories should not be interpreted as applying responsibility-sensitive criteria to issues related to people’s basic needs.

For example, Kok-Chor Tan writes that luck egalitarianism:

‘should not be seen to be speaking for an account of justice broadly conceived, let alone an account of the whole of morality. Questions of distributive egalitarian justice are distinct from questions of assistance or rescue....’<sup>44</sup>

In this way, Tan sees the Abandonment Objection as a kind of category mistake, since examples of people in extreme need that Anderson employs do not properly belong to the domain of distributive justice. According to Tan, to the extent that the requirement for health care would be considered a basic need, it would be provided under principles of beneficence, assistance or rescue.

Tan challenges philosophers who make the Abandonment Objection to suggest an example of a person who would be objectionably abandoned in a society which had adopted his formulation of luck egalitarianism, with the clear implications that no such cases exist:

‘this challenge will have to present a case of bad luck that has no institutional influence but that is also not so devastating to the unlucky person such that it falls under the domain of basic needs, on the one side, and on the other, that is intolerable enough that egalitarians should be moved by it. For example, even if we can say that a person who has been unluckily blinded is now at a serious disadvantage independently of any institutional cause, my institutional account of justice can nonetheless accept that this person ought to be assisted on humanitarian grounds.’<sup>44</sup>

Tan argues that to the extent that a requirement for health care would not be considered a basic need, then it would necessarily be such a minor issue that denying this kind of care would not generate moral intuitions about excessive harshness and abandonment. In this way, according to Tan, scope limitations of luck egalitarian theories dissolve the Abandonment Objection.

In a similar way, Shlomi Segall<sup>15</sup> argues that issues of distributive justice are only one aspect of morality. Segall writes that:

'Those who level the abandonment objection at luck egalitarians seem to ignore the complex nature of political philosophy as described here. Critics of luck egalitarianism (and especially Elizabeth Anderson) seem to burden distributive justice with instructing almost every conceivable aspect of our political morality. Anderson claims to demonstrate that "luck egalitarianism generates injustice;" but in fact she shows (at best) that luck egalitarianism leads to just policies that are undesirable for other reasons. Despite Anderson, we see now, the view that luck egalitarian distributive justice does not compel us to provide treatment to reckless drivers and unlucky smokers is compatible with the view that we should nevertheless do so, due to some other moral consideration... Luck egalitarianism is compatible with the view that equality (or egalitarian distributive justice) does not trump all other considerations of justice, let alone all moral considerations.'<sup>53</sup>

Segall thinks that it is morally wrong to let people's basic needs go unmet and that this provides sufficient reason to treat the imprudent within a luck egalitarian theory of justice. As an application to the question of health care rationing, he goes on to argue that health care is part of the social minimum that society is morally required to guarantee to its citizens, writing that:

'Another, perhaps even stronger reason to treat the imprudent is that we must not allow basic needs, including medical needs, to go unmet. The obligation to meet basic needs is a well-entrenched moral requirement in ethics and political philosophy. It is based on the recognition that individuals have a deep interest in having their needs met... We commonly think that there is some urgency about meeting needs, urgency that is not necessarily there when we consider meeting people's mere preferences. We consequently think that individuals would be harmed if their basic needs are not met. Since it is plausible to think that we owe each other equal protection from harm, this is often seen as capable of grounding a universal entitlement to health care. Health care, on this account, is simply part of the social minimum that society ought to guarantee to its citizens.'<sup>15</sup>

Segall argues that the requirement to meet everyone's basic needs comes from a belief in everyone's equal moral worth, and that society should respect all its citizens equally. In this way, concern for everyone's basic needs is a *complement* rather than a competitor to luck egalitarianism. In this way, Segall's envisioned luck egalitarian society would provide medical care for even imprudent patients.

Nicholas Barry argues that a luck egalitarianism should be combined with another egalitarian value which guarantees citizens an equal set of basic capabilities. As Barry writes:

'A key question in political philosophy is determining what citizens receive in return for agreeing to submit to the state's authority... In brief, it seems fair that each person is equally guaranteed the capabilities needed to participate fully in a democratic society, in return for the freedom that they have lost in the state of nature. The capabilities provided here would probably be similar to those guaranteed under Anderson's theory of democratic equality and would meet the basic needs of all citizens. Thus, luck egalitarianism should not be rejected because of the harsh treatment problem. Rather, it can be combined with another egalitarian value that guarantees all citizens an equal set of basic capabilities.'<sup>53</sup>

In Barry's view citizens are owed the capabilities they need to fully participate in a democratic society in return for the citizens giving up the freedom that they would have had in the state of nature, and Barry's envisioned capability set would meet the basic needs of all citizens. In this way, the Abandonment Objection would not arise in Barry's version of a luck egalitarian society.

Carl Knight, another luck egalitarian, responds to the Abandonment Objection by recommending that the state covers basic health care needs under a system of compulsory insurance. Knight argues that this system is not contrary to luck egalitarian responsibility-sensitive principles:

If the state makes health insurance compulsory by funding a public health service through taxation, there is not necessarily an inequality of health care nor, as regards health coverage, any differential exercise of responsibility. There is therefore nothing in the principle of equal opportunity for welfare that requires persons to be given the choice to opt out of health insurance. Moreover, under a more laissez-faire system it cannot simply be assumed that individuals are responsible for their failure to arrange health insurance. There may be economic and psychological barriers which undermine non-insured persons' responsibility for their circumstances. Universal health care may be a much surer way of matching levels of health care to levels of responsibility.'<sup>70</sup>

Knight goes on to comment on the unlikelihood of people being objectionably abandoned in a luck egalitarian society:

It is also worth noting that there is good reason to think that the nightmare scenario described by many opponents of luck egalitarianism, where someone has a very severe injury and no access to relatively inexpensive but vital health care on account of their irresponsibility, would never actually happen in an advanced industrial society ordered along luck-egalitarian lines. First, as noted previously, every advanced industrial society has a system of public health care in place, and luck egalitarianism gives, if anything, reasons for strengthening such systems. Second, it is fairly likely that even were such a system removed

for some (non-luck-egalitarian) reason, charitable donations would cover all occurrences of negligent victims who could not pay their medical bills. Third, even given that responsibility is possible, doubts about individual responsibility will usually result in the provision of urgent treatment... Victims of lung cancer may be responsible for a choice (or a series of choices) to smoke but they are not responsible for their susceptibility to the disease. Similarly, the seriously injured victims of road traffic accidents may sometimes be responsible for dangerous driving, but they will usually be comparatively unfortunate in that circumstances (road conditions, the behaviour of others, the innate tolerances of their bodies, the precise characters of the impacts their body suffered, and so on) meant that other dangerous drivers did not suffer such serious injuries. Finally, even were there no public health care system, effective charity network, or local doubts about responsibility, the luck egalitarian government would probably pay for every reasonably affordable and crucial treatment on account of doubts about responsibility itself.<sup>70</sup>

In this way, Knight argues, the Abandonment Objection is based on misguided and unwarranted concerns, and would be extremely unlikely to result in any negligent patients being harmed.

Thus, a number of luck egalitarians suggest that luck egalitarianism should not be rejected because of the Abandonment Objection. Rather, they argue that the limited scope of luck egalitarian distributive justice means that it is entirely consistent for luck egalitarian principles to be supplemented by other principles that would ensure that all citizens' basic needs would be met.

### **2.1 Problems with the Basic Needs response: The vagueness of the concept of basic health needs**

One problem with this response to the Abandonment Objection is the lack of clarity of the concept of basic needs. Health interventions cover continuums of urgency, importance and extensiveness which are not easily reducible to whether they cure or correct for health conditions. For example, medical corrections could include both standard reading glasses as well as expensive surgery. What it means to meet a person's basic health needs can vary enormously in expense. This is even true with a restrictive set of criteria, such as treating people for conditions for which they would likely die without treatment. For many, if not most, instances of cancer, patients are likely to die if they do not receive treatment. However, treatment for cancer can involve using only off-patent, relatively inexpensive medications, or the newest medications under patent, which can cost as much as \$US475,000 for one infusion.<sup>71</sup> Both approaches to cancer treatment could be described as meeting a person's basic needs. The differences with how basic needs are defined could mean the difference between spending a tiny proportion of GDP on health if defined very strictly, or a country's entire GDP if defined expansively.



Countries' expenditure on health care vary substantially, and it is difficult to judge whether the variation tracks to what extent the countries are meeting their citizens' basic health care needs. Even within the OECD, in 2018, the United States spent over \$US9,000 per person (purchasing power parity adjusted),<sup>13</sup> whereas Chile spent approximately \$US2,000 per person.<sup>72</sup> An observer could conclude that the greater health spending in the United States is an indicator that the US is better at meeting its citizens' basic health needs than Chile. Alternatively, an observer could conclude that the fact that Chile has a higher life expectancy than the United States means that Chile is performing better at meeting its citizens' basic health needs. Both conclusions may be unjustified, as not all health spending may necessarily contribute to meeting citizens' basic needs and there are many health conditions which do not primarily affect life expectancy. While the concept of meeting basic needs may initially seem to be a straightforward concept, it is in fact complex and ambiguous on further investigation.

This lack of clarity about the definition of basic needs creates a problem for those luck egalitarian accounts which state that even imprudent citizens should still have their health care needs met. This would occur whether the concept of basic health needs was defined broadly, using a lot of resources and covering many medical treatments, or whether the concept was defined narrowly, using relatively few resources and covering only the most basic treatments.

If the concept of basic health needs was defined expansively, then the argument that all citizens are entitled to have their basic health needs met (and are not able to waive their entitlement to health care) could prove too much. A society could, in theory, choose to spend almost all of its GDP on health. With an ageing population and high expectations in developed countries, it would be theoretically possible to use all social resources to fulfil what could be argued to be basic health needs. Under Segall's framework, for example, it seems it could be considered just if a society did decide to use its resources in this way. There are a number of problems with this. Firstly, there are many goods and services that social institutions should provide other than health care, such as education and environmental protection, and Segall's account of basic needs does not seem to have a limiting factor to prevent this enlargement of health care spending. Another problem is that an extensive definition of basic needs could result in the expansion of health spending, leaving no room for discretionary spending for individuals to be able to pursue their conception of the good. Many liberal theorists believe that reasonable citizens have a legitimate interest in being able to develop,

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<sup>13</sup> Purchasing power adjusted estimates in constant 2010 US dollars.

revise and pursue their conception of the good, and this conception of the good may not have health care as its core value. Given these other considerations, a very expansive definition of the obligation of social institutions to provide for citizens' basic health needs seems implausible.

If it is the case that everyone is entitled to an expansive set of medical procedures in order to meet their basic needs, then there are a number of implications. Among these implications is that luck egalitarian principles become substantially less useful as a way of making fair choices about medical resources in situations of scarcity. It would mean largely conceding my argument that luck egalitarian principles should not be applied in regulating medical resources under scarcity. It would also have the implication that the proper scope of luck egalitarian principles is very restricted and that different domains require substantially different principles of distributive justice. This would undermine the explanatory power that is part of the attraction of luck egalitarian principles to many theorists.

A different problem arises if basic health care needs were defined very narrowly, for example to only cover a small list of procedures. Any sort of definition of basic needs that is intuitive enough to avoid the Abandonment Objection will be connected to the norms and technology of the society in question. What people expect as a 'basic' level of treatment or intuitively regard as fulfilling the duty of equal concern and respect for a person is not a static list of procedures and medications but will be related to the health care practices and norms of their society. For example, in Australia in the early 1980s, Magnetic Resonance Imaging (MRI) machines were unusual, and physicians would more commonly use other techniques to detect the presence or absence of cancers or tumours. Thirty-five years later, the use of MRI machines has become more routine. If an Australian health care system today refused to allow a patient with a suspected brain tumour to access an MRI scan they are likely to be considered to be 'abandoning' the patient and demonstrating a harsh lack of concern for them. As medical technology improves, and people's expectations are shaped by the range of treatments and possibilities available, a basic set of procedures will increasingly be seen as unacceptable, constituting abandonment rather than avoiding it. Thus, Segall and Tan are unlikely to be able to avoid the Abandonment Objection by defining basic health care needs as a very limited set of procedures and medications.

## **2.2 Problems with the Basic Needs response: The scopes of distributive justice and basic needs**

A further problem with the basic needs response is that it seems to redescribe some issues that are intuitively matters for distributive justice. To separate basic needs from the domain of distributive justice is a substantial and counterintuitive redefinition of the concept. The vast majority of philosophical literature tends to include basic needs as an intrinsic part of the scope of questions of

distributive justice. For example, John Rawls describes justice as involving principles for the 'distribution of the benefits and burdens of social cooperation'.<sup>13</sup> There is no indication in Rawls' work that justice only involves the benefits and burdens of social cooperation when this falls above a particular threshold. Many discussions of distributive justice include questions about sufficiency thresholds. In these discussions, philosophers consider whether rather than goods being distributed equally or via another distributive rule, social institutions should instead ensure that everyone reaches at least a particular threshold of the good in question.<sup>73</sup> Sufficiency theorists such as Harry Frankfurt.<sup>74</sup> Martha Nussbaum<sup>75</sup> and Elizabeth Anderson<sup>76</sup> do not see the question of people's basic needs as being out of the scope of their theories. On the contrary, theorists such as Nussbaum, who focuses on the developing world, consider people's basic nutrition, education and health care needs in detail. Many liberal egalitarian theorists, such as Philippe Van Parijs.<sup>77</sup> argue for guaranteed unconditional incomes designed to meet basic needs on the grounds of principles of justice. Furthermore, historically, much of the urgency and importance of discussions of distributive justice has come from the perceived injustice of distributions in which some people have a lot of resources while others cannot meet their basic needs. When Tan and Segall argue that only distributions which are not related to the meeting of basic needs should be considered to count as distributive justice, they provide little justification for so radically redefining the concept.

A major shortcoming of the basic needs response for luck egalitarians is that in many ways it concedes the challenge posed by the Abandonment Objection rather than responding to it. If the luck egalitarian reply requires radically redefining the scope of distributive justice that luck egalitarianism is thought to apply to, then this supports the objection that luck egalitarianism does not have the internal resources to respond to the Abandonment Objection.

A luck egalitarian could respond here that there are other values which are separate from the domain of distributive justice which could be appealed to, in arguing that their theory does not require abandoning the imprudent. For example, a luck egalitarian could argue that the brute value of welfare, or of social equality, or the importance of duties of rescue justify providing assistance to the imprudent *all things considered*, even if the narrower domain of distributive justice does not. However, there are a number of problems with this reply. Welfare and social equality are typically thought of as part of the domain of distributive justice, not set apart from it. For example, an important branch of egalitarian theory, as represented by theorists such as Robert Goodin,<sup>78</sup> considers the distribution of welfare or utility by social institutions. While social equality may be considered in relational terms, such as in the theories of Elizabeth Anderson<sup>65</sup> and Samuel Scheffler,<sup>66</sup>

this is usually thought to have at least very substantial distributive consequences and thus not set *apart* from the domain of distributive justice.

### **2.3 Problems with the Basic Needs response: Basic needs and objectionable abandonment**

A further problem with invoking basic needs as a luck egalitarian response to the Abandonment Objection is that if meeting people's basic needs is defined as something like protecting basic capabilities needed for full participation in a democratic society, this would appear to be *compatible* with a type of harshness and abandonment that seems objectionable. For example, consider a hospital or doctor which decided not to save the finger of a negligent driver who got into an accident, say, to save money, or to teach negligent motorists a lesson.<sup>79</sup> Losing a finger is compatible with retaining full democratic capabilities, is compatible with living a decent life, and, for most people, is unlikely to mean that they will lose their job and be unable to support themselves. However, most people would condemn any doctor or medical system that made this decision, and find them guilty of malpractice.

What if in this case the hospital had limited resources, such that the medical staff did not have the resources to repair the fingers of all the people in the waiting room? If the circumstances required that some people would not be able to have their fingers repaired, would this then imply that the 'prudent' patients should be prioritised over the 'imprudent'? I disagree that responsibility-sensitive rationing would be an appropriate way to prioritise some patients over others in this situation. Later in this thesis, I will describe and argue for rationing principles which do not make use of attributions of individual responsibility. I argue that in making priority decisions we should take into account both the effect that health care is likely to have in restoring people's capabilities, as well as its effect on subjective well-being. In a case like this, assuming that losing a finger will have the same effect on all the patients' capabilities, priority decisions could be made based on the effects that the treatment would be likely to have on different patients' subjective well-being. For example, imagine that two patients, A and B, had the same injury, but A also had a pre-existing condition which heightens their sensitivity to pain such that they suffered more in the same situation than B. In a case like this, treating A first would be likely to have best effect for addressing suffering and using health care to improve patients' subjective well-being.

What about in a case where A and B have exactly the same injury, treatment for both would cost exactly the same amount, the treatment would have exactly the same likely effect on their

capabilities and subjective well-being, and the only difference between A and B is their level of prudence in incurring the injury? Even where individual responsibility is the only 'tie-breaker' and resources do not allow us to treat both A and B, I do not agree that our moral intuitions compel us to give the prudent patient consistent priority. Even in this case, there are multiple moral considerations to be taken into account in making priority decisions, and individual responsibility is a systematically weaker consideration than others. In this situation, I would advocate flipping a coin to decide whether to give priority to A or B. Flipping a coin is preferable in this situation because it demonstrates procedural transparency, is an efficient process, and effectively expresses equal concern for the suffering of both patients. Even in this highly unlikely situation in which individual responsibility is the only difference between two patients, there are many other values for social institutions to consider, which would outweigh any value of differentiating between 'prudent' and 'imprudent' patients in this context.

Nir Eyal, using a different example, argues that:

'We would also condemn, and our legal systems and professional societies could penalize, a physician known to have let an imprudent, generally healthy skier wait and suffer extreme pain from a dislocated shoulder so that she can first help other patients with lesser pain and medical urgency, but greater prudence and hence allegedly a prior claim to her assistance. Based on a reliable initial screening, the physician estimates correctly that the skier's level of pain is perfectly safe, given his young age and general good health, such that his survival needs and lifelong happiness are not in jeopardy. She lets the skier wait in agony for two long hours, without administering available anesthetic. We would normally condemn such physicians and accuse them of medical neglect. However, since two hours of agony are clearly compatible with a decent life, the decent minimum account cannot explain why we would condemn them.'<sup>79</sup>

Suffering a few hours of extreme pain is compatible with retaining basic capabilities and leading a decent life, yet many people would have a strong intuition that this treatment constitutes objectionable abandonment and is unacceptable.

#### **2.4 Problems with the Basic Needs response: Abandoning the innocent**

A further reason to think that there is no principled way to separate basic needs from distributive justice is that as resources are limited in health care, a luck egalitarian scheme which still provides medical care to the reckless results in *overruling* egalitarian justice. This is because in a luck egalitarian framework, the reckless have no justice-based claim to treatment, however, they should be provided with treatment because social institutions have a non-justice duty to meet their basic

needs. With a shortage of resources, however, treating the reckless at all means directing resources away from meeting society's duty of justice to aid the innocent, in order to aid those who have no claim of justice for assistance.

Within the assumptions made by a luck egalitarian account, this seems actively unjust to those who are not responsible for their health condition.

As Nielsen and Axelsen describe it:

‘The puzzling thing about luck egalitarian justice, in this case, is that if treating an innocent patient for a health deficit which she is not herself responsible for is a matter of justice whereas treating a reckless patient for a health deficit which he is himself responsible for is not, then [Shlomi Segall's scheme] is overriding the concern of luck egalitarian justice.’<sup>80</sup>

As discussed in the previous chapter, resource scarcity is the standard case for health care at present and this seems likely to only become more acute in the future with an aging population. Thus, more generally, providing for the basic health care needs of the reckless seems likely to result in fewer resources being available for the care of the innocent, causing them to suffer through no fault of their own. Given resource scarcity, a consistent luck egalitarian account cannot both meet its obligations of justice towards the innocent as well as meeting the basic needs of the reckless, and luck egalitarian distributive principles governing the allocation of resources would seem to point to the prioritisation of the victims of bad brute luck, rather than bad option luck. However, this would then leave the Abandonment Objection unanswered as a challenge to the plausibility of luck egalitarian principles.

### **3 The Solidarity response to the Abandonment Objection**

Other luck egalitarians have responded in different ways to the claim that luck egalitarianism results in an objectionable abandonment of people who have made reckless or imprudent choices. For example, Anca Gheaus<sup>81</sup> argues that luck egalitarian principles *themselves* imply that social institutions should treat the imprudent, and thus the Abandonment Objection does not apply.

Gheaus argues that luck egalitarian societies should still provide health care to the imprudent in order to preserve social solidarity. This is because social solidarity is an important good, which makes people's lives go better and substantially contributes to well-being. Gheaus defines social solidarity as ‘the disposition to support one's compatriots in the satisfaction of their fundamental interests, for instance, through adequate mechanisms of social welfare’.<sup>81</sup> For Gheaus, solidarity must also be morally motivated and non-excludable, arguing that:

‘Like public goods in general, solidarity displays the feature of non-excludability: the scope of solidarity as defended here—that is, solidarity with all individuals who compose that society, rather than solidarity with particular groups—includes, by definition, everybody. A society that systematically fails to provide essential support to some individuals does not count as a solidarity society. In other words, the political good of solidarity cannot be provided only to some: as soon as certain individuals are excluded—in the case at hand, the imprudent—the good itself is undermined.

Gheus argues that making health care responsibility-sensitive means potentially abandoning the imprudent and this would result in undermining social solidarity. By undermining social solidarity and thus well-being, responsibility sensitive health care makes prudent citizens worse off. This occurs because, among other ways, social solidarity is instrumentally good. Gheaus notes that:

‘Much prominent research has recently indicated that living in societies that are materially very unequal negatively affects everybody’s subjective well-being on measures such as physical and mental health and educational achievements. Health, in particular, is negatively affected by large social inequalities: poor people are, on average, in worse health than rich people, and most individuals living in very unequal societies are, for this reason, worse off in terms of health. This may be in part because large material inequalities generate hierarchical social relationships of dominance and subordination and undermine solidarity.’<sup>81</sup>

Luck egalitarian principles require that people should not be made worse off through no fault or choice of their own. Thus, in order to preserve for *prudent* citizens the value of social solidarity and the associated effect on their well-being, luck egalitarians have reasons to provide health care to imprudent citizens too. In this way, luck egalitarian principles themselves avoid the Abandonment Objection

In response to Gheaus’ account, I agree that luck egalitarian health care in its standard form would indeed be likely to damage solidarity. But Gheus’ solution of providing health care to the imprudent would undermine social solidarity too. This is because the state would be endorsing the view that imprudent patients are not entitled to health care, and many people would note that in conditions of resource scarcity, health care resources that are spent on the imprudent are then unavailable for other members of society. Instead of promoting solidarity, it would promote a form of resentment, encouraging the view that imprudent patients are taking what doesn’t belong to them, and that imprudent patients are not playing by the rules. While it is possible that some people in society today already believe that imprudent patients are not entitled by principles of justice to health care, a luck egalitarian society would, raise this judgement, in Elizabeth Anderson’s words, ‘to the status of officially recognized truth’.<sup>65</sup>

Gheaus could respond to these criticisms by arguing that in her scheme it is not necessary that the true (luck egalitarian) reasons and principles behind public policies are expressed to the public. If citizens do not know that the reason that some citizens receive health care is for the benefit of social solidarity, even though those citizens do not really deserve the health care themselves, then perhaps they will not resent the imprudent and solidarity would not be undermined. However, this response would raise further problems. While it is true that there is nothing inherent in luck egalitarian principles that requires the government to be able to justify its actions to the public, to accept this would make luck egalitarianism less plausible in the eyes of many liberal theorists. Many liberal philosophers argue that for the use of state power or coercion to be permissible, governments must justify this coercion to citizens.<sup>82</sup> Philosophers disagree about the detail of what public justification might involve, such as whether the reasons for permissible coercion must be able to be recognised as valid by all citizens, or only by all citizens in the circumstances of certain constraints or idealisations. However, Gheaus' version of a luck egalitarian society would be required to *actively deceive* citizens about the reasons behind a public policy, to avoid stoking resentment which would then lead to a decrease in social solidarity. This type of deception would not meet even the most limited requirements for public justification and, for many people, would be a significant factor undermining the attractiveness of luck egalitarianism.

Gheaus' proposal also requires seeing treatment of the imprudent, not as something to benefit them or to alleviate their suffering, but as an instrument or a means towards the well-being of prudent citizens. Endorsing the view that some citizens can be treated as means to other citizens' ends seems also likely to undermine social solidarity of a morally valuable kind. Someone may object here that it is acceptable to use a person as a means to the ends of others if that person will also be benefited in the process. I agree that it is certainly *better* to help someone than to harm them as a means to the ends of other people. However, this is still likely to express unequal respect between citizens - it would express that some citizens have the dignity and importance to be regarded as ends in themselves and other citizens do not. Many theorists believe that the state has an obligation to respect everyone equally and under this assumption, using some people as a means rather than an end would still be problematic.

Also, a theory which allows some citizens to be used as a means to the ends of others is strange in the context of Gheaus' reply to the Abandonment Objection. This is because the Abandonment Objection is motivated by a concern for the interests and well-being of the 'imprudent', which are argued to be threatened by responsibility-sensitive health care policies. A reply that suggests that the



interests and well-being of the 'imprudent' are in fact of less *inherent* (as opposed to *instrumental*) value to the state than those of 'prudent' citizens seems more likely to concede the objection (or argue that there is actually nothing wrong with 'abandonment') rather than respond to it by showing that responsibility-sensitive health care policies can in fact treat the 'imprudent' with due respect and concern. Thus, it appears that Gheaus' theory does not help luck egalitarian principles to avoid the Abandonment Objection.

#### **4. The All-luck-egalitarian response to the Abandonment Objection**

A different way in which luck egalitarians could respond to the Abandonment Objection is to adopt an altered theory, which Shlomi Segall refers to as 'All-luck-egalitarianism'<sup>15</sup>. All-luck-egalitarianism differs from standard luck egalitarianism in that all-luck-egalitarians are committed to neutralising the effects of option luck, whereas this is not part of standard luck egalitarian theories. All-luck-egalitarians argue that since all luck is morally arbitrary, suffering because of bad option luck (if this is considered relative to those with good option luck) is as unjust as suffering from bad brute luck. Theorists who endorse variants of this view include Thomas Christiano,<sup>83</sup> Kasper Lippert-Rasmussen,<sup>84</sup> Alexander Cappelen and Ole Norheim.<sup>85</sup>

One application of All-luck-egalitarianism to health might be to require pooling the costs of health care among people who make similar gambles with their health. For example, the costs of smoking-related diseases would be pooled among all smokers, rather than all citizens. Imagine two smokers who have smoked an identical number of cigarettes for an identical number of years (and so could be considered to be equally imprudent) and are also the same in every other morally relevant feature. If one smoker develops a smoking-related disease (experiencing bad option luck) while the other one does not (experiencing good option luck), then the costs of the one smoking-related disease would be shared equally by them both. To apply this idea to public policy, the costs of treating smoking-related diseases could be paid for by a tax on cigarettes or through forcing smokers to take out special insurance.<sup>85</sup> All-luck-egalitarianism would then be sensitive to individual responsibility for health behaviours without refusing medical care to those deemed imprudent. The attraction of All-luck-egalitarianism is that it appears to hold people accountable for the choices that they make and not the lucky or unlucky consequences of these choices. It avoids requiring the prudent to subsidise the imprudent, and proponents could argue that through its risk pooling of option luck, it avoids the charge of abandoning victims of bad option luck.

The most serious problem with this view is that, if applied consistently, it may still lead to abandoning many imprudent patients. One situation where this is likely to occur is if there are not

enough people who experience good option luck to provide enough resources to avoid abandonment of those with bad option luck. To take the previous example of smoking, avoiding abandonment of those who develop a smoking-related illness requires that there are enough people who smoke but remain healthy to contribute to the fund for unlucky smokers' health care. If a significant majority of smokers turn out to be unlucky, then there will not be enough resources available from the dedicated tax or insurance fund to pay for the treatment of smoking-related illnesses. Social institutions in this situation would then be left with two options. They can pay for the treatment of smoking-related illnesses from a general health care fund, thus violating the principle (that many luck egalitarians hold) that prudent citizens should not have to subsidise imprudent citizens and moving away from the centrality of choice and responsibility. Alternatively, social institutions could decide not to fund the treatment for smoking-related illnesses, leaving the Abandonment Objection unanswered.

Someone might object here that it is unlikely that people would engage in behaviours that are so dangerous as to result in there being not enough people with good option luck to subsidise those with bad option luck. Would not the very high risk of illness be its own deterrent for engaging in these kinds of behaviours? However, in fact people do engage in behaviours which predictably result in a very high rate of injury or illness. For example, a recent longitudinal study has found that in Australia, up to two-thirds of deaths in current smokers can be attributed to their smoking.<sup>86</sup> People choose to recreationally take drugs known to be addictive, such as heroin or methamphetamines, despite the high risk that they will become dependent on the drug. There is no guarantee that the highly dangerous nature of an activity will deter people from engaging in it. This means that All-luck-egalitarianism still potentially faces the problem that there will not be enough people with good option luck to avoid abandoning those with bad option luck, leaving the Abandonment Objection intact as a criticism of luck egalitarian principles as applied to health care.

### **5. The Social Value of Jobs response to the Abandonment Objection**

When considering the Abandonment Objection in relation to luck egalitarianism in health care, the majority of discussion has been focused on the treatment of people who are considered to be imprudent or negligent. However, abandonment concerns can also apply to people who choose to benefit other people at the cost of their own health. For example, being a carer for an elderly person or a person with a disability can be stressful and this stress can have a direct impact on the carer's health. As a review of literature on caregiving notes:

'It is now believed that the immune system does not operate independently from other body systems but rather communicates via pathways with the central nervous and endocrine

systems. Psychological variables such as caregiving stress may influence immunity and disease susceptibility through central nervous system innervation and hormonal pathways.<sup>187</sup>

Other ways in which caregiving can affect health is through increased likelihood of the carer adopting unhealthy behaviour patterns, either through lack of time or as a way to manage the stress. Furthermore, the demands of caregiving can have a substantial effect on the carer's mental health. Research indicates that between a third and half of carers suffer significant psychological distress, and experience higher rates of mental ill health than the general population.<sup>88,89</sup>

Critics of luck egalitarianism, such as Elizabeth Anderson, argue that luck egalitarians would penalise carers who themselves subsequently experience health problems, as these health problems would then be classified as bad option luck. Anderson argues that:

'[p]eople who want to avoid the vulnerabilities that attend dependent caretaking must therefore decide to care only for themselves. This is egalitarianism for egoists alone.'<sup>65</sup>

Some luck egalitarians might reply that in many modern societies, there is inadequate support for elderly people and people with disabilities, and so the decision by their family members, partners or friends to care for them is not a free choice but prompted by necessity. Due to these factors constraining their choices, health conditions that result from the stress of caregiving should be regarded as bad brute luck, not bad option luck. However, there are likely to be cases in which people choose to become carers even in societies with adequate state-provided support for the elderly and people with disabilities. It seems harsh to deny treatment or give lower priority to altruistically motivated people if they then develop health conditions as a result of their altruistic choices.

To illustrate this point, imagine the case of a woman who has an adult son with a range of severe intellectual and physical disabilities. While social institutions in her society provide free and high-quality residential care, her son is shy and would rather be cared for by family rather than professional caregivers. Therefore his mother cares for him instead, even though she finds the caregiver role stressful and time consuming, and this means that she doesn't have any time or energy to eat a balanced diet or exercise. Her unhealthy behaviours and subsequent ill-health are the direct result of her choice to benefit other people. However, by many luck egalitarian accounts, this is a result of bad option luck for which she should be accorded lower priority in the health care system.

Many people think that would not have been unreasonable or infeasible for the mother in this scenario to choose for her adult son to be cared for in free, high-quality residential care and do not think that she would have been morally required to care for him by herself when good alternative options exist. For these reasons, the mother's choice to be a caregiver cannot be categorised as a choice that it would be unreasonable not to make, yet we think that her choice is praiseworthy, and that she should not be penalised by being given lower priority in the health care system when she needs medical treatment as a result of her unhealthy behaviours.

Carl Knight provides a luck egalitarian response to cases such as these, arguing that social institutions should compensate people for the social value of their work. As caring has a high social value, even though it is not a choice that is well rewarded by the free market, other social institutions should compensate caregivers for the social value they provide. Knight writes that:

‘The choice to be a caretaker is a choice that benefits society; without it, the cost of caring for children and the infirm would be borne by society. This choice can therefore be rewarded on luck-egalitarian principles.’<sup>70</sup>

In this way, Knight argues that luck egalitarian principles recognise the value of altruistic choices, and do not have to result in considering carers who subsequently develop health problems to be those who should pay the costs for their own choices. Thus, Knight argues that luck egalitarianism can avoid this version of the Abandonment Objection.

However, it's not clear that this response would avoid the abandonment of people with altruistic motivations. Consider a different case, of an evangelist, who gives up all his income and possessions to spread his religious beliefs. He is, in fact, the only adherent of this religion in the world, and there is no form of social or other coercion for him to take up this evangelistic lifestyle. He becomes an evangelist for altruistic reasons, as he believes that his religious message would make the world a better place. This lifestyle has many stresses and hardships, which cause the evangelist to develop a health condition. As this health condition was the result of his decision to become an evangelist, it could be seen as bad option luck. Yet, unlike the case of the care-giver, it is unclear that social institutions would be able to compensate the bad option luck on the grounds of social value. Declaring that his lifestyle as an evangelist has social value is too similar to coming to a conclusion about the truth of his religious claims, which is not an option for a pluralistic society with many competing conceptions of the good. However, this concern about pluralism doesn't therefore imply that we think that the evangelist should be abandoned or given lower priority as a result of his bad option luck. In this way, Knight's way of avoiding harshness is very limited, given that it only protects

those who have socially endorsed or particular types of altruistic jobs, and does not prevent abandonment of the altruistic in general.

Someone may object here that all that is required to avoid abandoning altruistic citizens is to provide a more inclusive description of 'altruism' or 'social value'. However, this is a deeper problem than it appears. It is difficult to directly classify or measure another person's motivations and to correctly identify to what extent their actions were motivated by altruism. Therefore, if a luck egalitarian state wanted to avoid abandoning the altruistic, they would need to look at the results of the person's actions. How the state evaluates the results of a person's actions is likely to depend on which substantive moral theory they use. By choosing any substantive moral theory, it is likely that some citizens will have a different view of the good and their altruistically motivated actions will not be classified as such by the state, leaving them vulnerable to abandonment.

As an example, one group within society may think that the good life consists of everyone living in minimalist simplicity with few possessions, whereas another group may value everyone accruing greater wealth and possessions. What the first group considers a positive social outcome is likely to be considered a negative social outcome by the latter group and vice versa. Any 'altruistic' work<sup>14</sup> done by the first group to minimise people's possessions is likely to directly oppose the 'altruistic' work done by the second group who would aim to maximise people's wealth and possessions. There is also no guarantee that the groups will agree on other conceptions of the good which could provide the basis for some shared goals, for example they may have different views about what objectively constitutes well-being or the importance of people's subjective assessments of their own well-being. If the state is judging by social outcomes, then they are unlikely to be able to consistently judge that the work of both groups creates positive social outcomes. And if the state chooses the values of one group over the other, for example by agreeing with the second group about the value of everyone maximising possessions, then they are not able to recognise the 'altruistic' work done by the first group as such, and thus leaves them in danger of abandonment.

## 6. Conclusion

In the previous chapter, I described the key concepts and distinctions involved in responsibility-sensitive, luck egalitarian principles for allocating scarce health care resources. In this chapter I have examined the Abandonment Objection as a key objection to luck egalitarianism as applied to health care priority-setting. The Abandonment Objection was initially raised by Elizabeth Anderson and

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<sup>14</sup> I will assume that any 'altruistic' work done by either group to promote their goals here is peaceful and lawful.

argues that luck egalitarian principles lead to objectionably harsh treatment of people who are considered to have caused their own condition through negligence or imprudence. This 'abandonment' of imprudent patients, Anderson argues, is anti-egalitarian in effect and counter to commonly held moral intuitions.

A variety of luck egalitarian theorists have suggested replies to the Abandonment Objection. The luck egalitarian literature is voluminous, and I have not been able to discuss all luck egalitarian responses to the Abandonment Objection in this chapter. However, I argue that the most promising luck egalitarian responses discussed here still have serious problems and that this raises significant questions about whether luck egalitarianism can be a plausible moral account of allocating health care resources in conditions of scarcity.

The response that a luck egalitarian society would provide for everyone's basic needs would require a substantive definition of basic health needs which the proponents do not provide and would also require a strange restriction of the scope of the principles of distributive justice. Anca Gheaus' attempt to justify health care for imprudent patients through the value of solidarity seems likely either to undermine solidarity through resentment, or to require deception of citizens about the principles which their health care allocation system is based on. All-luck-egalitarian adaptations to luck egalitarian theory look promising but may result in being unable to provide health care to imprudent patients if a large enough proportion of the imprudent suffer bad option luck. Luck egalitarian theorists have also not shown that their theory would not abandon those who choose to damage their own health due to pursuing altruistic goals. For these reasons, I argue that luck egalitarian theorists have not been able to demonstrate that luck egalitarianism has the internal resources to be able to respond adequately to the Abandonment Objection.

In the next chapter, I focus on a different aspect of luck egalitarian principles for setting health care priorities fairly. I argue that luck egalitarian principles should not be used as a way of regulating health care resources in practice as these principles would be infeasible to implement into public policy.

## Chapter 3: Problems with Responsibility-Sensitive Health Care Policy

1. Luck egalitarianism as applied to public policy
  - 1.1 Luck egalitarianism in health care rationing policy
2. The dilemma for supporters of responsibility-sensitive health care policies
  - 2.1 The Practicality Principle
  - 2.2 Direct and Indirect Failures of the Practicality Principle
3. Indirect failure of the Practicality Principle - The Regressive Impact Objection
  - 3.1 Roemer's response to the Regressive Impact Objection
  - 3.2 Problems with Roemer's response to the Regressive Impact Objection - Information and Intrusiveness
  - 3.3 Problems with Roemer's response to the Regressive Impact Objection: Unsatisfactory Proxies for Responsibility
  - 3.4 Stemplowska's response to the Regressive Impact Objection
4. Direct failure of the Practicality Principle – the Lack of Information Objection and Epidemiological Knowledge
  - 4.1 Response to the Lack of Information Objection – the appropriateness of proxy variables in policy
5. Conclusion

In the previous chapter, I criticised luck egalitarian theories on normative grounds, suggesting that serious questions remain as to whether luck egalitarian theories have the internal resources to effectively counter the Abandonment Objection. Following on from the previous two chapters, the purpose of this chapter is to explore a different aspect of responsibility-sensitive health care - how principles of luck egalitarianism could be applied in practice to health care policy. Here, I focus only on that subset of luck egalitarian theories which advocate applications of luck egalitarian principles in health care policy. I argue that another reason to reject luck egalitarian principles as a way of regulating health care resources in practice is that they would be infeasible to implement. My argument in this chapter that it is infeasible to apply luck egalitarian principles in public policy provides further evidence that the principles for allocating scarce health care resources should not be sensitive to individual responsibility.

### 1. Luck egalitarianism as applied to public policy

Theories in political philosophy have a variety of goals and scopes. Some theories aim to describe how a perfectly just society would operate given certain normative demands, even if in practice few people are likely to accomplish what this theory demands. An example of this kind of theory is one which might claim that particularly talented people are required to make an especial effort to use their talents for the public good, even though these talented people do not receive any extra compensation or public esteem for their efforts. This theory would be one account of what justice requires, even if this theory does not claim that there is any way in which these particularly talented people can be motivated to work especially hard for society without extra incentives *in practice*, and thus does not make any kind of real world policy prescriptions.

Another goal that a theory might have is to describe a just society under certain idealisations, such as assuming that particular facts are different to the way that they are in the real world. For example, a theory might describe what a just society would look like if people's physical needs were different, such that they did not need to sleep. In such a world, there might be different requirements for just policies – perhaps it would be the case that it would be reasonable to raise standard working hours from 40 to 50 hours a week. Theories of this kind are hypothetical investigations of justice and are not making policy recommendations given the conditions of the actual world.

In this chapter, I am not addressing either type of the above theories. For these theories, it would be unreasonable to argue as an objection that they are impractical to implement in policy, as making policy prescriptions is not what these theories are trying to do. In this chapter I am focusing only on luck egalitarian theories to the extent that they advocate policy prescriptions.

In this chapter, I will be focusing on an intermediate level of idealisation which I call *pragmatic normative theory*. Pragmatic normative theory is not highly specific, such as proposing particular laws for a particular country, but neither does it propose theories with many hypotheticals, such as discussing what would be reasonable in a society where people don't need to sleep. It takes many facts about the world as given, such as assuming that people have the same physical characteristics, needs and moral psychology and respond to incentives in the same way as they do in the real world. For example, I take as granted that medical knowledge and technology and people's health care needs are roughly the way that they are in the real world. My project here is not to explore unlikely hypotheticals, such as how medical resources should be allocated if we lost the ability to manufacture vaccines, or if people never developed cancer, or if everyone perfectly followed medical



advice about diet and exercise. While this may also be an important type of project in applied philosophy, it is not my project in this chapter.

### **1.1 Applications of luck egalitarianism in health care rationing policy**

With these caveats noted, there are a number of luck egalitarian philosophers who *do* advocate for changes in health care policy to make it more sensitive to individual responsibility, such as by proposing that people who knowingly engage in health-damaging behaviour should not receive priority for health care if they develop a medical condition as a predictable result of these behaviours.

For example, Richard Arneson<sup>48</sup> argues that it is possible to find public policy implications of luck egalitarianism which can be implemented fairly. In arguing for this, Arneson makes a distinction between ‘fine-grained’ and ‘coarse-grained’ considerations when attributing responsibility. A coarse-grained approach looks only at whether a particular individual met a certain standard of behaviour. A fine-grained approach to responsibility looks also at that individual’s talents and capacities, and the many complex background factors which affect a person’s choice of conduct. For example, one coarse-grained consideration about responsibility might be where a group with voluntary membership has together chosen to publicly perform a wrongful act, and so I am held responsible given that I am a member of this group. A more fine-grained consideration might be that there are certain individual features of my psychology which render me much less responsible for the wrongful act than the average group member. While fine-grained considerations affect how responsible a person is for their conduct, it is easy to see how they may be too complex and detailed to affect public policy. However, Arneson argues that there are policy contexts where the fine-grained considerations either cancel each other out, weigh decisively in one direction, or are not significant enough to outweigh coarse-grained judgements.

Arneson<sup>48</sup> suggests that a number of health policies meet his standards for the implementation of luck egalitarian principles. One example of this is imposing higher tax rates to the estates of elderly people who insisted on expensive medical interventions at the end of their lives for a small benefit. This is because Arneson considers these elderly people to be acting in a ‘selfish and feckless fashion’ by insisting on using resources that could be spent on the health of others to greater benefit, and thus their interests should be discounted when forming public policy.<sup>48</sup> Another example Arneson suggests of a potential luck egalitarian policy is to impose ‘serious informal and formal penalties’ on drunk drivers. This is justified by the fact that the dangers of drunk driving in causing injuries or fatalities in car accidents is so well known that the act of drink driving is virtually never excusable,

and thus the state should act against the interests of (undeserving) drunk drivers in order to better support the interests of other road users.

Another luck egalitarian, Shlomi Segall,<sup>15</sup> argues that some luck egalitarian principles should be applied in public policy. Segall advocates a form of insurance to transfer resources from imprudent citizens to the health care system. Segall's insurance would have a number of characteristics. It would be progressive and means-based, to avoid allowing wealthy people to 'buy their way out of recklessness'.<sup>15</sup> The transfers would also be a form of upfront cost, for example by imposing a fee before a person engages in extreme sports, rather than a bill after receiving necessary medical treatment. The reason for this is that some imprudent patients might refuse medical treatment if they knew that they (or their next of kin) might be presented with a large bill for their medical care if it was deemed to be the result of imprudence. It is worth noting here that while Segall uses extreme sports as an example of reckless behaviour, he also counts many other behaviours as posing an imprudent burden on the health care system. For example, not following medical advice and repeatedly missing appointments are also given as examples of such behaviour.

Zofia Stemplowska also advocates imposing luck egalitarian principles in some health care rationing public policies. Stemplowska suggests that policies should be imposed in some (but not all) situations in which a person has acted imprudently and requires extra medical treatment as a result. She argues that

'when considering when to offer compensation/medical treatment free at the point of use in a given situation, we should ask the following question (where sacrifices are measured in terms of people's interests): *Does acting to avoid disadvantage (were not compensation available) require greater sacrifice than offering compensation should the disadvantage arise? If the answer is positive, then we should offer compensation/free treatment, and if it is negative, then we should withhold it.*<sup>143</sup> (emphasis in the original)

As an example of this, consider the case of people who cycle without a helmet and then crash, requiring extra medical treatment. Stemplowska argues in this situation that 'there is likely little value in not developing an easy system for remembering to take the helmet along on most occasions (for example, one can try to keep it near one's bike) and therefore little value in always cycling without the helmet, with the resulting inability to claim free medical treatment.'<sup>143</sup>

While luck egalitarians acknowledge potential practical difficulties in applying their ethical theory to public policy, a number of luck egalitarian philosophers have proposed health care policies that

favour the interests of the innocent over the reckless, or transfer resources from imprudent to prudent citizens.

## **2. The dilemma for supporters of responsibility-sensitive health care policies**

I argue that philosophers advocating for responsibility-sensitive health care in public policy face a dilemma. In trying to make health policy more sensitive to individual responsibility they must either focus on health behaviours directly or focus on certain health outcomes as a proxy for these behaviours. Either option, I will argue, is problematic.

The first horn of the dilemma is if policymakers choose to track each person's health behaviours directly and to make each person's priority for health care to be at least partially dependent on these measured health behaviours. This would be unacceptable because it would be likely to result in penalising people who are already socioeconomically disadvantaged. Attempts to avoid this result would be likely to have other highly undesirable effects, such as creating policies that are unreasonably intrusive and require such detailed information that they are prohibitively expensive.

The second horn of the dilemma is if policymakers choose to track measurable health *outcomes* as a *proxy* for health behaviours, and to make each person's priority for health care at least partially dependent on these measurable outcomes. This approach would also lead to unacceptable results. There are very substantial gaps, biases and uncertainties in our knowledge of epidemiology and medical science, and the relationship between health behaviours and health outcomes is highly complex. Due to this, a policy relying on tracking measurable health outcomes as a proxy for health behaviours would result in such a high degree of error that the policy would not in fact be responsibility-sensitive.

As both horns of this dilemma lead to unacceptable outcomes, I argue that this provides a strong reason for believing that responsibility-sensitive health care policy would be impractical to implement.

### **2.1 The Practicality Principle**

I argue that theories which propose public policy changes can reasonably be judged by a principle which I will call the *Practicality Principle*.

*Practicality Principle:* It is legitimate to require of public policy that, given facts about the world, it's sufficiently likely to deliver on the goals of the policy without sabotaging the delivery of other important public policy goals.

This practicality principle should be contrasted with other feasibility-related concerns about public policy. For example, this principle has important differences with the familiar principle that 'ought implies can'. For example, philosophers commonly find it intuitive that it is not the case that I *ought* to run ten kilometres in one minute because I *cannot* run ten kilometres in one minute. This is an important way in which feasibility could be relevant to normative theory, however, it is not what I am focusing on in the Practicality Principle. For example, one difference is that 'ought implies can' is about the *decision making* process. In deciding whether or not I ought to run ten kilometres in one minute, a decisive consideration is whether I can run ten kilometres in one minute. In contrast, the Practicality Principle is not focused on the moral decision-making process, but on consequences of policies after they are implemented.

## **2.2 Direct and Indirect Failures of the Practicality Principle**

There are at least two ways in which a policy can fail the Practicality Principle. It can be a *direct* failure - a failure on the same dimension on which it was intended to improve. For example, a policy designed to save lives from road accidents by making the roads wider and less congested may actually cause more road deaths if people feel empowered by the improved roads to drive faster, for longer distances and more recklessly. In this way, a policy that directly fails the Practicality Principle is self-defeating.

Another way in which a policy can fail the Practicality Principle is through an *indirect* failure - a failure on a different dimension. This means that a policy may achieve its desired goal, but that goal is outweighed by negative policy consequences in another area. For example, a policy forbidding people to drive on highways at all may be successful in reducing road deaths, but this is at the cost of interrupting supply chains, causing severe shortages of food, and destroying large parts of the economy.

To apply this dilemma to the case of responsibility-sensitive health care policy, if the policy is responsibility-sensitive by tracking health behaviours directly, then the result is likely to penalise people who are already socioeconomically disadvantaged. I call this the Regressive Impact Objection, and this is an example of an *indirect* public policy failure, as the purported luck egalitarian benefits of making health policy more responsibility-sensitive are outweighed by the extent of the policy's

undesirable outcomes. There have been a number of theories which could potentially be used to attempt to avoid the Regressive Impact Objection, but I argue that these also fail with a different manifestation of an indirect policy failure - the policy becomes intrusive and it is prohibitively costly to get the necessary information.

However, if policymakers focus on tracking health outcomes as a proxy for health behaviours, then they run into an example of a *direct* policy failure. Due to lack of information about the relationship between behaviours and outcomes, they will not be able to accurately make health policy responsibility-sensitive. This is a direct policy failure because it is a failure on the same dimension that the policy intends to target, and means that the policy is not succeeding in doing what it is intending to do.

### **3. Indirect failure of the Practicality Principle - The Regressive Impact Objection**

A key objection to responsibility-sensitive health care is that it ends up further penalising already disadvantaged groups. For example, one policy proposal advocated by Segall requires more expensive insurance for 'imprudent' citizens.<sup>15</sup> Low income people would be disproportionately affected by this scheme under Segall's definition of 'prudence', as it is generally low income people who miss doctors' appointments,<sup>90</sup> exercise less frequently,<sup>91</sup> eat foods with a high concentration of fat and sugar,<sup>92</sup> and consume low levels of fruit and vegetables.<sup>93</sup> Richard Arneson's suggested scheme of severe penalties for drink driving<sup>48</sup> would also be likely to have a disproportionate impact on Australians of low socioeconomic status<sup>94</sup> and Australians living in rural and remote areas,<sup>95</sup> who are significantly more likely to drink alcohol at risky levels.

While it is true that there are some things that affluent people do which may be regarded as gambling with their health (such as extreme sports), the scale of this is minor compared to the impact of 'reckless' health behaviours that are more common among people on low incomes. For example, assume (as Segall does) that smoking is regarded as an imprudent behaviour. Smoking is highly correlated with socioeconomic status in Australia, as it is in many other countries. In 2015, people aged 14 years or older who were living in areas with the lowest socioeconomic status were more than twice as likely to smoke daily than people from areas with the highest socioeconomic status.<sup>96</sup> In the United States, a national study found that people with low income, low educational attainment, and menial 'working class' jobs were substantially more likely to smoke. While the likelihood of a person to attempt to quit smoking was unrelated to their socio-economic status, people with higher socio-economic status were more likely to be successful in their attempts to quit.<sup>97</sup> In England, rates of smoking were four times higher among the most disadvantaged than the

most affluent groups.<sup>98</sup> In Australia, in 2008, Aboriginal and Torres Strait Islander people were more than twice as likely as non-Indigenous people to be current daily smokers.<sup>99</sup> Smoking contributes to the most common causes of death in Australia, cardiovascular disease and lung diseases. In Australia, recent longitudinal studies indicate that nearly two-thirds of deaths in current smokers aged 45 years and over can be attributed to their smoking.<sup>86</sup>

In comparison, deaths from extreme sports are classified as deaths from 'external causes', and are not usually listed separately, making it hard to gather exact statistics. However, when all deaths in Australia from falls, exposure to heat and cold, water transport, drowning, poisoning and other accidents are grouped together (excluding car accidents and suicide) fewer than 200 people died of these causes in 2014.<sup>100</sup> These figures indicate that imprudent activities leading to poorer health that are more practised by people of lower socioeconomic status are on a much larger scale than those more practised by people of higher socioeconomic status. Poorer people would be enormously more affected by policies that aim to make health care sensitive to 'imprudent' health behaviours.

Some people might reply that the Regressive Impact Objection is only a problem because existing holdings of resources do not reflect a luck egalitarian account of distributive justice. Roemer and Stemplowska's potential responses to the Regressive Impact Objection, which I explore below, can be read as suggesting ways to compensate for the fact that existing distributions of resources are not necessarily fair from the perspective of luck egalitarian principles. For example, many people have fewer resources than others through no fault or lack of effort on their part, and Roemer and Stemplowska suggest ways in which these unchosen factors may affect health behaviours. However, I argue that these mechanisms for compensating for the fact that other holdings do not reflect a luck egalitarian account of distributive justice are not likely to be practical or fair. The absence of other plausible mechanisms to adjust for the effects of pre-existing inequality and injustice is a substantial problem for the project of applying luck egalitarian principles into public policy. After all, if we needed to wait for *all* other holdings to be fairly distributed before luck egalitarian principles could be applied to the distribution of health care resources, then this is largely conceding that they can *never* feasibly be applied.

### **3.1 Roemer's response to the Regressive Impact Objection**

One comprehensive and thoughtful luck egalitarian response to the Regressive Impact Objection could be given by John Roemer,<sup>42</sup> who suggests a scheme detailing how an egalitarian planner could neutralise the effect of existing disadvantage on individual behaviours. Roemer makes a distinction

between individual choice and effort (which he considers to be factors under an individual's control) and other circumstantial factors, which are not. In Roemer's scheme, people within a given society should be first classified into 'types', grouping them with other people of broadly the same social, economic, genetic, or other relevant unchosen circumstances. Within any 'type' there will be a distribution of levels of effort made by the individual, with some individuals choosing to work very hard (or make certain other sorts of prudent choices) and others choosing to work less hard.

Roemer argues that people at the same percentile of the effort distribution *across* 'types' should be enabled to achieve welfare and success equally. For example, suppose that people with a disability who also grew up in poverty were grouped as one type (Type A), and people who do not have a disability and grew up in a wealthy household were grouped as another type (Type B). The person who puts in the median amount of effort in Type A should be able to achieve the same success and welfare as the person who puts in the median amount of effort in Type B. These people in Type A, due to their relative disadvantage, are likely to need more social resources to achieve at the same level as those in Type B. In Roemer's view, these extra resources should be provided to them by society, as having a disability and growing up in poverty are factors outside an individual's control.

Why should people be first divided into 'types'? Why not simply argue that people who make the same amount of effort should be enabled to achieve the same results or rewards? This complication is important because it provides for the possibility that different 'types' will have differently shaped distributions of effort. In each set of social circumstances, different levels of effort may seem more reasonable or worthwhile. Roemer<sup>47</sup> gives a simplified example of comparing children in Type 1 (here defined as children who live in poverty, with family disruptions, and parents who did not finish high school), with children in Type 2 (here defined as children from stable, affluent homes, whose parents both have university degrees). In this scenario, imagine that the median child in Type 1 displays an effort level at school of 2 hours of schoolwork a week (and Type 1 children have an effort range of 1 to 7 hours per week). However, the median child in Type 2 might display an effort level at school of 5 hours of schoolwork a week (and Type 2 children have an effort range of 3 to 8 hours per week). The difference in the distributions between Type 1 and Type 2 children occurs because children in Type 2 have been encouraged to see the value of education and have grown up in an enriching environment. In contrast, a child in Type 1 perhaps does not know anyone who has obtained obvious benefits from education (such as a high paying job). The experience of Type 1 children may have been that school is a dull, under-resourced place with a focus on standardised testing. From these different experiences it is reasonable for children in Type 2 to see education as being important to their future, and for children in Type 1 to see education as a pointless waste of time, and thus to

adjust their levels of effort accordingly. Roemer calls these considerations of circumstances, rather than absolute effort level alone, a 'principle of charity'. The idea is that if I had been in that other person's unchosen circumstances, I would have been likely to have thought in the way that they did, and to have behaved as they had.

Which factors should be used to classify individuals into 'types'? Roemer argues that each society through its own political process should decide what sorts of factors should count as being both relevant to individual success, and out of an individual's control. These factors will necessarily differ from society to society. People would only need to be asked questions about their social and demographic characteristics to determine their 'type', for evaluation of how well public policies approximate the desired distribution of resources.

Roemer applies his ideas to health care,<sup>42,47</sup> beginning by noting that there are many health conditions which are strongly affected by choices and behaviours under a person's control. Lung cancer is in many cases caused by smoking. Smoking is a behaviour under individual control that is widely known to have health risks. Yet many people continue to smoke. The number of years that an individual will smoke (and the heaviness of their smoking) in this example is analogous to 'effort' in Roemer's previous applications of his theory. This is because it is a behaviour under an individual's control, but also to some extent reliant on social and demographic variables that are outside an individual's control. For example, a female academic is less likely to smoke than a male steelworker. The application of Roemer's egalitarian theory to health care would demand that a male steelworker who has smoked for median number of years for his 'type' (e.g. thirty years) be held equally accountable as a female academic who has also smoked a median number of years for her 'type' (e.g. one year). The relevant resource being distributed in the case of health care might be the level of an individual's health insurance premiums, or perhaps whether an individual should be subject to additional taxation. In this case, this would require that the median male steelworker and the median female academic pay the same health insurance premiums. In this way, Roemer's scheme aims to control for the effect of socioeconomic status and other unchosen variables on people's health behaviours, and thus provide an account of luck egalitarian health care which is less vulnerable to the objection that it compounds existing disadvantage.

### **3.2 Problems with Roemer's response to the Regressive Impact Objection - Information and Intrusiveness**



However, there are some serious problems in using Roemer's scheme to neutralise the effect of existing disadvantage on health behaviours, and thus avoid the objection that luck egalitarianism has regressive effects.

One problem for Roemer's scheme is being able to gather and process enough information about people's health behaviours and socioeconomic characteristics to measure them against their 'types'. This is the case even if this scheme is deliberately simplified, such that people are only classified into a small number of 'types'. Collecting data about health behaviours directly is likely to be cumbersome and invasive of privacy, and self-reported data about health behaviours is often inaccurate even when there are no incentives to misreport (as there would be in this case).<sup>101</sup> Also, even with a relatively small number of factors dividing individuals into 'types', the complexity of the system soon becomes impractical. Robert Solow<sup>102</sup> describes this issue with reference to six unchosen factors which he assumes are related to employment and career success: ethnic background, height, physical attractiveness, gender, birth order, and region of origin within a country. If these factors have an average of four conditions (while gender is often considered to have two conditions, other factors may well have more), then these six factors would then lead to 4096 ( $4^6$ ) 'types' of people, which is clearly infeasible from a planning or public policy perspective. Even *measuring* the progress made towards achieving equal welfare or success across 'types' using a social survey (as Roemer suggests) would be impractical with so many comparison groups.

These problems about lack of information seem likely to only grow more severe in the future. Roemer recommends using social surveys to gather data about people's socioeconomic characteristics. Household survey data sets are currently a leading source of information about health, unemployment, poverty, and inflation, and have a significant influence in the distribution of government resources. The way that this data is currently used is much less difficult than Roemer's scheme would be, as statistics are compiled at higher levels of aggregation. However, even given this, the quality and reliability of this survey data is threatened by large decreases in the response rate of households, leading to high measurement error for these economic indicators.<sup>103</sup> International trends towards low and unrepresentative response rates for household surveys are substantial in size, and seem unlikely to reverse in the near future.

In Roemer's scheme, the state seems likely to also be intrusive, unnecessarily determining people's social identity. For example, imagine a society that was divided by religion, such that a person's religious identity was an important factor chosen by the political process used to classify people into 'types'. Given the connection between religion and other socioeconomic or demographic

characteristics in many parts of the world, religion seems a likely factor to classify people into ‘types’. This would leave little room for people who fall between these religious types, such as children with one Muslim and one Christian parent, whose family celebrates both Christmas and Eid. A scheme like Roemer’s seems likely to make these children choose either a Christian or Muslim religious identity, rather than an identity which incorporates elements of both (or neither) religion. It does not seem to be the role of the state to impose these kinds of limits on people’s public identities, especially (as in the case of religion) if these identities are connected to important aspects of people’s conceptions of the good. A scheme with unrealistically high information demands and high intrusiveness approaches another type of indirect failure of the Practicality Principle, as the policy’s other negative consequences are likely to outweigh its benefits.

### **3.3 Problems with Roemer’s response to the Regressive Impact Objection: Unsatisfactory Proxies for Responsibility**

A further problem is that Roemer bases his scheme on the idea that an individual is less responsible for their actions if these actions are more prevalent within their type. However, this appears to be confusing the concepts of how responsible someone is for their actions (given their social background) and how much they differ from the norm, whereas in fact they are different concepts. The reason his scheme sounds plausible is that we can think of many situations where the prevalence of someone’s behaviour within their social context may in fact make them less responsible for it. For example, if everyone in your social circle does X, you may be less responsible for doing X yourself, if the social context means that you do not know that there is an alternative to this behaviour, or you are not aware of the risks. However, without this more detailed explanation for how the prevalence of an action affects individual responsibility, Roemer’s scheme is much less plausible and may in fact involve penalising people just for being idiosyncratically different from the norm.

For example, suppose there is a society where all alcohol and drugs are equally illegal and difficult to obtain. Nevertheless, in this society, alcoholism is much more common than drug addiction. Fred and Jake have the same socioeconomic status, the same time preferences, the same knowledge about health risk, the same level of weakness of will, the same lack of concern about addiction. However, Fred happens to hate the taste of alcohol, and becomes addicted to benzodiazepines<sup>15</sup> instead. Jake has no such aversion to alcohol and becomes an alcoholic. In Roemer’s scheme, Fred would be significantly more responsible for his addiction than Jake, as benzodiazepine addiction is much more

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<sup>15</sup> Benzodiazepines are a class of prescription drugs which can produce similar effects to alcohol intoxication. Many countries have a problem of non-prescription use of benzodiazepines, which can result in addiction and dependence on the drug.

uncommon within the 'type' that Fred and Jake share. But this seems implausible, as there doesn't seem to be a way in which Jake has shown greater or lesser effort or concern about his health than Fred. The difference between them rests on a morally arbitrary idiosyncrasy (Fred disliking the taste of alcohol) rather than considerations that plausibly mitigate or enhance someone's responsibility for their behaviours.

Roemer might argue here that the problem with these types of examples is one of description. Rather than seeing alcohol and benzodiazepines as entirely separate for the purpose of public policy, they should be grouped together as addictive and health-damaging substances. When appropriately described, the reason that socioeconomically disadvantaged people engage in more health damaging behaviours is not likely to be the result of some morally arbitrary traits. Rather it is likely to be the results of some underlying causal mechanism which works to mitigate the responsibility of people of lower socioeconomic status. In this way, Fred and Jake would be judged to be equally responsible for their respective addictions.

However, the problem with this response is that this method of adjusting for arbitrary individual differences is likely to only increase the informational demands discussed earlier. After all, in the example given above, rather than only needing to gather and process information about people's 'types' and alcohol consumption, the state would also need to gather information about which other types of behaviours are substantially equivalent to alcohol usage. Benzodiazepine usage may fall easily into this category, but other health-related behaviours are likely to be more ambiguous. For example, the extent to which marijuana usage is harmful or addictive is largely unknown, and epidemiological evidence remains limited.<sup>104</sup> Whether heavy use of marijuana should be treated in the same way as heavy use of alcohol is a matter on which many people disagree. Controlling for individual differences by redescribing health behaviours seems likely to add to the already impractical informational demands imposed by Roemer's scheme.

A further problem is in the way Roemer uses proxy variables in his scheme. Rather than measuring the impact of social conditions on individuals' moral responsibility directly, which would likely be impossible, he uses other variables to calculate this indirectly. For example, he uses income and occupational variables to calculate how social factors may have diminished an individual's responsibility for smoking. However, it seems that there is then a significant element of luck involved in *which* proxy variables are used. An individual may appear to be more responsible for their decision to smoke when their 'type' is defined with reference to their income and occupational category, and less responsible for the same decision when their type is defined in reference to their place of birth

and their parents' educational background. In Roemer's attempt to create a scheme which controls for socioeconomic luck in relation to health behaviours, he then adds another form of luck – the way in which the choice of variables grouping people into 'types' affects attribution of responsibility to an individual and thus their life prospects.

As Roemer's scheme appears to be infeasible and require unacceptable costs, it would not help the luck egalitarian to avoid the claim that responsibility-sensitivity in health would end up penalising already disadvantaged groups.

### **3.4 Stemplowska's response to the Regressive Impact Objection**

Zofia Stemplowska presents an account which could provide a different kind of luck egalitarian response to the Regressive Impact Objection. Stemplowska argues that the reason why unhealthy behaviours of people of lower socioeconomic status should not be penalised in a luck egalitarianism system is that it is too demanding for social institutions to require that they forgo these behaviours. Stemplowska writes that:

'At least in Britain, for example, binge drinking is often the only way for some people to be accepted into a community of peers. And, again in Britain, smoking is to a large extent a class issue. Thus I agree with the former British Secretary of State for Health John Reid, who suggested that for many very poor people in difficult situations (he singled out lone mothers in public housing), smoking is an essential and rare escape from stress.'<sup>143</sup>

However, I disagree that this response is strong enough to yield the conclusion that people of lower socioeconomic status should not be penalised for disproportionate levels of unhealthy behaviours. While it may be the case for some poorer people that smoking and binge drinking are inescapable for reduction of stress and for social inclusion, in many cases it will be just that people prefer to smoke, and their preferences have been shaped by the higher prevalence of smoking around them. For example, in the 1950s, smoking was ubiquitous in the most privileged social classes, not only people in high stress situations who needed to feel a bond with others.

Currently, in many developing countries, the prevalence of smoking is increasing, not because of increased stress, but because as prosperity increases, more people are able to fulfil their preference to smoke. For example, in Indonesia, while 56% of men<sup>16</sup> smoked in 2000, 76% of men did in 2015.<sup>105</sup> The causes of this increase have been attributed to continuing economic development in Indonesia

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<sup>16</sup> In many countries, smoking preferences are strongly gendered and thus it is often more illuminating to report male and female smoking rates separately.

since the 1990s, which has resulted in increased disposable income for the average Indonesian household and also the entry of foreign investment and mechanisation into the Indonesian tobacco market.<sup>106</sup> In China, as in OECD countries, people of lower socioeconomic status are more likely to smoke, but the proportion of Chinese men who were heavy smokers increased from 1993 to 2003 due to greater prosperity and economic growth in this timeframe.<sup>107</sup> One important reason for smoking in China is that it is a symbol of individual freedom and choice,<sup>108</sup> and smoking trends are affected by people's associations with these cultural meanings. There are a variety of reasons why both poorer and wealthier people choose to begin smoking, increase or reduce their cigarette consumption, and many of these reasons do not track Stemplowska's suggested reasons of escape from stress or social inclusion. It is odd to argue that it is too demanding to expect low income people not to smoke, in situations where the reason for taking up smoking is due to *increased* income, opportunities and chances for personal freedom and expression.

Stemplowska might respond to this by arguing that the primary focus of distributive justice is not the change in behaviours over time, but across the population at each point in time. Thus, the fact that a higher proportion of Indonesian men smoke now than they did twenty years ago, and the reasons for this increase in smoking, are irrelevant. What is relevant is to look at the distribution of the benefits and burdens of social cooperation at each point in time, and to assess whether it is too demanding to expect lower income people not to smoke given the situation that they *currently* face. Stemplowska might argue that however the situation in the present differs from that in the past, it is too demanding to expect already disadvantaged people to give up pleasures or be different from their peers. While they may be significantly better off than people in the past, they are relatively disadvantaged compared to others in the present, and that given this relative disadvantage, it would be unreasonable to expect them not to smoke.

However, if it is only relative levels of disadvantage at a particular point in time that matter to demandingness, then this argument may prove too much. For example, imagine a particularly prosperous society, where the income ranges between \$A300,000 to \$A1 million (and the cost of goods and services remain at 2018 Australian levels). In this society, also imagine that most people give very little to overseas humanitarian assistance.<sup>17</sup> In this society, those earning \$300,000 per year would be considered to be 'relatively disadvantaged' even though their actual standard of living is very high. It would seem unreasonably permissive to argue that it would be too demanding for these people to give more to overseas humanitarian aid, given that they are 'relatively disadvantaged'.

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<sup>17</sup> In this example, I am assuming that this humanitarian assistance is a duty of rescue, not a duty of distributive justice.

Patterns of smoking are often not an essential response to stress or a desire to be socially included, but due to a range of social factors, which can include people becoming *less* disadvantaged. If an absolute standard of demandingness is used, in these cases, many lower income people would still be considered responsible and penalised for their higher rates of smoking, which is likely to have undesirable effects. If a relative standard of demandingness is used, then this would have the counterintuitive consequence of exempting people from moral duties when they are ‘relatively disadvantaged’ in extremely affluent societies.

#### **4. Direct failure of the Practicality Principle – the Lack of Information Objection and Epidemiological Knowledge**

Earlier in this chapter, I argued that responsibility-sensitive health care policies targeting health behaviours directly are an example of an indirect failure of the Practicality Principle. Any benefits of implementing the policy are outweighed by the intrusive nature of these policies and the effect that they are likely to have in penalising the already socially disadvantaged.

In this section I present the other horn of the dilemma – that policymakers looking to measure outcomes as a proxy for behaviours in order to implement responsibility-sensitive health care will tend to face a *direct* failure of the Practicality Principle. This is because our lack of detailed information about how outcomes relate to behaviours make these proxy variables unsuitable for this purpose. While there are relationships between behaviours and outcomes, they are not nearly direct or fine-grained enough to be able to infer that a particular disease was caused by a particular behaviour pattern, either individually or on average.

What does it mean to say that a public policy is not doing what it intends to do due to a lack of information? There are a number of different things that ‘lack of information’ could mean in this context. For example, some policies might require solving coordination problems which have so many variables that they require enormous computing resources to delineate all the possible permutations and combinations and then find the ones that meet the necessary requirements. Lack of information and computational resources was one important reason behind the failure of Soviet central economic planning.<sup>109</sup> Another reason that lack of information can prevent the implementation of a public policy is that the answer that is being sought may not exist. As unlikely as this would be, if a policy required that we be able to identify a single number as the largest prime number, then that policy could not achieve its aims as the largest prime number does not, in fact, exist.

The above examples are different from what I mean when I argue that social institutions don't have enough information to be able to implement responsibility-sensitive health care by using measurable health outcomes to infer health-related behaviours. In this chapter I do not mean the 'lack of information' where the information is in principle unable to be gathered by anyone, in any context ever. What I mean by 'lack of information' is that there is no way in which people in particular geographical or temporal circumstances are reasonably able to gather it. For example, I have the information and ability in 2018, with a very high likelihood of success, to prevent myself from dying of tetanus by having myself immunised against it. It would be clearly infeasible for a person living in 1700 to do the same thing, as they did not have the relevant knowledge of the causes of tetanus and were not able to produce a vaccine to reliably protect against it. While the person in 1700 may not have in fact contracted tetanus, this would have been a matter of good luck and does not affect the claim that they lacked the information for them to reliably protect themselves against it. In the below discussion, I argue that we are currently in the same position regarding being able to infer about health-related behaviours from measurable health outcomes – we lack the information to do it reliably and that this makes it impractical to base policies on our ability to make this inference.

A significant problem with responsibility-sensitive health care is that many models of causation in medical research are highly complex and do not provide ready sources of information about causation. It is particularly difficult to isolate specific causes in the field of epidemiology, given the large number of documented causes of health conditions and the complex way in which these causes interact with each other. It has long been noted that many health conditions have an array of different types of causes at multiple levels, which not only interact with each other, but also interact with the condition that they cause.<sup>110</sup> For example, the research on obesity (a risk factor in many health conditions) indicates that exercise patterns affect obesity, however, conversely, obesity also affects exercise patterns. Research on obesity has found endogenous causes (such as genes), as well as individual-level, neighbourhood-level and national-level causes, which affect each other but are not able to be reduced to each other.<sup>110</sup> Measuring a person's body mass index is an unsatisfactory proxy for a person's diet and exercise behaviours as many factors unrelated to health behaviours, such as inadequate sleep<sup>111</sup> and whether a person's parents were obese<sup>112</sup> can affect a person's probability of becoming obese. This network of causes makes it difficult to clearly model what types of causes result in which health conditions.

An additional complication in classifying the causes of health conditions occurs when a patient has multiple health problems which interact with each other. This is not uncommon, especially in older

or chronically ill patients. For example, if a patient suffers from both endometriosis and depression, then the chronic pain of endometriosis could exacerbate the low mood and fatigue that are common in depression. It is also the case that depressive symptoms can affect the experience of endometriosis pain. In many cases a patient's symptoms and treatment depend on the particular interaction of their conditions. Comorbidity makes it even more complicated and difficult to neatly categorise the causes of health conditions. Furthermore, in the case of many health conditions, we lack even *basic* knowledge about what type of factor they are typically caused by. In a sense this is not surprising, as much medical research is focused on methods to *treat* health conditions most effectively, rather than determining causation.

A luck egalitarian might suggest that one way to address these problems could be to say that rather than being wholly caused by individual choices, or wholly caused by bad luck, conditions instead would have to be classified as a mixture of types of causes, for example 70% due to individual choice and 30% bad luck. However, it is hard to think of many health conditions in which there would be enough epidemiological evidence to assign percentages such as these in a non-arbitrary way.

Medical research is constantly changing and it is not unusual for previously widely held views about medical conditions to undergo complete reversals. For example, it used to be widely believed among doctors and medical researchers, that stomach ulcers were caused by high stress and poor diet. In the 1990s, further research indicated that stomach ulcers are caused by the bacterium *Helicobacter pylori* and can be treated very effectively with antibiotics.<sup>113</sup> However, more modern research<sup>114</sup> has suggested that in fact there is a complex interaction between stress hormones, lifestyle factors and *Helicobacter pylori*. The mechanisms for these interactions are contested in the scientific literature.

Robert Sapolsky summarises the relationship between factors causing ulcers:

‘The trouble is that one bacterium can’t be the whole story. For starters, up to 15 percent of duodenal ulcers form in people who aren’t infected with *Helicobacter*, or with any other known bacterium related to it. More damning, only about 10 percent of the people infected with the bacteria get ulcers. It’s got to be *Helicobacter pylori* plus something else.

Sometimes, the something else is a lifestyle risk factor—alcohol, smoking, skipping breakfast habitually, taking a lot of nonsteroidal anti-inflammatory drugs like aspirin. Maybe the something else is a genetic tendency to secrete a lot of acid or to make only minimal amounts of mucus to protect stomach linings from the acid. But one of the additional factors is stress. Study after study, even those carried out after the ascendancy of the bacteria, show that duodenal ulceration is more likely to occur in people who are anxious, depressed, or undergoing severe life stressors (imprisonment, war, natural disasters). An analysis of the



entire literature shows that somewhere between 30 and 65 percent of peptic ulcers have psychosocial factors (i.e., stress) involved. The problem is that stress causes people to drink and smoke more. So maybe stress increases the risk of an ulcer merely by increasing the incidence of those lifestyle risk factors. But no—after you control for those variables, stress itself still causes a two- to threefold increase in the risk of an ulcer. Helicobacter is relevant to ulcers, but it is only in the context of its interactions with these other factors, including stress.’<sup>114</sup>

Given the complexity of the interactions between factors causing well-studied conditions such as stomach ulcers, any attempt to infer about people’s health-damaging behaviours from the presence or absence of a health condition is likely to be highly inaccurate.

In addition, epidemiological evidence requires interpretation and is subject to a number of important systematic biases. The philosopher of science Jacob Stegenga provides a helpful summary of different types of biases in his book *Medical Nihilism*,<sup>115</sup> and explains how they can seriously undermine the quality of medical and epidemiological knowledge.

One of the most straightforward examples of bias is confirmation bias, which occurs when people give unjustified weight to evidence which supports their pre-existing beliefs. For example, suppose that an ill person believes that a particular medication is very likely to be an effective treatment. If this person receives the medication and then recovers from their illness, the patient is more likely to attribute their recovery to the medication than to the fact that illnesses often get better without intervention. Both scientists and the general public are prone to confirmation bias, and this bias need not be intentional to distort the body of scientific evidence.

While methodological safeguards such as the use of double-blind randomised control trials are intended to mitigate the effects of confirmation bias, in many cases these safeguards can be ineffective. A randomised control trial is an experiment in which the participants are randomly separated into two groups, one group who receives the experimental intervention (for example a new medication) and the other group (the control group) who does not receive this. Ideally, a randomised control trial should be ‘double blind’, which means that neither the participants nor the researchers know which participants are in the control group and which are in the treatment group. Control groups are used in experiments so that researchers can more accurately determine whether any improvement should be attributed to the new treatment or to other factors. ‘Blinding’ is to avoid researchers or participants altering their behaviour, data reporting, or interpretation of results (consciously or unconsciously) in such a way that would promote the confirmation of their existing

beliefs. However, some recent research indicates that blinding is highly ineffective in practice. For example, participants in a number of studies were asked to guess (after the study was over) whether they were in the experimental group or the control group. The participants guessed correctly at a rate far higher than that of chance, and in some cases were correct 90% of the time.<sup>115</sup> If participants (and by extension, researchers) are in fact able to know who is in the experimental group and who is in the control group, then this provides opportunities for them to change their behaviours and reporting in ways which are subject to confirmation bias. This suggests that in many cases, the methodological safeguards against confirmation bias are less effective, and medical research less robust, than previously believed.<sup>115</sup>

Once the data is collected, medical researchers and epidemiologists can also introduce bias in the way they analyse their data (this is also known as p-hacking). One way in which analysis bias can happen is if researchers make many different statistical comparisons between participants in the control group and participants in the experimental group. This is a problem because in many studies, there is a large number of ways to group the data for the purposes of statistical comparison, and some comparisons are likely to be statistically significant by chance alone. For example, in many studies the researchers can choose to analyse the data of participants by age, by geographical variables, by gender, by socioeconomic status, by educational attainment, by ethnic background or any combination of these. These variables can also be demarcated in different ways. For example, if the researchers collected participants' date of birth, then they can then choose whether to group this data by month, year, two-year, or five-year intervals for the purposes of statistical testing. If five percent of statistical comparisons would be expected to be statistically significant by chance alone, and researchers perform twenty analyses (which is easy to do given the size of many studies), then we would expect there to be one statistically significant finding even if there are in fact no real differences between the outcomes of the control group and the outcomes of the experimental group. While there are methodological controls intended to prevent this kind of bias, many of these decisions about how to analyse data are subjective and are difficult to regulate. Many researchers are under substantial pressure from their employers to produce interesting and publishable results, and so it is not surprising that some researchers analyse the data until they find statistically significant results, even if these results are in fact spurious.<sup>115</sup>

Another important bias is known as 'publication bias' and this refers to the fact that research findings with statistically significant differences between control and experimental groups are much more likely to be published than those with negative findings. It is easy to see how this distorts the body of medical and epidemiological knowledge. For example, suppose a medical treatment undergoes ten

clinical trials, and of these clinical trials, seven indicate that the treatment is ineffective and three indicate that the treatment is effective. If only the three positive results are published, then the scientific community and policymakers will have a much stronger belief in the effectiveness of the treatment than is warranted by the full body of evidence. Publication bias is an important problem in current medical research. For example, Stengenga notes that:

‘A demonstration of the ubiquity of publication bias and reporting bias was provided by a German health technology assessment agency, which analyzed 101 trials for sixteen drugs that had been evaluated by the agency over a recent five-year period. Of the 101 trials, thirty-six had no corresponding publication. Among all the trials there were 1080 outcomes measured, but in the corresponding publications there was data presented on only 250 of the outcomes. In other words, 77 percent of measured outcomes had not been reported in publications.’<sup>115</sup>

The existence of confirmation bias, analysis bias, publication bias and other distortionary effects indicate that the evidence about causation of health conditions is not complete or uncontentious enough to base important policy decisions. For these reasons, a responsibility-sensitive health care policy based on inferring health behaviours from health outcomes is highly likely to fail in its aims, and thus be a direct failure of the Practicality Principle.

#### **4.1 Response to the Lack of Information Objection – the appropriateness of proxy variables in policy**

Supporters of this form of responsibility-sensitive health care might object here that the point of public policy is not necessarily to have the fairest and most optimal distribution for every individual citizen, but to have a rule which is better than other plausible rules for society as a whole. Therefore, even if a public policy rule produces a sub-optimal or inaccurate outcome for some individuals, it may be the best plausible policy for society considered as a whole. Richard Arneson elaborates about this kind of objection to implementing principles in public policy, arguing that:

‘Sometimes we inappropriately hold it as a black mark against a principle that the best available proxies for implementing it are very imperfect and uncertain. But if the principle captures what morally matters and the extant proxies are the best we can do to facilitate the implementation of what matters, flawed implementation is a problem of life, not a defect in moral theory.’<sup>116</sup>

In this quote, Arneson is objecting to the rejection of the use of proxy variables in public policy. In an imperfect and complex world, it is unreasonable to expect of public policy that it functions perfectly

as intended all the time. What matters is that the policy does better in achieving its morally important aims better than any available alternative.

I agree with Arneson that the imperfections of proxy variables do not necessarily mean that we should never apply moral principles in public policy. However, there are substantial differences between the use of successful but imperfect proxy variables and the case of inferring health behaviours from observable health outcomes. For example, consider a successful proxy variable used in public policy: age. People psychologically and physically mature at different rates in a way that affects whether they can responsibly buy and drink alcohol. However, rather than trying to measure these individual differences in maturity, public policy implements a blanket rule: it is illegal to buy alcohol before the age of 18 in Australia. This is an imperfect proxy variable in the sense that it is likely to underestimate the maturity of some 17-year-olds and overestimate the maturity of some 18-year-olds. However, it is a successful proxy variable in the sense that it is much better than trying to infeasibly measure individual maturity, or not having legal rules about who can buy and drink alcohol at all. For example, few people think that the law should allow an 8-year-old to buy cheap wine with their pocket money.<sup>18</sup>

However, health outcomes are not a successful proxy variable for health behaviours. I explore this idea in relation to a much more limited example of responsibility-sensitive health care than discussed previously. It is more limited because it only aims to take account of one outcome (body mass index, abbreviated as BMI), which has been reduced to a binary (above or below a threshold) and makes some simplifying epidemiological assumptions. Perhaps it is the case that while some cases of being overweight and class 1 obesity (defined here by a BMI of 25 to 34.9<sup>19</sup>) are caused by a range of complex interacting factors. However, suppose that for type II and type III obesity (defined as a body mass index over 35), imprudent food consumption is a significant causal factor in the vast majority of cases.<sup>20</sup>

Accuracy in inferring about a person's eating behaviours could be improved by excluding people for whom there is a known alternative external cause for the obesity. For example, it is known that the most common and effective drug treatments for schizophrenia (risperidone, clozapine and

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<sup>18</sup> Bottles of wine can be bought from Australian supermarkets for as little as \$3 per bottle (approximately \$0.40 per standard drink), well within an eight-year-olds' pocket money budget.

<sup>19</sup> Body mass index is a widely-used measure of body fat mass. It is typically calculated by the formula:

$$\text{BMI} = \frac{\text{person's weight in kilograms}}{\text{person's height in metres square}}$$

<sup>20</sup> I am unclear whether this is in fact the case in the real world. I am suggesting here that we suppose that this is the case for the sake of argument.

olanzapine), also cause substantial weight gain.<sup>117</sup> In a case such as this, people with a BMI over 35 who also take these medications could be excluded from the inference that their own food consumption patterns were an important cause of their obesity. While this might not be an accurate inference in every individual case (there being both false positives and false negatives in every diagnostic scheme) it might be relatively accurate on a population level. According to Arneson's theory, perhaps these inaccuracies are the inevitable result of the problems of life, and not indications that we should not implement these principles in public policy in this way.

However, there are important dissimilarities between age as a proxy variable for maturity and health outcomes as a proxy variable for health behaviours. For example, requiring that people are 18 years old before buying alcohol is a clear standard, which is both straightforward to understand and implement, and it is easy to see that everyone is being treated impartially (practices in place such as checking identification can ensure that everyone is subject to the same rules equally). This is very unlike any plausible scheme to track responsibility for health behaviours. For example, it would be impractical and ineffective to implement blanket rules banning or restricting types of food, or attempting to ban alcohol use altogether. Given the ambiguity involved, it will be apparent that there is no clear actionable difference in behaviour between people above and below a BMI of 35.

Given that there may well be no clear difference between the behaviour of people who are above or below a BMI of 35, and recommended behaviours such as eating healthy food and exercising are inevitably a matter of degree, using health outcomes as a proxy for health behaviours seems likely to weaken trust in other people and in social institutions. There has been a considerable amount of sociological and economic research in the last thirty years on the nature of trust and how this can profoundly affect the workings of institutions and economies. 'Social trust' can be defined as 'a generalised belief that a person may safely rely on the future actions of others – that favours are returned and deals are kept.'<sup>118</sup> One of the earliest pieces of research in this field was a study by Robert Putnam showing that level of trust between citizens in Italy had a substantial effect on the quality of democratic institutions in that area.<sup>118</sup> A lot of research has been based on the 'trust' question in the World Values Survey, which asks "Generally speaking, would you say that most people can be trusted, or that you can't be too careful in dealing with people?" Social trust is measured using this question by looking at the percentage of people who agree that 'most people can be trusted' and comparing this percentage in different circumstances and countries. This question in the World Values Survey has been asked to over 250,000 survey participants in 80 countries since 1981,<sup>119</sup> providing a rich resource for researchers to investigate the causes and effects of social trust. Higher social trust has been found to have many positive effects on society. For

example, higher levels of social trust in a society is likely to increase economic growth,<sup>120,121</sup> perhaps as a result of lower transaction costs<sup>122</sup> and higher willingness to enter into commercial contracts even in cases where legislation cannot completely protect commercial ventures.<sup>123</sup> Higher trust societies also benefit from investing more in education than similar low trust societies.<sup>124</sup>

A related concept is the level of trust in institutions, such as the government or the police, which I will call 'political trust'. Political trust has also been the subject of empirical research, such as the National Election Survey in the United States, which asks questions such as 'How much of the time do you think you can trust the government in Washington to do what is right . . .?' and 'Do you think that quite a few of the people running the government are crooked . . .?'<sup>125</sup> Higher levels of trust in government can also bring social and economic benefits to a country. For example, for the government to successfully implement reforms, it is necessary for citizens to trust that the inevitable short-term losses that will result from the reforms will be more than offset by long term gains.<sup>126</sup> Without this kind of trust in government, it will be very difficult for government to respond effectively to social, demographic or economic changes. Citizens without high political trust are also more likely to evade taxes,<sup>127</sup> making government revenue collection less equitable and efficient. Political and social trust can also affect each other. For example, higher levels of social trust can lead to more efficient and less corrupt governance<sup>128,129</sup> which in turn can lead to greater political trust.

An important problem with applications of responsibility-sensitive health care in public policy is that it seems likely to decrease political trust. This is because one of the major contributors to trust in institutions is perceived reliability, in the sense of minimising the uncertainty of citizens in their social and economic outcomes. A key part of retaining political trust is being able to have faith that the government will live up to its word in a clear and visible way. For example, political trust declined significantly in OECD countries during the 2008 financial crisis, as citizens' expectations that the government would manage risk effectively were unmet, and activities that were widely considered to be 'prudent' (such as investing in the housing market) suddenly led many people to considerable financial hardship.<sup>130</sup> In a similar way, it is a problem for political trust that there is no clearly defined behavioural standard that will reliably lead to a particular health outcome. For example, it is not the case that eating more than X number of calories per day will lead to a BMI of over 35, which will then lead to health care rationing consequences, as there are too many other variables involved to make this connection reliable. Thus, this form of implementing responsibility-sensitive health care is likely to be seen as unfair and arbitrary. The lack of clear correspondence between people's health behaviours and social penalties on the 'imprudent' makes it difficult for the government to

demonstrate that they are behaving in a fair and equitable manner and is likely to stoke claims that the government is corrupt and ineffective.

Lowering political trust is likely to have serious negative consequences. For example, losing public trust in institutions means that governments are likely to be less able to operate efficiently and to maintain the rule of law without relying heavily on coercion. Perceptions that government policy is unreliable or arbitrary are likely to not just affect political trust but also social trust. Some research now suggests that in addition to social trust affecting political trust, political trust can also affect social trust. For example, if people suspect that the government will not fairly uphold rules and arbitrate disputes, this may lead them to also lose trust in their fellow citizens and decide that behaviour which demonstrates trust is in fact gullibility.<sup>131</sup> Political and social trust tend to go together and support each other.<sup>132</sup> If the government implemented policies such as this kind of responsibility-sensitive health care, which are likely to appear arbitrary and inconsistent to the public, they risk undermining both political and social trust.

These substantial problems are likely to mean that even this more limited form of using outcomes as a proxy for health behaviours is likely to be an infeasible and unsustainable public policy to implement. It is possible to imagine scenarios in which people have substantially different incentives and moral psychology, and in which policies such as those described above do not reduce perceived reliability and trust in government. However, given that this chapter is working within the constraints of pragmatic normative theory, the way that people do in fact lose trust in government is important for assessing the feasibility of implementing responsibility-sensitive health care.

## 5. Conclusion

In this chapter, I have focused on only those versions of luck egalitarian theory which are intended to apply to public policy. I have argued that attempts to apply responsibility-sensitive health care policies in settings resembling the real world need to either focus on health *behaviours* directly (such as actual calorie consumption), or alternatively to focus on more easily monitored health *outcomes* as a proxy for health behaviours (such as a person's body mass index).

This choice constitutes a dilemma for the proponents of responsibility-sensitive health care policy. If they focus on regulating health behaviours directly, they face an indirect failure of public policy. The policy is likely to have negative consequences outweighing its intended benefit, as it is likely to further penalise the socioeconomically disadvantaged. If on the other hand, advocates of responsibility-sensitive health care policy focus on a broad range of health outcomes as a proxy for

health behaviours, then they face a direct failure of public policy. Given the complexity and limitations of our epidemiological knowledge and the multiple and interacting causes for the vast majority of health conditions, it is not possible to reliably infer about people's health behaviours given their health outcomes. Even given some simplifying assumptions (such as focusing on a BMI cut-off only), this policy faces substantial indirect problems relating to the perceived unreliability of the policy and the resulting effects of lowering political and social trust. Thus, it appears that attempts to implement responsibility-sensitive health care in practice are likely to face such severe obstacles as to render them impractical.

In the past three chapters, I have argued that, although responsibility-sensitive health care may initially seem like an attractive method for rationing scarce health care resources, it in fact faces very substantial normative and practical problems. In chapter 1, I described the extent to which the demand for health care is affected by people's behaviours – such as smoking, high consumption of alcohol, and excessive consumption of calorie-dense food, and why many philosophers and non-philosophers believe that principles based on personal responsibility for health behaviours are effective and fair ways to allocate scarce health care resources. I have focused on luck egalitarian principles in this thesis, as these appear to be the most promising and philosophically nuanced formulation of principles to guide the allocation of scarce health resources in a way that is sensitive to personal responsibility. In chapters 2 and 3, I rejected responsibility-sensitive principles for allocating health care resources on both normative and practical grounds. As I argued in chapter 2, there remain serious questions as to whether luck egalitarian principles as applied to health care resource allocation can adequately respond to the Abandonment Objection. In this chapter I have argued that responsibility-sensitive health care based on luck egalitarian principles would be infeasible to implement in practice.

My exploration of responsibility-sensitive health care in these chapters also has implications for my positive account of how to allocate health care resources fairly in conditions of scarcity. My argument in chapters 1, 2 and 3 provides reasons for thinking that the principles that social institutions use to allocate health care resources should not take account of individual responsibility for health-related behaviours. Accordingly, in the second part of this thesis, I will explore other principles for allocating health care resources that do not focus on individual responsibility for health behaviours. In chapter 4, I will consider accounts which argue that health care resource allocation should be entirely determined by market forces. In chapter 5, I will consider two metrics which are currently widely used to value health and ration health care – Quality Adjusted Life Years (QALYs) and



Disability Adjusted Life Years (DALYS). I argue that leaving health care allocation decisions to the market, as well as using QALYS and DALYS to allocate health care, are both inadequate solutions. In chapters 6 and 7, I outline my positive account, arguing that health care prioritisation decisions should be largely made on the basis of two factors - to what extent is health care likely to improve a patient's subjective well-being, and to what extent is health care likely to improve a patient's morally relevant capabilities.

## Part 2: Responsibility-*Ins*ensitive Health Care

### Chapter 4: Markets in Health Care

- 1 Efficiency and health care provision – rationing health care through the market
  - 1.1 Rationing health care through market forces
  - 1.2 Health insurance markets
  - 1.3 Health insurance markets – Structural problems
  - 1.4 Health insurance markets – Moral hazard
  - 1.5 Health insurance markets – Adverse selection
  - 1.6 Government interventions in health insurance markets
  - 1.7 Objections to government interventions in health insurance markets – lowering regulation and improving competition
- 2 The impermissibility of government intervention – Nozick and individual rights
  - 2.1 Problems for Nozick’s view – Historical injustice
  - 2.2 Problems for Nozick’s view – Baseline holdings before redistribution
- 3 Conclusion

If societies should not ration health care according to responsibility for health behaviours, as I have argued in previous chapters, what other principles could provide guidance for rationing fairly? One possibility is for social institutions to regard health care in the same way as they do other goods and services and allow the provision of health care to be determined solely by the market. In this chapter I will address two reasons why someone may argue that the market alone should regulate the allocation of resources. In Section 1, I address the claim that the market is the most efficient and effective way of allocating resources to meet people’s needs, and thus market forces should be allowed to allocate health care resources without government intervention. I argue that the market for health care and health insurance products has structural problems that necessitate government intervention. In Section 2, I address a more deontological libertarian argument that the allocation of health care and health insurance should be left to market mechanisms – that government intervention necessarily infringes on people’s rights and that this is never justifiable. I will argue that strong libertarianism in this form is implausible, and thus it is justifiable and necessary for the government to intervene and redistribute resources in at least some cases.

## **1. Efficiency and health care provision – rationing health care through the market**

Scarcity is not a problem that is unique to health care. The production and distribution of many goods in society (including important goods such as food items) are primarily determined by the intersection of demand and supply, resulting in an equilibrium price. In this way, rationing is managed by individuals deciding how much of a good to demand given their preferences and budget constraints, and by businesses in deciding how much of that good to supply, given their expectation of profit. In the rationing of most products, the role of moral principles is mainly focused on background conditions such as the rules for treatment of employees, as well as consumer safety and environmental regulations. These rules affect the demand and supply of products, but do not determine directly the distribution or the rationing of these products.

### **1.1 Rationing health care through market forces**

There are a number of benefits of market-based rationing. One benefit is that, in general, individuals tend to have the most accurate information about their own needs. Respecting individuals' autonomy is also an important value. In liberal societies individuals make the primary decisions about their own lives, such as where they live, what they study, where they work, with whom they form relationships, and how they spend their money. This is the case unless there is a good reason for these decisions to be made by a group, by the government, or by a regulatory agency. Given the value of individual autonomy and the level of detailed information that people have about their own preferences and situation, whether an individual buys health care, and the amount and type of health care that they buy may seem to be something which that individual themselves should decide. This conclusion could be seen as an implication of the widely-accepted importance of informed consent in medical ethics. As Jessica Flanigan argues,

‘the core of the moral justification for informed consent appeals to the widespread beliefs that each person is entitled to ‘power over the proceedings’ for decisions that affect her, and that the right to make intimate and personal decisions about one’s own body is fundamental.’<sup>133</sup>

Patient autonomy can be argued to be especially important given the intrusive nature that health care can take and the substantial effect that health care can have on people’s well-being.

However, many people believe that the provision of health care has moral dimensions that makes it inappropriate to compare it to discretionary purchasing choices, such as whether a person buys a luxury car or not. The consequences for not being able to access many types of health care when required are likely to be much more serious than whether a person can buy other consumer items and may include prolonged suffering, permanent disability, disfigurement and early death. A

person's state of health is likely to also affect all their other opportunities, level of resources and involvement in society, such as where and whether they can be employed, their level of income and wealth, their participation in civil society and the public sphere, and their relationships with family and friends. As Norman Daniels notes, most people think of health, and health care as being 'special', in that they regard inequalities in accessing at least some health care to be morally objectionable in a way that they do not regard similar inequalities of income and wealth to be objectionable.<sup>14</sup>

A person in favour of using market forces to ration health care resources might respond here that although health care can have a very substantial effect on people's well-being, this is not *in itself* a reason against thinking that health care rationing should be determined by individuals interacting through market forces. One reason for this is that even though health is a valuable good, other goods are also important. Letting decisions about setting priorities be made by market forces allows each individual to decide how they value health care as compared to the value of education, housing, rest and leisure time, or other things that affect their quality of life. The relative value of these goods may be different for different individuals and across the life span of an individual. As Flanigan argues:

'Experts have extensive knowledge about health or mortality or accident fatalities, but they do not have extensive knowledge about how remaining healthy would balance against other values for a particular person. How health or safety is valued when it conflicts with other values, like the pleasure of eating fatty foods or feeling the wind in one's hair, will vary from person to person. By enforcing policies that penalize or prohibit unhealthy and unsafe choices, public health officials substitute their own judgment about this weighing of values for each person's.'<sup>134</sup>

These considerations would support the view that decisions about health care allocation under scarcity should be made by individuals interacting through the market.

A further response for advocates of market-based rationing might be to argue that what is required is for people to be able to decide whether and how much health care to purchase, *given a fair distribution of income and wealth*. Perhaps the factor that makes it objectionable that some people do not have access to health care when they need it is that these inequalities in health care access are driven by existing inequalities of income and wealth (which few people regard as being fair). If society had a fair distribution of income and wealth (whether this is thought to require strict equality or some other distributive criterion), and some people still do not have access to health care, then perhaps this would not be unjust. In this way, concerns about inequality in health care access do not provide a reason to reject the view that health care rationing should be determined by individuals in

a free market. Instead, they would provide a further reason to address unfair inequalities of income and wealth.

However, even a prior fair distribution of income and wealth would not be able to justify the claim that health care rationing should be determined primarily by market forces. One reason for this is that demand for health care is unlike the demand for many other consumer goods in its variability and unpredictability. A person may require minimal health care in one year, and then be involved in an accident, which results in them requiring extensive hospital, surgical and rehabilitative treatment in the following year. There is considerable unpredictability about whether a given person will develop a chronic and ongoing health condition.<sup>135</sup> Furthermore, some proportion of the population will suffer from multiple comorbid health conditions. For many of the people with multiple conditions, the cost of health care will be so large that only the very wealthy will be able to pay for even immediate and urgent treatment without facing bankruptcy.

## 1.2 Health insurance markets

Managing the costs of health care through health *insurance* products may help to reduce some of the risk and uncertainty associated with the need for health care. Health insurance companies analyse data, calculate estimates of the probability of insurance policy holders claiming for particular types of health care, and set insurance premiums, and terms and conditions accordingly. These insurance terms and conditions are a form of health care rationing, set by market-based probability estimates.

So, would it be a viable solution for health insurance markets to govern the allocation of health care resources without government intervention? One starting point for addressing this question are two fundamental theorems in Welfare Economics, which were first described by Kenneth Arrow in the 1950s. Daniel Hausman summarises:

‘The first theorem says that equilibria in perfectly competitive markets are Pareto optimal, and the second says that any Pareto optimal allocation, with whatever distribution of income policy makers might prefer, can be achieved as a perfectly competitive market equilibrium, provided that one begins with just the right distribution of endowments among economic agents... The two fundamental theorems of welfare economics go some way toward explaining why mainstream economists, whether they support *laissez-faire* policies or government intervention to remedy market imperfections, think of perfectly competitive equilibria as ideals.’<sup>136</sup>

In this definition, 'Pareto-optimal' refers to a distribution of resources such that there is no alternative allocation of resources where one person is better off without making another person worse off. It is worth noting that Pareto optimality does not imply fairness. In certain situations, a distribution in which one person holds all the resources and everyone else holds nothing may be Pareto optimal, but grossly unequal and unfair. It is also important to note that there is not one single Pareto optimal outcome – there may be many Pareto-optimal possible outcomes, some of which society finds more desirable than others. For example, suppose that a new resource is discovered,<sup>21</sup> such that no one already has a claim upon it. One Pareto-optimal outcome would be to distribute this resource equally among all citizens. However, another Pareto-optimal outcome would be to give all of this resource to one person only. Because at least one person is better off and no one is worse off in both distributions (compared to before the resource was discovered), they are both Pareto-optimal distributions.

Another way of describing the first Theorem is that given certain assumptions, an equilibrium between demand and supply in a perfectly competitive market will tend towards an efficient (Pareto-optimal) distribution of resources. This would seem to provide a strong initial presumption against government intervention in markets.

### **1.3 Health insurance markets – Structural problems**

However, what is meant by a 'perfectly competitive market' in this context? Unruh and Rice identify a partial list of characteristics implicit in what Arrow describes as a 'perfectly competitive' market.

These include (but are not limited to) that:

- A person is the best judge of his or her own welfare.
- Consumers have sufficient information to make good choices.
- Consumers can accurately predict the results of their consumption decisions.
- Individuals are rational.
- Social welfare is solely the sum of individual utilities.
- There are no positive or negative externalities of consumption.
- Consumer tastes are predetermined.
- Supply and demand are independently determined.
- Firms do not have any monopoly power.
- There are not increasing returns to scale.

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<sup>21</sup> For the sake of simplicity, I am assuming that this new resource is something like a large treasure chest of gold, which does not require any cost to extract or distribute, and which is initially owned by no one.

- Firms maximize profits.
- Profit maximization results in the most efficient production and the highest consumer welfare.<sup>137</sup>

While *some* of these criteria may apply (to varying extents) to existing markets, many of these characteristics involve very substantial simplifications and idealisations of actual markets. The assumptions implicit in the first Theorem's concept of a perfectly competitive market do not generally apply in real-world market situations, and particularly not in health insurance markets.<sup>137</sup>

There are a number of assumptions for the First Theorem which are false of health insurance markets. Among these are that individuals and firms have perfect information about the products that they are buying and selling, that there are no externalities from consumption (positive or negative effects from consumption that go to people other than the consumer), that there are no firms with monopoly power.<sup>137</sup>

There are clear positive and negative externalities from consumption of health care resources. One obvious case is that of contagious diseases – if I choose not to buy health insurance, and this choice results in my being unvaccinated or having an untreated illness, then the choice not to consume health care insurance is likely to spread illness to other people. Externalities from health insurance consumption also are likely to apply in the case of non-communicable health conditions. If I choose not to buy health insurance and then am injured in an accident, my subsequent rehabilitation and care needs are likely to affect my family, who were not involved in the individual decision to forgo health insurance. Many economists argue that in cases of externalities, individual consumption decisions in a free market will lead to an outcome that is not socially optimal. For example, if individuals are required to pay the full cost of being immunised, then this will result in too few immunisations being supplied. In this situation, government intervention to subsidise choices with positive externalities and tax choices with negative externalities may be justified.

Another important way in which health insurance markets do not meet the conditions of the First Theorem is that consumers and firms do not have anything resembling perfect information in making their consumption decisions. Situations where the buyer or seller in a market has important information that the other party does not have is known as a situation of *asymmetrical information* and can lead to inefficient outcomes. Health economists have identified two types of important structural problems caused by imperfect or asymmetrical information in health insurance markets. These two structural problems are known as *moral hazard* and *adverse selection*.<sup>138</sup>

#### 1.4 Health insurance markets – Moral hazard

Moral hazard<sup>22</sup> refers to the tendency of people with insurance to incur higher costs than they would have incurred if they had not been insured. In the case of home insurance, for example, moral hazard may lead an insured home owner to be less careful to avoid damage to their property than they would have been if they had not been insured, knowing that the insurance company will compensate them for their losses. In the context of health, having health insurance is not thought to be a major factor encouraging people to take risks with their health, as the pain and suffering involved in illness is also a deterrent. However, moral hazard can take place through over-utilisation of the health care system. This can occur both in the case of patients who seek out medical care for more minor conditions or use more expensive medical care than they otherwise would have. The fact that the insured person does not pay their medical bill directly can also mean that medical professionals have incentives to order medical testing that they would otherwise have deemed unnecessary, as insurance will pay them for each service rendered,<sup>138</sup> and the person with insurance is not paying the bills themselves.

Moral hazard is a structural problem in the health insurance market because the information asymmetry disconnects the amount of money that insurers must charge in premiums in order to stay in business, and the amount that individuals are willing to pay for the insurance. Insurers must set premiums in such a way that they can recover enough money to pay for the claims of their customers, given the actual behaviour of customers. However, individuals are only willing to pay enough for insurance to cover their expected health care usage, *not* taking in account their extra utilisation of services from behaviour under moral hazard. This difference between what the insurer needs to stay in business and what the individual is prepared to pay in premiums can lead to incomplete insurance markets, where many insurance products needed to pool risk are not available in the market.<sup>138</sup>

To take a very simple example, suppose that a group of people without health insurance decide the amount (\$X per person) that they would be prepared to pay for health insurance premiums. This amount is based on their current spending on health care as well as how much they are prepared to pay to avoid the risk of expensive medical bills in the future. They purchase insurance with premiums equal to or lower than this amount. However, as a result of now having insurance, some of the members in this group substantially increase their health care spending. They see the doctor more often than they otherwise would have, and their doctor, knowing that they now have insurance,

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<sup>22</sup> Note that the term 'moral hazard' in health economics only refers to incentive structures, and, despite the name, does not refer to normative issues.



orders more expensive tests and medications for them than previously. Due to this increased usage, the cost of health care for this group to the insurer now exceeds \$X per person, and the insurer is losing money.

Crucially, the insurer is unable to directly observe the behaviour of each group member and accurately estimate the risk that each person will overuse health care in the future. They do not know whether Person A in the group has had an expensive medical test because they are seriously ill, or because their doctor knew that they had insurance and thus ordered an unnecessary test. This means that they are unable to accurately predict whether A's health spending in the future will continue to be high due to patterns of overuse, or whether it will drop as their temporary health crisis will soon be over. This means that their only way to stop losing money is to raise premiums on everyone in the group, to a total of  $\$X + \$a$  (where  $\$a$  takes account of the expected utilisation of the group). However, other members of the group, especially those who have not increased their consumption of health care, may be unwilling to pay this higher premium cost, meaning that they discontinue their insurance coverage. In some serious cases, the inability to be able to set premiums accurately based on the riskiness of an insurance holder can result in some health insurance products ceasing to be offered in the market.

Even if it is possible in theory for insurance companies to perform greater monitoring and information collection to address the asymmetrical information problem, the transaction costs of doing this are likely to be sufficiently expensive as to make this impractical.<sup>139</sup> As noted by Greenlaw and Shapiro:

Imperfect information is the cause of the moral hazard problem. If an insurance company had perfect information on risk, it could simply raise its premiums every time an insured party engages in riskier behavior. However, an insurance company cannot monitor all the risks that people take all the time and so, even with various checks and cost-sharing, moral hazard will remain a problem.<sup>140</sup>

While it is difficult to directly measure the extent of moral hazard in existing health insurance markets, there is evidence that the presence of health insurance does lead some health care professionals to order more medical tests, charge more, and perform more procedures than would be justified by their patients' health status or the likely outcomes. For example, researchers compared the treatments given to Medicare patients in different regions of the United States. Doctors received the same payment for each procedure from Medicare whichever region they were in, and the study was careful to compare patients in each region who had similarly severe illnesses

and similar education and socioeconomic status.<sup>141</sup> Despite having similar costs and levels of medical need, Medicare spending varied enormously across regions. The most expensive region (McAllen, Texas) spent an average of \$21,123 per patient on end of life care, while the least expensive (Grand Junction, Colorado) spent only \$8,366 per patient.<sup>141</sup> A related study also found that hospitals in more expensive regions, despite ordering more tests and more doctors' visits, actually delivered *lower* quality of care than less in expensive regions. This suggests that the presence of health insurance does lead to some overconsumption of medical care, and that this overconsumption is not justified by the severity of patients' illnesses and does not result in better patient outcomes.<sup>141</sup>

### **1.5 Health insurance markets – Adverse selection**

Another important structural problem is that of adverse selection, which in the context of health insurance markets means that rational consumers will be more likely to buy health insurance if they expect to need costly health care in the future.<sup>138</sup> This means that the pool of people who are insured are more likely to be older and have existing health problems, and thus make more health insurance claims than the average for that society. As the health care of this group of older, sicker insurance holders becomes more costly to cover, premiums will rise, and eventually it will only make financial sense for the most unwell members of society to buy this expensive insurance. This situation can occur even if premiums can be adjusted to group characteristics, because an individual necessarily knows much more about their own health status than the insurance company. For example, if I am looking to purchase insurance, for reasons of practicality the insurance company will only be able to set premiums based on some basic demographic and medical criteria (such as sex, age, place of residence, smoking status and perhaps a few past diagnoses). In contrast, I know much more detail about my own health status, symptoms, and family medical history, and so will likely be a better predictor of my likelihood of needing medical treatment in the future. The process of adverse selection is known colloquially as a 'death spiral'<sup>142</sup> and typically results in the insurance plan ceasing to be offered due to becoming financially unviable.

Adverse selection is not just a theoretical possibility but has been documented in practice by health economists. In the mid-1990s, Harvard University provided health insurance for around 10,000 employees through the insurance company Blue Cross/Blue Shield. Two plans were offered, a Preferred Provider Organisation (PPO) plan with larger benefits, and a more constrained Health Maintenance Organisation (HMO) plan. A PPO plan typically has higher monthly premiums but provides a greater variety of treatment options to the insurance holder, allowing them to visit specialist doctors without referrals and to visit doctors who are affiliated with a different company than their insurance company (also known as an out-of-network provider). In contrast, a HMO plan

typically has lower monthly premiums and lower out-of-pocket costs, in return for less flexibility in which health professionals the company will pay for the insurance holder to visit.<sup>143</sup> The premiums paid by employees for Harvard's PPO and HMO plans were initially relatively similar.

In response to a budget deficit, Harvard implemented new rules, the effect of which was to raise premiums for the PPO plan. The employees who dis-enrolled from the PPO plan were on average, healthier and younger than those who remained enrolled. As a result of this, the PPO lost money in 1995 and had to raise premiums in 1996. The PPO plan, which cost approximately \$US400<sup>23</sup> in employee contributions for a family plan in 1994, cost more than \$US2000 in 1996. As a result, the enrolment of the PPO fell rapidly, to approximately 9% of eligible Harvard employees, and again those who dis-enrolled from the PPO were younger and healthier on average than those who remained enrolled. Given the extent of their financial losses, Harvard and the health insurer Blue Cross/Blue Shield disbanded the PPO plan. This occurred only three years after the rule change that triggered the adverse selection spiral.<sup>144</sup>

While the First Theorem of welfare economics indicates that a competitive health insurance market would lead to efficient (Pareto-optimal) provision of health insurance, this theorem makes certain assumptions that do not hold in real-world conditions. In particular, the First Theorem assumes that there are no positive or negative effects of the choice to buy health insurance for anyone other than the consumer themselves, and that both the buyer and seller of health insurance have perfect information. The fact that buyers and sellers of health insurance in the real world have imperfect and asymmetrical information leads to the structural problems of moral hazard and adverse selection, which in turn leads to incomplete and inefficient health insurance markets.

### **1.6 Government interventions in health insurance markets**

While markets in real life often have structural problems, this does not, in and of itself, mean that the government should intervene in the health insurance market. Some forms of government intervention could exacerbate existing problems or create new inefficiencies. To take a deliberately extreme example, a government could prohibit all companies from charging more than \$5 per person per year for health insurance. This policy would create a 'price ceiling' and would likely result in no forms of health insurance being offered on the market at all, as no insurance policy would be profitable if premiums were so low. This type of counterproductive government intervention creates an inefficiency called a 'deadweight loss', where prospective buyers and sellers are unable to reach

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<sup>23</sup> Dollar amounts in this case study are given in 1996 US dollars.

an equilibrium price and quantity. However, other types of government interventions can help markets to work more efficiently. For example, government regulation can require firms to accurately label their goods, meaning that consumers can make more informed purchasing decisions, and this can result in reduced informational asymmetry and more efficient market allocations.

In general, economists try to weigh the likely costs of a particular government intervention against the costs of non-intervention to come to a policy recommendation, all things considered. The results of these cost-benefit analyses are likely to differ depending on what assumptions are used and the limitations of the economic data under analysis. This being said, there are structural problems and unacceptable outcomes caused by markets. In response to these problems, a wide variety of economists support government intervention.

For example, many economists support using the tax system to reduce the misallocations of resources from positive and negative externalities. Government intervention can be used to address externalities through taxing activities that create negative externalities and subsidising activities that create positive externalities. If I choose to be vaccinated against influenza, not only does this health care consumption decision reduce the risk of my becoming sick, but also reduces the risk that I will pass on influenza to other people, especially to the very young and old who are prone to developing more severe effects of the illness. However, typically, my choice whether to get the influenza vaccine is primarily determined by the expected benefit to me as an individual and does not take proper account of the effects on other people. Thus, subsidising the influenza vaccine can promote consumption of the vaccine to the socially efficient level, taking account of externalities. In typical economics models, it is efficient for society to consume health insurance until the social benefit from the next (marginal) unit of health insurance is equal to the social marginal cost of that additional unit of health insurance.

Many economists support government subsidies for health insurance to encourage greater consumption of health care, given the positive externalities from being insured. Economists may also support government intervention to reduce the effects of information asymmetries and the structural problems that they can cause. For example, one action that the government can take is to require everyone in society to buy health insurance, in order that the insurance pool remains large enough to be financially viable. Instances of this type of policy can be seen in the reforms to the US health insurance market which took effect in 2014. This policy required all individuals who were not already covered and who had the means to do so to purchase health insurance. However, this solution requires the younger and healthier members of society to subsidise the older and sicker

members. This takes health insurance away from being a discretionary consumer product whose distribution is determined by the rationing of the market, and becomes a good substantially regulated, provided and guaranteed by government. To be clear, I am not objecting here to requiring the younger and healthier members of society to subsidise the older and sicker members in order to create proper risk pooling and a viable insurance market. I raise this in order to demonstrate that addressing the structural problems of health care insurance markets will require significant government intervention, which means that it is not viable to simply look to the unregulated market to allocate health care resources in conditions of scarcity.

### **1.7 Objections to government interventions in health insurance markets – lowering regulation and improving competition**

Some theorists who favour regulating health care through the market like any other good or service argue that the problems caused by adverse selection and moral hazard are not unique to health care and could be made less severe by lowering regulation. For example, many American libertarians argue that the reason that people are forced to rely on insurance rather than savings to pay their health care bills is because the prices for health care are inflated due to burdensome government regulation. Examples of these regulatory burdens include unnecessary restrictions on who can perform certain medical procedures, such as preventing qualified nurse practitioners from performing straightforward procedures<sup>145</sup> and a complicated and lengthy process for meeting regulatory standards for pharmaceutical products.<sup>146,147</sup> Other examples of regulations which reduce competition include the fact that in 35 US states, a prospective new hospital requires a 'Certificate of Need'. In states such as Illinois, this Certificate can only be granted by a board who has an explicit mandate to defend the profitability of existing hospitals in the area. This regulatory system often leads to the provision of fewer hospitals and higher health care prices than would have been available had this regulatory hurdle not been required by law.<sup>148</sup>

Other theorists point to market mechanisms such as caps, co-pays, excesses, and waiting periods to reduce the problem of moral hazard and asymmetrical information in health insurance markets. A cap in this context refers to a limit, specified in an insurance policy's terms and conditions, that an insurer will pay per insurance holder over a particular time period (usually a calendar year). For example, depending on the policy type, an insurer may only be willing to pay \$1000 per year per policy holder for general dental treatment. This reduces the financial risk for the insurer of moral hazard problems, such as the risk of a policy holder choosing the most expensive cosmetic dentistry because they have taken out insurance. A co-pay is usually a proportion of the cost of each medical treatment (e.g. 20%) which must be paid for by the policy holder rather than by the insurer. An

excess is an amount (e.g. \$250) per medical procedure which must be paid for by the policy holder before the insurer will pay the rest of their costs. Excesses and co-pays can reduce moral hazard problems by requiring the policy holder to pay a portion of their marginal medical costs. Having to pay a co-pay or an excess may reduce the risk that a policy holder will choose unnecessary medical treatments, as they have to pay a portion of the cost of each treatment even though they have insurance. A waiting period for certain benefits can also reduce the financial risk of asymmetrical information to the insurer. For example, various Australian private insurance policies, such as NIB health insurance, impose a waiting period of 36 months on very expensive procedures, such as Cochlear implants.<sup>149</sup> This is to reduce the risk that people who already know that their child will need a Cochlear implant will buy a family insurance policy, immediately claim for this expensive procedure, and then discontinue their policy as soon as the Cochlear implant benefit claim has been paid. Insurers cannot know who among their policy holders would be planning to do this, so the mandatory waiting period means that people must pay insurance premiums for a minimum of 36 months before claiming, reducing the risk of significant financial losses to the insurer.

Some of these mechanisms for reducing risk are substantially regulated or prohibited by government regulations, motivated by the desire to make insurance coverage more reliable and reduce financial risks to consumers. For example, before the implementation of the Affordable Care Act in the United States (also known as Obamacare), many health insurance plans had a lifetime cap on benefits of \$US1 million per policy holder. The Affordable Care Act prohibited health insurance providers from providing plans which enforced this cap.<sup>150</sup> The Affordable Care Act also reduced the ability of health insurers to enforce waiting periods or exclusions for pre-existing conditions, increasing their financial risk from asymmetrical information.<sup>150</sup>

Theorists who support market mechanisms for allocating health care argue that government regulations such as these prevent insurers from using existing mechanisms for dealing with moral hazard and adverse selection problems and unnecessarily stifle competition among health care providers. They point to the regulatory burden, rather than structural problems, as being the most important factor explaining high and increasing health care prices. With a lower regulatory burden, some theorists argue, more companies will enter the market, and competition will drive down prices, making health care more affordable for people even without insurance.<sup>148</sup>

However, while it is possible that some regulatory changes in countries like the United States may help to reduce the price of health care, it seems unlikely that they will prevent the price of health care from rising faster than inflation, or reduce the need for people to be covered by insurance to

pay for health care. If a lack of competition in health care was the primary cause of high health care prices forcing people to rely on insurance, then we would expect to see evidence of the converse occurring in countries with a more competitive health care sector.

While not conclusive, comparisons of different countries' health care sectors do not appear to support this conclusion. For example, there are a range of rules for regulating health care across Europe, but health care costs are rising faster than general inflation in every country.<sup>151</sup> Even in Switzerland, which has a robust and competitive range of private health care providers, health care and health insurance costs are higher than the average for OECD countries and are higher than general inflation. This is the case even though Swiss health insurance already uses co-pays and requires citizens to pay an excess before making a health insurance claim to address the problem of moral hazard.

Another example is that of Singapore, a country with a highly competitive health care sector, relatively low regulations on private health care and pricing, proactive support for innovation, and a high level of private savings.<sup>152</sup> Singapore already extensively uses many mechanisms to address the problem of moral hazard, including co-pays and requiring citizens to pay for many expenses directly through health savings accounts. Although Singapore's health care costs have been historically been lower as a proportion of GDP than other OECD countries, now the cost of Singaporean health care is also rising rapidly and significantly above the rate of general inflation. The concern in Singapore about rapidly rising health care costs is widespread, such that 72% of Singaporeans report anxiety that health care is unaffordable.<sup>153</sup> It is also worth noting that even Singapore, which is a country with a strong historical track record of embracing the free market to provide goods and services, sees a need for government intervention to provide health insurance to low income and chronically ill citizens. It is unlikely that even more competitive markets will yield outcomes that people will regard as acceptable. The examples of Singapore and Switzerland do not point towards a fully market friendly solution to the problem of healthcare provision.

Those in favour of using the market alone to allocate health care resources could also argue that voluntary non-profit organisations and charities could provide health care and health insurance services, and that this role does not need to be filled by government. Some advocates of this approach point to the spread of voluntary and fraternal societies in the United States throughout the nineteenth century up until the 1960s.<sup>154,155</sup> These societies provided health insurance, accident benefits and in some cases unemployment benefits, paying for these benefits by charging their members small ongoing fees. Other health care costs could be paid for by charitable organisations.

These alternatives, advocates argue, would be able to provide low cost health insurance without requiring government intervention.

However, the historical and more recent record of charities and fraternal societies does not indicate that they would be a suitable replacement for government involvement. One of the main reasons for this is the fragmentation of fraternal societies and charities. This meant historically that many people missed out on health care which it would have been easy and cost-effective to offer with government-provided insurance. To discuss fraternal societies first, even at their peak before the introduction of government health insurance, they did not cover the majority of Americans.<sup>154</sup> These organisations were often small and local, catering for only a single geographical region, religious or ethnic group, and their small size made it more difficult to pool risk than nation-wide government-provided health insurance. Some fraternal societies imposed behavioural restrictions on their members, such as expelling members who married outside their religious faith.<sup>156</sup> Furthermore, the scope of these benefits was often time-limited, making them unsuitable for many people who had sustained permanent illnesses or disabilities.

Voluntary charitable organisations also seem unlikely to be able to take up the role of providing health care to the needy in the absence of significant government involvement. Past instances of withdrawal of government services does not suggest that non-profit organisations are able to substantively take the place of government-provided services. For example, sociological research following welfare reform in the 1990s in the United States indicates that charitable organisations were not able to come close to filling the gap opened by reduced government payments and health care to sole parents and those living in poverty.<sup>157</sup> Canadian research has also highlighted the difference in values, organisation and service delivery between government and charitable services. Charitable organisations often have a focus which is highly specific, and the availability of charitable services varies widely, not always tracking variations in need.<sup>158</sup> A reliance on voluntary organisations such as fraternal societies and charities seems likely to leave significant gaps in coverage, meaning that many people will suffer illness, disability or death which could have been cost-effectively prevented with greater government involvement and regulation of health insurance.

Furthermore, it is notable that even economists who generally oppose government intervention in markets *do* endorse some government involvement in health insurance markets. For example, Milton Friedman, in a 2001 essay, advocated for a replacement of the current US government insurance schemes Medicare (for the elderly) and Medicaid (for people with very low incomes) with government-provided catastrophic insurance for all US families.



'A more radical reform would, first, end both Medicare and Medicaid, at least for new entrants, and replace them by providing every family in the United States with catastrophic insurance (i.e., a major medical policy with a high deductible). Second, it would end tax exemption of employer-provided medical care. And, third, it would remove the restrictive regulations that are now imposed on medical insurance—hard to justify with universal catastrophic insurance. This reform would solve the problem of the currently medically uninsured, eliminate most of the bureaucratic structure, free medical practitioners from an increasingly heavy burden of paperwork and regulation, and lead many employers and employees to convert employer-provided medical care into a higher cash wage. The taxpayer would save money because total government costs would plummet. The family would be relieved of one of its major concerns—the possibility of being impoverished by a major medical catastrophe—and most could readily finance the remaining medical costs.'<sup>159</sup>

Friedman's goal in the above quote is not for health care to be entirely allocated by market forces. Rather he advocates for government to provide a limited safety net for everyone, by providing health insurance that protects people against high and unexpected medical expenses. This government-provided insurance would allow other reforms to the US health care system which, in Friedman's view, would enable the health insurance market to be more transparent and competitive and would reduce medical costs overall.

John Cochrane, an academic economist who generally opposes government interventions in markets, also argues that governments have a role in allocating health insurance. Cochrane writes that:

'In addition to the need for genuine charity care, there can still be lots of government help in various places...The vast majority of any help and transition smoothing can and should be given in the form of on-budget, lump-sum subsidies or vouchers, leaving marginal incentives intact, and avoiding programs, protections and incentives that last forever.'<sup>148</sup>

Cochrane does not oppose government intervention in the US health insurance market to provide care for people who otherwise may not be able to afford health insurance. His primary concern with government interventions is that they may distort the incentives of consumers and businesses, leading to less competitive markets, higher health care costs, and lower quality services. Even Cochrane does not argue against all government intervention in health care and acknowledges the importance of government in creating more equitable outcomes. He recommends that government intervention occur in ways which are most conducive to supporting efficient and competitive markets.

These are examples of economists who very strongly support market allocative processes in general, but who also argue for a role for government in the provision of health insurance and health care. These examples indicate that the position that *in no situation* should governments intervene in health insurance markets is rare even among academic economists who typically favour market-based solutions to the provision of goods and services. While this consensus of academic economists does not in itself demonstrate that there is a legitimate and important role for government in the provision of health insurance, it is suggestive that the complexities involved in providing health insurance cannot be straightforwardly solved by market processes.

## **2. The impermissibility of government intervention – Nozick and individual rights**

Opponents of government intervention in the health insurance market may agree that there are structural problems in health insurance markets, and that the services of non-profit organisations are fragmented. They may also agree that these two factors together can cause a situation where substantial portions of the population are unable to be covered by health insurance. However, they may still argue that it would be impermissible for governments to intervene to provide health insurance. Their objection claims that the benefit of the end goal (enabling everyone to have health insurance) does not justify the means of achieving this goal, if the means requires coercively requiring people to pay taxes to provide health care or coercively requiring people to buy health insurance. These theorists might argue that just as we would not consider forced labour an acceptable means of building even an important and necessary piece of civic infrastructure, government provision is not an acceptable way of fixing market failures in health insurance.

An example of this type of objection can be found in Robert Nozick's work, in particular in *Anarchy, State and Utopia*. Nozick argues that no government other than the most minimal can be justified, as every more expansive form of government violates people's rights.<sup>160</sup> In particular, Nozick criticises conceptions of distributive justice which focus on the pattern of different people's levels of resources at a particular point in time. For Nozick, the way to decide whether a particular distribution of resources is just is purely a *procedural* question. A just distribution at a later time is the result of a just distribution at an earlier time plus free exchange or free gifts of resources. A just distribution of resources, according to Nozick, should not be considered in terms of particular patterns, such as everyone holding the same amount of resources, or inequality being limited to a particular extent.<sup>160</sup> As an example of this, he refers to the (then) popular and successful basketball player Wilt Chamberlain. Many thousands of people wanted to watch Chamberlain play, and would willingly pay \$0.25 to Chamberlain from the cost of a ticket so that they could watch him play. If enough people wanted to watch Chamberlain, the combined total of each of these \$0.25 payments could mean that

Chamberlain receives income of \$250,000 per year, well over the median US income now, and an even more substantial sum in 1974 when *Anarchy, State and Utopia* was written. Nozick's point with this example is that while this results in a very unequal distribution, as Chamberlain ends up receiving an income far greater than most people, it is intuitive that Chamberlain does not receive this income unjustly, as it was the result of many freely given payments from people who wanted to watch him play basketball.<sup>160</sup>

Nozick writes that:

'Patterned principles of distributive justice necessitate *redistributive* activities. The likelihood is small that any actual freely-arrived-at set of holdings fits a particular pattern; and the likelihood is nil that it will continue to fit the pattern as people exchange and give. From the point of view of an entitlement theory, redistribution is a serious matter indeed, involving as it does, the violation of people's rights.'<sup>160</sup>

Someone could question Nozick here as to whether it is permissible for the government to intervene for a greater benefit or to avoid a greater harm. For example, even if redistributive taxation violates the property rights of a few very wealthy people, perhaps it could be justified to provide urgent health care for a much larger number of people. Nozick disagrees with this assessment, arguing that:

'no moral balancing act can take place among us; there is no moral outweighing of one of our lives by others so as to lead to a great overall social good. There is no justified sacrifice of some of us for others.'<sup>160</sup>

Here, Nozick rejects utilitarian arguments that overall social utility would be maximised by at least some government intervention. He argues that it is not the case that a nation can be properly described as a single entity, which might sacrifice certain parts of itself for the benefit of others. For Nozick, each person is a separate holder of rights. For Nozick, violating (as he sees it) one person's rights to benefit a large group of other people is necessarily unjustifiable.

### **2.1 Problems for Nozick's view – Historical injustice**

While this issue raises questions about the nature of rights which fall beyond the scope of this thesis, I disagree that government intervention to make health insurance available is impermissible. Take the case of government intervention to redistribute resources, which would be necessary in order to ensure health insurance is available to everyone. Subsidising the health insurance of low-income people with revenue collected from taxation is a form of redistribution. Requiring everyone to buy health insurance is also a form of redistribution, as it requires younger and healthier people to buy health insurance even if they are unlikely to need this insurance, and thus subsidise the older and sicker members of the insurance pool.

Arguments about the permissibility of redistribution tend to rely on identifying a baseline amount of resources, which is the amount that the owner of the goods validly held prior to redistribution or government intervention. For redistribution to be morally impermissible, the original holder of this baseline level of resources must hold valid and enduring claims to the continuing ownership of these resources. Without this valid claim, redistribution may be an uncontroversial example of *restoring* rightful ownership. For example, if A steals B's car, then the subsequent redistribution of the car back to the ownership of A would be permissible or morally required, as B never had a valid claim to the ownership of the car.

Nozick recognises that it is not necessarily the case that a person has the moral right to own the property which they currently claim to own. A person may currently claim property that they forcefully seized from others in the past, or may inherit property which was seized in this way. Nozick also recognises that due to historical injustices, entire groups of people may have been unjustly deprived of their property. Examples of this might include the descendants of Indigenous peoples dispossessed of their land and of access to natural resources. When people's rights are violated, according to Nozick, a transfer of resources to them is an example of *rectification* not *redistribution*. Nozick argues that it is important that each society studies its history to find an operable 'rule of thumb' that will best approximate the results of a detailed application in that society of the principle of rectification. Thus, the policies that should be applied to rectify historical injustice are likely to look very different in Australia as in Estonia, due to their different histories.

Nozick discusses the topic of historical injustice very briefly and in general terms. However, it is very difficult to attempt to use Nozick's principles to argue against the permissibility of any form of taxation and government redistribution in actually existing societies. This is not only a problem for countries built on land which was stolen from Indigenous peoples. Given the pervasiveness of coercion and violence in human interactions, it would be difficult to provide even one example of a society in which current property holdings are primarily the result of just acquisition and transfer according to Nozick's principles. Nozick explicitly rejects a 'patterned' theory of distributive justice, focusing instead on the *historical process* of acquisition and transfer. The fact that the vast majority of current property holdings are the results of injustice and violent dispossession stretching for millennia makes it less plausible that people have a 'natural right' to any particular property in actually existing modern societies. This also means that it is difficult to use Nozick's theory to argue that actually existing governments always violate people's rights when they tax and redistribute property and that this redistribution is always impermissible.

## 2.2 Problems for Nozick's view – Baseline holdings before redistribution

Even if no historical injustice had ever occurred, it would still be very difficult to identify a baseline holding of resources, where this baseline is the amount that individuals validly hold and which the government should not tax or redistribute. As Thomas Nagel and Liam Murphy argue, property rights are not a pre-existing entitlement from a state of nature, but are a result of a whole system of laws and the workings of social institutions.

Nagel and Murphy argue that:

'It is illegitimate to appeal to a baseline of property rights in, say, —pretax income for the purpose of evaluating tax policies, when all such figures are the product of a system of which taxes are an inextricable part. One can neither justify nor criticize an economic regime by taking as an independent norm something that is, in fact, one of its consequences.'<sup>161</sup>

In general, many economic decisions are made and incomes earned given the assumption that government taxes and spending programs exist and will continue in something resembling their current form. This is particularly true in complex, interconnected modern economies. This is not just the case for people who are directly taxed or receive direct government payments, but everyone in the economy.<sup>162</sup> For example, many economic decisions are made on the understanding that key infrastructure will function, that those without an income will not be left destitute and incentivised towards crime, and that public health measures will prevent the spread of epidemics. These factors are all only possible in practice because of government taxes and interventions. In specific reference to health insurance, many economic decisions are made on the understanding that a severe illness of oneself or a family member will not result in bankruptcy. This is only made possible by functional health insurance being available, which in turn is made possible because of government intervention given the market failures caused by moral hazard and adverse selection problems. The lack of an identifiable baseline, which is the amount that people are entitled to hold in the absence of government redistribution, makes it difficult to argue that this redistribution necessarily represents the moral equivalent of 'theft' or 'forced labour'.

Christian Barry notes that:

'There are, no doubt, reasons for considering certain economic systems just, and others unjust, but it has turned out to be difficult to use the concept of redistribution to mark out differences between them.'<sup>162</sup>

The permissibility of government involvement to provide health insurance does not necessarily mean that every way that a government might go about making health insurance available would

automatically be just. It does however mean that direct government intervention in health care markets remains an available solution to market failures.

### **3. Conclusion**

In chapters 1-3, I argued that the principles that social institutions use to allocate health care resources in conditions of scarcity should not be sensitive to individual responsibility. In this chapter, I have considered the claim that health care resources should be allocated by the free market without government intervention. As I have argued, due to market failures and the substantial differences between health care and other services, appealing to individuals' ability to buy health care or health insurance is not an efficient or effective solution to the problem of fair health care rationing. Nor is it plausible to argue for a purely market-based allocation of health care resources on the grounds that all taxation and government intervention necessarily infringes people's rights. This means that we require ways to allocate health care resources fairly under conditions of scarcity to be both responsibility-insensitive as well as involving some level of government intervention.

In the following chapter, I will discuss two metrics which are currently used to allocate health care resources: Quality Adjusted Life Years (QALYs) and Disability Adjusted Life Years (DALYs). These metrics are used by government agencies to help allocate health care resources and are insensitive to individual responsibility. Even though these metrics may seem to be a promising way to compare different types of health care and make decisions about which health care interventions to prioritise, I will argue that methodological and ethical problems mean that QALY and DALY metrics are unsuitable for this purpose. In chapter 6 and 7 I will present my own view, which builds on some core insights from Norman Daniels and Capability theorists but emphasises that health care prioritisation decisions should also take into account the effect that health care is likely to have on patients' subjective well-being.

## Chapter 5: Health Care Metrics and Rationing in Practice

1. Quality Adjusted Life Years (QALYs) and Disability Adjusted Life Years (DALYs)
  - 1.1 Using QALYs and DALYs
2. Problems with QALYs and DALYs
  - 2.1 Problems with QALYs and DALYs – Inaccurate views of disability
  - 2.2 Problems with QALYs and DALYs – Disability and incommensurability
  - 2.3 Problems with QALYs and DALYs - Distributive concerns
3. Responses to problems with QALYs and DALYs
  - 3.1 Responses to problems with QALYs and DALYs: the purpose of health metrics
  - 3.2 Responses to problems with QALYs and DALYs: Fixing the metrics
4. Alternative metrics
5. Conclusion

In the previous chapter, I argued that the allocation of health care resources should not be entirely left to market forces but requires some level of government intervention. In this chapter, I consider ways in which government policymakers currently measure the value of health care interventions and allocate health care resources in practice. Two of the most common metrics used for this purpose are Quality Adjusted Life Years (QALYs) and Disability Adjusted Life Years (DALYs), and these metrics are insensitive to individual responsibility for health behaviours. I describe how these metrics are constructed and how they are used to set health care priorities in the United Kingdom and Australia. QALY and DALY metrics might initially seem to provide an efficient and fair way to allocate scarce health care resources. However, I argue that these metrics are a poor choice for use in public policy as they use inaccurate assumptions about people with disabilities, obscure issues of distributive justice, and inappropriately conflate the goods of additional lifespan and quality of life, which should be valued separately.

### 1. Quality Adjusted Life Years (QALYs) and Disability Adjusted Life Years (DALYs)

Over the last thirty years, there has been a substantial increase in the use of metrics in health care priority setting. One reason for this is the increasing diversity of medical interventions. Medical interventions and research projects vary widely: in the types of conditions they target, the means that they use and the population that they help. For example, some health projects focus on prevention, such as vaccinations, whereas other interventions focus on increasing lifespan for people who already have a serious illness. Some medical treatments involve expensive technology, like fMRI

machines, Other interventions are relatively low cost, like a checklist to ensure that clinicians always wash their hands. Some health interventions are only targeted to a small population, such as people who have a type of rare cancer, whereas others focus on conditions for the entire population. However different these interventions seem, ideally, they could be compared. This is because for policymakers the money to fund them often comes out of the same budget.

Another reason to use metrics in the allocation of health care resources is to try to improve efficiency, with the aim of getting the best health care outcomes that are possible from limited resources. Efficiency can also be seen as an important condition to achieve fairness, rather than being an independent concern. Given limited resources, money that is wasted is money that cannot be used to relieve suffering or extend someone's life. Inefficiently spent resources are difficult to justify to the people who would otherwise have been able to receive medical care if there were more funds available.

One approach to help allocate health care resources in practice is to produce a metric which includes *both* the number of years lost or gained by an intervention, as well as the state of health these years are lived in, in a single metric. The two best known metrics of this kind are Quality Adjusted Life Years (QALYs) and Disability Adjusted Life Years (DALYs). Both DALYs and QALYs multiply a number of years by the 'quality' of those years. QALYs and DALYs can be thought of as complementary concepts. QALYs are years of healthy life lived, and DALYs are years of healthy life lost. In general, health policy would aim for fewer DALYs and more QALYs. DALYs and QALYs aim to incorporate many effects of health care in a single measure in a way that enables easy comparisons between individuals and populations.

Quality Adjusted Life Years<sup>24</sup> are a construct used by many health economists. The QALY construct assumes that a social utility function is the aggregation of individuals' utility functions, and many health economists assume that the most appropriate goal for resource allocation is to maximise this social utility function. They are calculated by multiplying a number of years lived in a health state by the 'utility' of living in that state.

So how can we assess the 'quality' or 'utility' of living in a state of health? Work by von Neumann and Morgenstern created the mathematical framework which enables researchers to generate a cardinal

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<sup>24</sup> In this chapter, I focus more on QALYs than DALYs, as they are more widely used. There is also a larger empirical and philosophical literature on QALYs than DALYs. However, given how similar the two metrics are, both methodologically and conceptually, criticisms of one metric generally applies to both.



utility function from a set of ordinal preferences. This framework assumes that the preferences in question satisfy a number of formal properties, including completeness, reflexivity, transitivity and continuity.<sup>163</sup> Researchers generate a set of ordinal preferences by using a number of techniques, such as the standard gamble, time trade off, and the person trade off. These methodologies ask participants in a study to choose between certain probabilities or lengths of time of having a particular health condition, compared to an amount of time being spent in perfect health. The person trade-off is a choice between curing  $x$  number of individuals in one disability class with the choice of curing  $y$  number of individuals in another disability class.<sup>25</sup>

There are a number of existing scales (known as multi-attribute utility indices) that have used these techniques to create an extensive set of utility weights for states of health. Probably the most commonly used scale of this sort is the EQ-5D set of instruments, created by the EuroQol Group based in Rotterdam, The Netherlands. The EQ-5D instrument works by first defining health states within five domains. To define a patient's current health state, the patient completes a short questionnaire asking about their mobility, their ability to perform self-care activities, their ability to perform their usual activities such as work or housework, their current levels of pain or discomfort, and their current level of anxiety and/or depression.<sup>164</sup> For example, within the domain of 'mobility' in the EQ-5D-5L, a patient is asked to choose from the following five options:

- 'I have no problems in walking about
- I have slight problems in walking about
- I have moderate problems in walking about
- I have severe problems in walking about
- I am unable to walk about'<sup>165</sup>

A person who was in perfect health would choose the first option in all five domains, and so would be assigned a health state within the EQ-5D-5L of '11111'. The earlier version of the EQ-5D instrument had only three options available within each domain, and so defined a possible  $3^5 = 243$  health states. As the EQ-5D-5L instrument includes 5 options within each of 5 health domains, there are  $5^5 = 3,125$  possible health states defined by this instrument.

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<sup>25</sup> Other, far less common techniques used by researchers include the 'rating scale' technique. For this, participants in the study are asked to rank health states directly on a linear scale. For example, if participants locate a state of health at point 60 on a scale from zero to one hundred, then it receives the value of 0.6. The magnitude estimation technique asks direct questions about the value of time spent in one state compared to another state.

To create QALY calculations though, the EQ-5D goes beyond defining health states to valuing them. This is done through large-scale studies of community preferences, most commonly using the time trade off methodology. Studies do not measure preferences over all 243 or 3,125 health states individually as this would be too time consuming and expensive, so the researchers used regression models to be able to extrapolate community preferences to other health states.<sup>164</sup> These studies enable the generation of a QALY weight for each health state, as a representation of a population's preferences. For example, in the EQ-5D-3L, someone who was confined to bed, but otherwise healthy would have a health state of '31111', which according to US population preferences would be given a QALY weight of 0.442315. This means that while 10 years of life for someone in perfect health (health state '11111') would be 10 QALYs, the same ten years for a person in health state '31111' would only be 4.42 QALYs.<sup>166</sup> In this way, the QALY construct assigns utilities to functional health states ranging from 1.0 (perfect health) to 0 (death).

### 1.1 Using QALYs and DALYs

Most OECD countries currently use QALYs or DALYs or both in deciding which health interventions to cover in public health insurance. They are used to different extents in different countries. QALYs are most commonly used in making national health policy, whereas DALYs are more often used by the World Health Organisation and related research and development agencies. DALYs are most commonly used as a measure of the 'burden' that a disease imposes on a population as a whole

The most extensively documented use of QALYs in public policy is by the National Institute for Health and Care Excellence (NICE), which is a policy and research agency for the National Health Service (NHS) in the United Kingdom. NICE provides best practice guidelines for medical practitioners in the UK, and develops quality standards, performance metrics and information for health care administrators and providers.<sup>167</sup> NICE also determines which medical treatments are considered cost effective and will be provided by the NHS. NICE is transparent about its extensive usage of QALY metrics in its cost effectiveness calculations, noting that

'NICE usually expresses the cost effectiveness of an intervention as the 'cost (in £) per quality-adjusted life year (QALY) gained.' This is based on an assessment of how much the intervention costs and how much health benefit it produces compared to an alternative.'<sup>167</sup>

NICE does not set an exact QALY threshold, such that interventions costing less than a certain number of pounds per QALY is considered cost effective, and interventions costing more than this number of pounds per QALY will not be considered cost effective. However, it does suggest that in general, £20,000-£30,000 per QALY is a reasonable cost to pay for an intervention.<sup>168</sup> There is an expectation

that NICE should explain its reasons when it decides that an intervention below £20,000 per QALY gained is not cost effective; and when an intervention of more than £20,000 to £30,000 per QALY gained is cost effective.

As an example of how QALYs are used in specific cases, NICE recommended that health care agencies and medical practitioners across England develop and deliver programs to increase the proportion of people who receive flu vaccinations each year. Their reasons for supporting these flu vaccination programs are that:

'Flu vaccine side effects lead to an additional QALY loss of 33.34 QALYs, but the reduction in flu cases avoids a QALY loss of 3,243. The incremental cost effectiveness ratio is therefore £2,645 per QALY. This is below £20,000 per QALY and therefore implies it would be cost effective to spend money to increase the uptake of the flu vaccination. Calculating the monetary net benefit, it would be cost effective to spend up to £5.50 per targeted child to increase uptake by 10%. Similar calculations find that it would be cost effective to spend up to £11.48 per targeted child to increase uptake by 25%. The maximum that an intervention could cost and be cost effective at £20,000 per QALY depends on the baseline coverage level.<sup>169</sup>

In this analysis, NICE calculates the total number of QALYs lost through vaccine-preventable flu cases. It also takes into consideration the number of QALYs that might be lost through additional vaccine side-effects if the vaccine was more widely administered. However NICE concludes that the problems from vaccine side-effects are vastly outweighed by the benefits of administering the flu vaccine. After calculating the magnitude of potential benefit for preventing flu cases with more widespread vaccination, it can then provide precise guidance to policymakers and administrators about to what extent it would be cost effective to spend more on additional flu vaccine programs, as compared with competing health care priorities.

In Australia, QALYs are used to assess which medical treatments are considered cost effective for Medicare to cover and are also used by the Pharmaceutical Benefits Scheme in deciding which medications the Australian government should subsidise.<sup>26</sup> But they are not used in assessing which medical research to fund or how many medical students to train. Australia does not have an explicit

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<sup>26</sup> The only direct evidence that Australia uses QALYs in government decision making is in the Appendix 7 of a couple of technical reports, which are addressed to health professionals about how to make submissions to Medicare and the Pharmaceutical Benefits Scheme. On a personal note, the only way I found out about these reports and how to interpret them was through the extensive help of a health economist who used to be on the committee that set Medicare rebates. The example of NICE indicates that would be possible to be much more open and transparent about the use of QALYs and DALYs in public policy than Australia is, and this failure to do so raises a number of concerns about public justification of Australian health care policy.

QALY threshold. However, in practice, treatments that cost less than \$AUD 50,000 per QALY are usually considered to be good value and are more likely to be funded.<sup>170</sup>

## **2 Problems with QALYs and DALYs**

### **2.1 Problems with QALYs and DALYs – Inaccurate views of disability**

One major problem with the use of QALY and DALY methodologies is that they give an inaccurate evaluation of what it is like to have many disabilities and health conditions. One reason for this is that the disability or utility weights are separated from the social context in which disability exists. An individual's quality of life living with a disability is likely to be highly dependent on the support services that are either publicly available or can be bought with private incomes. For example, in the DALY metric, blindness in the United Kingdom has the same disability weight as blindness in Niger in spite of structural interventions in the UK that make the disability less severe than in Niger.<sup>171</sup> Quality of life and opportunities are also likely to be dependent on the accessibility of facilities in the community. A person in a wheelchair is likely to experience less exclusion in a society where every multi-story building has a lift, than in a society where lifts do not exist (and all buildings are multi-story). Disability accommodation also affects the 'social cost' of disability, for example, whether people with disabilities are able to participate in employment or are required to rely on government benefits.

It could be argued that this lack of inclusion of the social context of disability is actually a desirable and necessary aspect of these metrics, in order to make it easier to compare diseases and disabilities across countries. QALYs and DALYs are frequently used in health economics, and it would be an advantage if the metric allowed health economists to compare the cost effectiveness of health care systems in different countries. Christopher Murray, one of the principal architects of the DALY metrics, defends the lack of social context, arguing that a person's health status is an attribute of themselves, and does not depend on features of their neighbour.<sup>172</sup>

However, it does not matter if an attribute in a metric is desirable, if this then means that metric is no longer measuring what it is intended to measure. It would be better to have a more limited metric that does not attempt to make international comparisons, if the alternative means that by ignoring social contexts, health and disability weights have little connection to actual quality of life.

A different aspect of QALY and DALY construction that seems likely to lead to inaccuracy is that the participants in the studies which evaluate health states are highly unlikely to have experienced many of the conditions themselves. Some bioethicists have argued that while able-bodied people may not

know directly what it is like to be blind, or deaf, or unable to walk. By the fact that they have experienced sight and hearing and walking they are therefore able to imagine what it would be like to be without these capabilities. However, the problem with this reply is that people without the disability in question inappropriately extrapolate from their own experience. For example, the experience of not being able to see in a blackout is very different to being permanently blind. As Elizabeth Barnes points out, many people with disabilities do not experience a *restricted* set of capabilities but a *different* set from those of able-bodied people.<sup>173</sup> A sighted person is unlikely to be able to imagine the experience of extra tactile sensitivity of those who are permanently blind. Furthermore, studies have indicated that people without disabilities systematically underestimate the quality of life and well-being reported by people with disabilities. For example, Peter Ubel and his colleagues calculated that while patients without colostomies estimate the HRQoL of living with a colostomy at 0.80, while patients with colostomies rate their own HRQoL at 0.92.<sup>174</sup> These considerations indicate that these evaluation of health states in QALY and DALY construction are likely to be significantly inaccurate.

A further likely cause of inaccuracy is the presence of prejudice and discrimination towards people with disabilities. This is a factor which is present in both medical professionals and the general public, thus affecting both QALY and DALY health utility weights. Many negative judgements about health states may be the result of arbitrary social preferences, and it seems highly inappropriate to ascribe these to a health state itself. For example, suppose Sam is noticeably taller than average (with no functioning restrictions and no pain), but lives in a society where being tall is considered ugly and deformed. Participants in studies creating QALY metrics in Sam's society are likely to rank being tall as being one with very low utility weights, as the study participants feel aversion to imagining themselves to be 'deformed'. But this locates the 'badness' of the state of being tall as being intrinsic to the tallness itself, rather than locating it in the mechanisms of social exclusion.

One objection to this claim about prejudice against people with disabilities is to say that although arbitrary stigma may be morally unacceptable, *the existence of social stigma itself* creates disutility for the people with the stigmatised condition, and that is what is measured by the QALY or DALY weight. The analogy can be drawn with people with severe facial damage as a result of a car accident. While much of the suffering of people with facial differences such as these may well be a result of prejudice and social stigma, the most *cost-effective* way to address this might be for that individual to be given the option to undertake facial surgery, rather than to change the attitudes of the whole society. It is this that the QALY calculations aim to show. However, there are a number of problems with this reply. Firstly, it is disrespectful towards people with disabilities to expect them to

shoulder the extra burden of receiving health interventions in order to receive the equal respect of other citizens. Furthermore, with the current and reasonably foreseeable state of medical knowledge, many disabilities and health states will not be able to be addressed to the extent of being able to avoid social stigma, meaning that the issue cannot be resolved in this manner.

It could also be objected that these misperceptions about how bad the lives of people with disabilities are may actually have a positive consequence. This would be to incentivise the health system to invest in more preventative health care. However, this seems to be unlikely to happen in practice. For example, researchers<sup>175</sup> surveyed 245 health interventions available in Australia and evaluated and compared the cost of each intervention in terms of cost per QALY. They found that adding *treatment* interventions were actually cheaper per QALY and adding more preventative health care interventions (such as diagnosis and screening) was more expensive.

The lack of inclusion of social context, the lack of knowledge about health conditions in the general public and the existence of prejudice against people with disabilities in the construction of the QALY and DALY metrics point towards the unreliability of the scales for resource allocation.

## **2.2 Problems with QALYS and DALYS - Disability and incommensurability**

Another important ethical problem is the conflation of quality of life and length of lifespan in QALY and DALY metrics. An immediate problem with this is that it can lead policymakers to act with systematic bias against people who have permanent disabilities. For example, when deciding between an intervention that will give a blind person an extra ten years of life, as compared to giving a person with no disabilities ten years of life, a scheme to maximise QALYs will always choose the person with no disabilities. This is because if the utility weight of being blind is 0.7, then the intervention that extends the life of the person with no disabilities results in an extra 10 QALYs, whereas the same extra ten years of life for the blind person only produces a gain of 7 QALYs. The construction and use of DALY and QALY metrics tend to conflate two ethical questions that should usually be considered separately. One question is how to evaluate an intervention that assists the quality of life of someone with a disability. The other question is how to evaluate an intervention that extends the life of someone with a disability. People presented with hypothetical situations may make trade-offs between lifespan and health state. However, when people with pre-existing disabilities are given this choice, they indicate a strong unwillingness to trade any life expectancy for an improvement in their health condition. For example, consider a person who had a health condition and was only willing to trade a month of life span for ten years of improved health. This means that their current health state utility would be 0.99. This also means that this health

improvement would have a maximum value of 0.01, which seems an unhelpful way to evaluate the importance of this intervention.

The counter-intuitiveness of conflating these two types of interventions can be clearly seen in Arneson and Nord's account of interviewing study participants involved in setting utility weights for DALY construction. Many study participants responded that extended life for 1000 disabled people was as valuable as extended life for 1000 people without disabilities. However, this response was regarded as unreasonable:

'Anyone who chose this option was told that he or she was implying that being disabled is as good as being nondisabled and that there is no need to spend resources on disabled people. It was suggested that he or she should therefore indicate a number higher than 1000... In spite of their reported view that the two questions ask about different things, participants at the workshop eventually accepted the requirement of consistency. Some explained that they felt they were participating in a game of little practical consequence. Others reported that rather than making person trade-off judgments, they picked disability weightings that "looked reasonable" and then selected corresponding person trade-off numbers. Perhaps some also accepted the authority of the facilitators and assumed that they were right in what they were demanding, or tried to avoid unpleasantness.'<sup>176</sup>

It could be argued that these trade-offs between life extensions for people with and without disabilities are unlikely to occur very often in the actual practice of health policy making, and so these concerns can be dismissed as marginal cases. For example, in defending NICE in its usage of QALYs, Cookson writes that:

'I doubt NICE advisory committees ever find themselves having to consider a cost-effectiveness argument for discriminating against the disabled, since subgroup analyses of cost-effectiveness based on severe disability are rarely if ever performed.'<sup>177</sup>

However, even if an explicit judgment that extending a disabled person's life is not as valuable as extending a non-disabled person's life are not directly implemented in policy very often, this does not thereby exonerate QALY methodology. The fact that these judgements and assumptions are embedded in the methodology and practices used to make decisions in health policy still *expresses* disrespect for people with disabilities and fails to treat them as equal citizens.

I suggest that the problem that QALYs and DALYs seem to produce counterintuitive and discriminatory results in regards to people with a disability is a clue to a broader problem with QALY

and DALY methodology, which is that this methodology treats extending lifespan and improving quality of life as straightforwardly commensurable goods. The terms ‘commensurability’ and ‘comparability’ have been used in different ways in the philosophical literature. I want to differentiate my application of these terms from those of James Griffin. Griffin describes a type of incommensurability called ‘trumping’, in which ‘takes the form: any amount of A, no matter how small, is more valuable than any amount of B, no matter how large’.<sup>178</sup> In other words, Value 1 in any amount always outweighs any amount of Value 2. This is not what I mean by saying that additional lifespan and quality of life are incommensurable. It would be difficult to imagine accepting torture in exchange for a few extra seconds of lifespan, which would be the case if lifespan ‘trumped’ quality of life in this way. It would also be improbable that anyone would willingly give up almost their entire lifespan (say 80 years where 80 years is approximately the life expectancy of a person in an OECD country) for a few moments of bliss, which is what would be the case if quality of life completely trumped lifespan.

Another of Griffin’s senses is that of ‘discontinuity’, in which ‘so long as we have enough of B any amount of A outranks any further amount of B; or that enough of A outranks any amount of B’.<sup>178</sup> This would mean that no *extra* amount of lifespan could outweigh *any* amount of quality of life, or conversely that no extra amount of quality of life could outweigh any amount of lifespan. This also seems implausible as an account of how people think about lifespan and quality of life. Neither lifespan nor quality of life typically has a clear cut-off point, at which people would say that they had enough. It is unclear what ‘enough’ quality of life would even mean in this context, such that people would not value or prefer further any improvement in their quality of life. It is true that in the case of lifespan, there is a concept of a ‘fair innings’ which is a full typical lifespan in which a person could have achieved their life plans. However, this concept is used in the context of how to fairly allocate limited health care resources across age groups, which is very different to considering people’s preferences and trade-offs between lifespan and quality of life. The existence of the transhumanist movement, and descriptions of desires for immortality throughout centuries of religious and secular literature suggests that for many people, there is no age at which extra lifespan would cease to give them value.

Ruth Chang has a different and more applicable concept to help think about the relation between lifespan and quality of life. I suggest that the relation between values which Chang calls ‘on a par’, may be a fruitful way to think about the relationship between lifespan and quality of life, which may also help to explain the difficulties in QALY and DALY methodology. Chang explains the relation of ‘on



a par' and how two things can be related differently from 'better than', 'worse than', and 'equally good':

'Suppose you're contemplating a choice between two rather different things – maybe a career in law and one in sky diving -- about which you're pretty sure that neither is better than the other. Now ask yourself whether a small improvement in one of them – say a \$100 increase in salary – would necessarily make it better than the other. If not, then they aren't equally good.

If A is better than B, then the evaluative difference between them favors A. If A and B are equally good, then there is a zero evaluative difference between them. If A and B are on a par, there is a non-zero evaluative difference between them, but that difference doesn't favor one over the other. One reason it's hard to wrap our minds around the idea of parity – or non-zero, non-favoring evaluative differences – is that we're so used to understanding value on the model of the reals. Once you assume that value behaves like mass or length, you're stuck with the view that one value has got to be more, less or equal to another since mass and length can be measured by real numbers, and real numbers must stand in one of those three relations...

On a par' and 'equally good' are different relations because they have different formal properties. 'Equally good' is reflexive – a is as equally good as a -- and transitive -- if a is as equally as good as b which is as equally good as c, then a is as equally as good as c. 'On a par' is irreflexive -- a isn't on a par with itself – a is as equally as good as itself -- and nontransitive -- if a is on a par with b which is on a par with c, it doesn't follow that a is on a par with c. But they are both ways in which items can be compared.<sup>179</sup>

In this quote, Chang notes that people are used to thinking that the only ways in which two things, A and B, can be related are that: A can be *better than B*, A can be *worse than B*, or A and B can be *equally good*. Chang argues that A and B can also be *on a par*. One indication that A and B are *on a par* is that a small improvement in A does not necessarily make A better than B. The relation of *on a par* can occur when two things are sufficiently different from each other, such that straightforward comparisons are not always possible, such as in Chang's example of a career in law compared to a career in skydiving. Chang also argues that it is not the case that these two things are *completely incomparable* – practical reason does not break down altogether in choosing between these two careers.<sup>179</sup>

If lifespan and quality of life are indeed 'on a par' for at least some quantities of these goods, then this would go some way to explaining why it seems that QALYs and DALYs come at the cost of forcing people to make counter-intuitive trade-offs which do not accurately reflect their beliefs or

preferences. The construction of QALY and DALY metrics are based on the assumption that people's preferences between quality of life and lengths of lifespan have certain formal properties, such as reflexivity, transitivity and continuity. However, if for some lengths of lifespan and measurements of quality of life these two values are actually 'on a par' rather than being 'better than', 'worse than', or 'equally good', then there is no reason to suppose that people's preferences would have these kinds of formal properties necessary for calculating QALYs.

Chang has a more extensive theory than I can address in this thesis about the implications of the relation of *on a par* for decision-making, agency, and normative theory. However, here I will just note that at the least, if lifespan and quality of life are *on a par*, this undermines the formal and normative basis for the QALY and DALY metrics.

It may be desirable for policymakers to have a single metric to compare all health interventions. However, assuming that lifespan and quality of life are related in the way required by QALY and DALY methodology leads to counterintuitive and discriminatory results which do not accurately reflect people's values or help to solve the problem of ethically allocating scarce health care resources.

### **2.3 Problems with QALYs and DALYs: Distributive concerns**

Another ethical problem raised by the use of QALY and DALY metrics is that aiming at QALY and DALY maximisation, which is a common way of using these metrics, does not accurately capture people's ethical intuitions to prioritise the worst-off. This issue was memorably illustrated in the case of the state of Oregon's proposed changes to insurance in 1990, using a similar cost-effectiveness metric. Capping teeth, which is a minor dental procedure, was given priority in this metric to operations removing an appendix for appendicitis, even though failure to have this operation for people who need it is life threatening. This is because the aggregate benefit from many teeth being capped was considered to be greater and more cost effective than performing a smaller number of appendix operations.<sup>180</sup> These judgements seem highly counterintuitive, as most people consider that an ethical requirement for health care funding is that it prioritise benefiting the worst off, even if this is at the expense of maximising aggregate benefits.

There are a number of philosophical interpretations which are consistent with this moral intuition of preferring appendix operations to tooth capping. A person might prefer the appendix operations because they value an *equal distribution* of QALYs. There are many types of egalitarian views, but some egalitarians, such as Larry Temkin,<sup>181</sup> value helping the worst off in order to achieve an equal distribution more highly than achieving a maximum overall amount of the good in question. A

prioritarian would be likely to favour the same action of choosing the appendix operations in preference to maximising overall QALYs, but for different reasons. Prioritarians disagree with egalitarians in that they tend to believe that there is no non-instrumental value to an equal distribution *per se*.<sup>182</sup> However, a prioritarian such as Derek Parfit<sup>183,184</sup> may argue that QALYs are more valuable to those who have fewer of them, and so the worst off should receive priority in the distribution of health care resources and procedures. A sufficientarian, such as Roger Crisp,<sup>185</sup> may also choose the appendix operations over the tooth capping. Sufficientarians tend to believe that when people are badly off such that we should be compassionate towards them, then we have reason to give priority to one person over another. However, when people meet a standard such that they're "sufficiently" well off, there is no reason to give priority to one person over another *just* because one person is worse off. Choosing appendix operations is compatible with sufficientarian views because a person who urgently requires an appendix operation seems to be badly off enough to warrant our compassion, and to morally require us to give them priority.<sup>185</sup> Egalitarian, prioritarian and sufficientarian policy prescriptions will come apart in some circumstances but this situation is not one of them.

Some health economists and policymakers have responded to this objection by suggesting that in fact attempting to maximise QALYs is the most egalitarian and impartial approach to health policy. For example, the economist Alan Williams, whose work was influential in the creation of NICE, argued that:

'The simplest and commonest use of QALY calculations at present is based on the assumption that a year of healthy life expectancy is to be regarded as of equal value to everybody. Note that this does not say that it is of equal value to everybody, because that is unknowable... A strong egalitarian case could be made for that assumption, since it implies that it does not matter at all who the beneficiary is. Like Justice, it is Blind. There is no discrimination on grounds of race, sex, occupation, family circumstances, wealth or influence. In this respect it follows precisely the assumptions underlying the use of the more conventional outcome measures used in clinical trials, which just count the number of people with the specified outcomes characteristic.'<sup>186</sup>

It is true that trying to maximise QALYs treats people equally in the sense that it is free from some types of discrimination, such as discrimination against people on the grounds of sex, ethnic background, religion, or socioeconomic status. However, we do not accept that this is a form of 'egalitarian' distribution in many other areas of life. For example, most people think that it is justifiable or morally required for the state to engage in some form of progressive taxation, such that

wealthier people pay a higher proportion of their marginal income than the less well-off. This is true even though the state is unable to know for certain whether a dollar is of equal or different value (or utility) to two different people. While there are obvious differences between a QALY and a unit of income and wealth, there are also similarities. For example, a person's income can have a very substantial effect on many aspects of their quality of life, and policies to maximise or distribute QALYs are also affect the quality of life that people are likely to have. A policy that required maximisation of QALYs on the 'egalitarian' ground that a QALY should be regarded of equal value to everyone would prove too much and would run counter to many other widely held views about distributive justice.

### **3. Responses to problems with QALYs and DALYs**

#### **3.1 Responses to problems with QALYs and DALYs: the purpose of health metrics**

A reply could be made here that these objections about QALYs and DALYs miss the point, and criticise these health metrics for not being able to do something that they were never designed to do. An example of this response was given by John Broome, who argues that 'QALYs are aimed at assessing the total of good', and that while they do not take into account justice or fairness, that this is not what they are designed to do. Broome writes that 'Assessing the total of good is worthwhile, and it has a part to play in allocating resources. Only it is not everything.'<sup>187</sup> To recognise the limitations of a measure is not to say that this measure is useless, it only indicates that issues of distributive justice need to be considered separately, in addition to these metrics.

However, to the extent that QALYs and DALYs are inaccurate about the experience of life with a disability, and misrepresent people's preferences by forcing participants in studies to make trade-offs between life span and health improvement, they do not actually represent the total of good. Given that we are dealing with scarce resources, I think that this is more than just inaccuracy and is unfair to the people who would have received medical treatment except for misunderstandings built into the prioritisation system.

However, the problem goes beyond that. QALYs and DALYs displace other metrics and other information, making it more difficult to consider these issues of distributive justice. There are many aspects of the world that we can choose to focus on. For example, I could choose to make a metric that adds together the number of birds currently in Canberra, with the number of letters in the middle names of all the politicians currently in Canberra. Suppose I then tried to use this metric to measure air pollution in Canberra. While the number of birds in Canberra may plausibly be related to Canberra air pollution, combining this with an irrelevant measure (the number of letters in

politicians' middle names) actually gives us *less* information than we had before. In the same way, even if some aspects of the QALY measure are relevant to measuring the amount of good in health care interventions (just as the Canberra bird population may be related to Canberra's air pollution), the dilution of this with other irrelevant information (just as the number of letters in politicians' middle names is irrelevant to Canberra air pollution) makes the metric much less useful. The extent to which QALYs and DALYs are distorted by irrelevant and misleading information means that they are unlikely to be useful even for more restricted purposes.

### **3.2 Responses to problems with QALYs and DALYs: Fixing the metrics**

Another response that a defender of QALYs might make here is to concede that there are methodological problems with the ways that QALYs are currently calculated and used, but to argue that these problems could be fixed at reasonable cost, and so an improved version of the QALY could be retained as a useful metric for public policy. For example, perhaps the preferences of people with disabilities can be better incorporated into the process of valuing health states as compared to lifespan. Incorporating the views of people with disabilities may ameliorate the effects of prejudice or ignorance of abled-bodied people that exist in the current QALY methodology. Another change that could be made is to reject QALY maximisation as a public policy goal, and instead to adopt a form of QALY prioritisation for the worst off. Would a revised and improved QALY methodology be enough to respond to the criticisms made earlier in this chapter?

I agree that there are a number of possible methodological improvements which could be made to QALYs and DALYs. However, I disagree that these improvements would suffice to adequately respond to these criticisms.

To take the problems in turn, it would be possible to include more people with disabilities into the groups of study participants who create QALY and DALY weights, in order to better inform the weighting process with people's lived experience. However, this methodological change would require not just the inclusion of people with disabilities in general, but a classification of participants' different types of disabilities and a process to match participants' lived experiences with the health states that they are providing utility weights for. This is important because there are a wide variety of health conditions and disabilities. Lived experience of one disability would not necessarily mean that a participant would have more accurate insights about a different disability. For example, a person who has severe problems with mobility, but no pain, would not necessarily have special insights into the life of someone who has severe pain but no mobility problems. While this methodological change would be possible in theory, in practice it would add considerable complexity to the process of

constructing multi-attribute utility indices such as the EQ-5D, which already have 243-3,125 different specified health states.

Another possible response to criticisms about QALY methodology could be to create a variant of the QALY metric which identifies some people as the 'worst-off'. Identifying these people using a metric may make it easier for policymakers to give them priority in the distribution of health resources. While this project is experimental, early attempts do not look promising, and seem to exacerbate other problematic effects of QALYs. For example, one group of researchers tried to identify the 'worst off' by calculating the lifetime QALYs for different groups.<sup>188</sup> In the lifetime QALY approach the group that the measure decided were 'worst off' were profoundly deaf children and the most cost-effective intervention was giving them a cochlear implant. This was ranked more highly than treating older people for who had just had a stroke, or had arthritis, or had other conditions which involved chronic pain. Given the disagreement within the deaf community about whether deafness should be considered to be a disability at all, or simply a community with different capabilities, language and cultural characteristics, and the ambivalence among many recipients of cochlear implants in later life, this method of deciding who is worst off seems to come to counterintuitive conclusions.

Another possible response to distributional concerns is that of equity weights, where some QALYs are weighted more heavily than others. The attempt to set equity weights is intended to be based on the preferences and moral views of the general population. However, the strength of people's preferences for the worst off in health care priority setting were found to be highly unstable and dependent on the wording of the study.<sup>189</sup> Furthermore, while egalitarians, prioritarians and sufficientarians may all disagree with the QALY maximising approach, they are unlikely to agree about how QALYs should be weighted. Should the worst off only be given priority under a certain threshold, and if so, what should the threshold be? Should a more equal distribution of QALYs be favoured even if it involves levelling down, and if so, in what circumstances? What sorts of trade-offs are acceptable to make between priority for the worst off and overall health system efficiency? Being able to come to a widely agreed resolution of these issues about equality, priority, sufficiency and efficiency, within the equity weights system seems unlikely

However, the most serious criticism of QALYs, and one which is highly unlikely to be remedied through methodological changes, is the problem that years of lifespan and quality of life are not straightforwardly commensurate goods in the way that the QALY methodology requires. If this is the case, then this is a problem at the core of the QALY and DALY concept. The point of creating QALYs and DALYs is to include the many effects of health care on quality of life and years of lifespan in a

*single measurement*, in order to be able to rank and prioritise health care interventions. If, as I have argued, these two goods cannot be traded off against each in such a way that they can properly be included in the same measurement, then this is a criticism of QALYs that an upgraded methodology is unlikely to solve.

#### **4. Alternative metrics**

While there are significant problems with the use of DALYs and QALYs, the issue of priority setting in health care remains, and is likely to grow more acute with aging populations. The appropriate response is not to abandon the use of metrics for rationing resources entirely. Instead we should learn from the over-ambitiousness of previous attempts to quantify the value of health interventions and health states in a single number.

In the process of evaluating health interventions, policymakers should consider both '*objective*' metrics of functioning, such as to what extent a person has lost their sight, as well as *subjective* judgements about quality of life made by patients themselves. The inclusion of the preferences and views of patients, rather than members of the general public faced with hypothetical scenarios, reduces the risk of inaccurate information and prejudice tainting the priority setting process.

As people with disabilities in practice have a strong aversion to trading lifespan for improved health status, a process that focuses on the preferences and experiences of patients would take this into account. In this way, the priority setting process would be respectful and responsive to the experiences of patients themselves rather than treating them as anonymous repositories of socially defined utility. The decision-making process should also use criteria and reasons that treat all citizens equally, are easily publicly available, and subject to review through the democratic political process.

An example of an existing metric that incorporates some of these desirable criteria is the World Health Organization's Disability Assessment Schedule (WHODAS) and its companion metric, the World Health Organization Quality of Life instrument. WHODAS is a tool for assessing a person's global functioning across six domains: cognition, mobility, self-care, interactions with others, life activities and social participation.<sup>190</sup> It incorporates the way in which a person's health condition interacts with their social context to measure the person's functioning in practice. It has been internationally normed and validated, making it useful for cross-country epidemiological comparisons. The World Health Organisation Quality of Life instrument asks patients about their subjective well-being for their health condition and functioning.<sup>191</sup> Both objective functioning and

subjective well-being should be taken into account when evaluating the health of a population or potential health interventions.

As an example about how this might be used in practice, incorporating World Health Organisation quality of life data might make social institutions take chronic pain more seriously. The extent to which chronic pain has a profound effect on well-being has been measured by the WHO quality of life instrument, and it doesn't appear that there is a large adaptation effect with chronic pain. The QoL instrument was also able to identify certain subtypes of chronic pain which had the largest effects on well-being. Another instance of an area that may receive more priority is the treatment of depression, especially when this occurs in conjunction with other health conditions. Researchers using this QoL metric have found that depression is a very significant mediating factor between a number of health problems and the patient's subsequent quality of life.<sup>192</sup> Treating depression not only as a standalone condition but also as something that interacts with other conditions could become more of a health care priority.

## 5. Conclusion

In this chapter, I have described the methodology of QALY and DALY construction, and how these metrics are currently used in setting health care policy. I agree with the proponents of QALYs and DALYs that it is important to measure health outcomes and patients' quality of life, and I further agree (as argued in previous chapters) that the allocation of scarce health care resources should be responsibility-insensitive and should allow for some level of government intervention. However, as I have argued in this chapter, there are a number of substantial problems with QALY and DALY construction, including the way that QALYs and DALYs ignore the lived experiences of people with disabilities and that the usage of QALYs and DALYs obscures issues of distributive justice. However, the most serious problem is the way in which QALY and DALY methodology requires that length of lifespan and quality of life are straightforwardly commensurable goods which can be traded off against each other at every quantity. If, as I have suggested, the more accurate relation between these goods (for at least some quantities) is that they are *on a par*, then some of the formal properties necessary for turning the preferences of study participants into QALY and DALY weights do not hold.

In the last two chapters of this thesis, I describe and explain my own view of how health care resources should be allocated. My view builds on the work of Norman Daniels and of Capability theorists. However, I argue that allocation of scarce health care resources should be made on the



basis of how the health care is likely to affect people's morally relevant capabilities, as well as to what extent the health care is likely to affect people's subjective well-being.

## Chapter 6: Capabilities, Functionings and Health Care

1. The importance of health and health care: its contribution to capabilities and functionings
  - 1.1 Norman Daniels
  - 1.2 The Capability Approach
2. The central insight of the functionings and capabilities view
3. Why the functionings and capabilities view isn't enough: the problems of terminal illness and chronic pain
4. The problems of terminal illness and chronic pain: Potential responses from the functioning and capabilities view
  - 4.1 Response: The plausibility of achieving capabilities and life plans while suffering chronic pain?
  - 4.2 Response: Incorporating the effect of chronic pain into non-basic capabilities?
  - 4.3 Response: Incorporating chronic pain within Capability Theories?
  - 4.4 Response: Incorporating chronic pain within Norman Daniels' theory?
  - 4.5 Response: Intuitions about chronic pain versus capabilities
5. Conclusion

In the previous chapters of this thesis, I have considered a number of ways of allocating scarce health care resources and argued that they all have major flaws. In Part 1, I rejected luck egalitarian, responsibility-sensitive principles for priority-setting in health care. In Chapter 4, I argued against the view that health care resources should be allocated by market forces without government intervention. In Chapter 5, I rejected the use of Quality Adjusted Life Years (QALYs) and Disability Adjusted Life Years (DALYs) for health care priority-setting. In the final two chapters of this thesis, I will develop and argue for my own view.

In this chapter, I describe two prominent theories about why health care matters and how we can ration health care ethically: Norman Daniels' theory, and the Capability theories of Martha Nussbaum and Sridhar Venakapuram. Daniel's theory and Capability theories are similar in that they both emphasise that the value of health care is in its ability to protect and improve people's capabilities and functionings (what people can do and can be).

I agree with Daniels' and Capability theorists' central insight that much of the moral importance of health care lies in its role in protecting and improving human capabilities and functionings. However, this insight is insufficient to be able to allocate health care resources fairly in conditions of scarcity.

This is because an exclusive focus on capabilities and functionings has trouble taking account of the crucial role that health care plays in relieving pain and suffering. There is a subjective element in the experience of pain which is difficult to incorporate in Daniels' and Capability theorists' objectively defined sets of capabilities and functionings. This creates serious problems for their theories, as it means that they do not have the internal resources to explain why the relief of pain and suffering is an important health care priority in and of itself. Pain relief is intrinsically important, not just valuable to the extent that it improves objective capabilities and functionings. I address five potential responses to this argument and conclude that theories of health care prioritisation also need to include consideration of how health care improves people's subjective well-being.

## **1. The importance of health and health care: its contribution to human capabilities and functioning.**

### **1.1 Norman Daniels**

Norman Daniels has developed a sophisticated philosophical account which extends Rawls' theory of justice. This account aims to explain why health matters, why people are entitled to health care, and principles for rationing health care in conditions of scarcity.<sup>14</sup> For Daniels, people are entitled to receive health care which enables them to function normally, as normal functioning is an important prerequisite for achieving fair equality of opportunity.

Daniels argues that health should be defined in terms of biologically normal species functioning. In Daniels' account, people need health care when they cannot function normally in some regard. An illness or a disability is defined as a harmful aberration from normal functioning.<sup>27</sup> Thus, having lower than normal agility or cognitive skills could be classified as a health problem. Having greater than normal agility or cognitive skills would not be classified as a health problem unless there are side effects which impair other aspects of the person's functioning. In Daniels' account, there are objective criteria for whether a condition should be classified as a health problem – this definition does not depend on the preferences of individual patients. As an example of this, infertility is considered a disease or disorder because it is a deficit in normal species functioning, regardless of whether the particular couple in question wants to have a baby or not.<sup>14</sup> Daniels argues that people generally agree on what is included or excluded from this set of health needs.

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<sup>27</sup> A biological function is one that makes a causal contribution to a species-typical goal, such as survival or reproduction.

Daniels argues that there is a strong connection between normal functioning and opportunity, one of Rawls' primary social goods. The *normal opportunity range* is the set of life plans that reasonable people within a society are likely to construct for themselves.<sup>193</sup> Illness or disability can restrict the range of opportunities available to people, such that they are unable to pursue life plans that would otherwise have been reasonable for them to strive towards. Thus, providing health care is an important prerequisite for a society to achieve fair equality of opportunity.<sup>14</sup> As Daniels writes:

'Meeting health needs has the goal of promoting normal functioning: It concentrates on a specific class of obvious disadvantages and tries to eliminate them. The fair equality of opportunity principle, as Rawls uses it, does not correct for all differences in talents and skills: It accepts their natural distribution as a baseline and leaves it to the difference principle to mitigate the effects on opportunity of being born with less marketable talents and skills. Similarly, the fair equality of opportunity principle applied to health needs does not rectify or level all inequalities in function among people. It aims only to keep people functioning normally and thus to assure them the range of opportunities they would have in the absence of disease or disability.'<sup>14</sup>

Daniels notes that as normal opportunity ranges differ from society to society, the same condition may impair opportunity to different extents. For example, dyslexia is likely to be a more severe impairment in a highly literate society than a largely illiterate one.<sup>14</sup> Also, opportunity ranges are about *options*, rather than about the extent to which a disease or disability in fact affects different individuals. For example, a disease that causes a loss of manual dexterity may, in fact, have a more severe impact on the career of a tradesman than an academic. However, if they both began with the same level of manual dexterity, then their shares of the fair opportunity range have been curtailed by the same extent. Daniels' concept of opportunity is broader than that of Rawls, who is mainly concerned about jobs and employment. Daniels' view of opportunity also includes other plans of life, such as writing a novel for pleasure rather than income.<sup>28</sup> Daniels does not argue that normal functioning is intrinsically important and of basic moral value (like a capability). Rather, it is part of what is necessary for people to have fair equality of opportunity and to be able to interact as free and equal citizens.

Daniels emphasises that social institutions, not individuals, bear the primary responsibility for protecting health. One reason for this is that, in Daniels' view, public health and society-level factors have more impact (more causal relevance) in the distribution of health outcomes than individuals'

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<sup>28</sup> Daniels thinks that this is a natural extension of Rawls' theory.

decisions about their own health behaviours. He also argues that the social responsibility for health is ‘epistemically’ primary. That means it is possible to specify what society should provide for health needs without knowing what decisions the individual should make or has made.<sup>40</sup> Daniels believes that social institutions are responsible for the just distribution of the social determinants of health, for example basic rights and liberties, income, wealth, education, and the social bases of self-respect. In addition, social institutions are also responsible for traditional public health measures such as the provision of clean air, clean water, sanitation and immunisations, as well appropriate medical care for people who need it.<sup>40</sup>

Daniels acknowledges that social institutions need to set limits when allocating health care resources. This is not just an unfortunate reality in societies with few resources but is a general requirement of justice. This is the case because many things, such as education, job creation and law and order affect opportunity, not just health.<sup>135</sup> Furthermore, opportunity is not the only important social good. For example, people’s basic rights and liberties must also be protected. While the fact of limited resources means that not every health care need can be met, allocating health care resources should be done on the basis of need and not willingness or ability to pay.

Daniels’ theory of justice in health care rationing is not just concerned with fair distributions, but also with fair decision-making processes. To argue for the importance of fair processes, Daniels provides examples of health care rationing decisions which rely on value judgements with which reasonable people may disagree.<sup>135</sup> For example, it would be possible to have an extreme position on health care rationing that social institutions should give complete priority to the worst-off patients, such that a small group of very badly-off people use the majority of health care resources. A different extreme view could be that social institutions should give priority to whichever treatments produce the greatest net benefit per dollar spent, regardless of which patients are treated. In practice, most people reject both of these extremes, opting for a position in the middle. However, reasonable people can disagree about how this trade-off between priority and efficiency should be made and exactly where this middle road should be placed.<sup>135</sup> In the process of making these decisions, Daniels argues that health care rationing decisions should be made using the following four principles, which he jointly calls ‘accountability for reasonableness’:

- ‘1. **Publicity Condition:** Decisions regarding both direct and indirect limits to care and their rationales must be publicly accessible.
2. **Relevance Condition:** The rationales for limit-setting decisions should aim to provide a *reasonable* explanation of how the organization seeks to provide “value for money” in meeting the varied health needs of a defined population under reasonable resource

constraints. Specifically, a rationale will be reasonable if it appeals to evidence, reasons, and principles that are accepted as relevant by fair-minded people who are disposed to finding mutually justifiable terms of cooperation.

**3. Revision and Appeals Condition:** There must be mechanisms for challenge and dispute resolution regarding limit-setting decisions, and, more broadly, opportunities for revision and improvement of policies in the light of new evidence or arguments.

**4. Regulative Condition:** There is either voluntary or public regulation of the process to ensure that conditions 1–3 are met.<sup>135</sup>

There are a number of aspects to note about these criteria. One is that decisions must be made transparently, recognising the fundamental interest in finding a justification for health care rationing decisions that everyone can accept are reasonable. This is consistent with Daniels' Rawlsian commitment to public justification. Another aspect is that decisions should be revisable, and that learning from the past and responding to disagreements should be an important part of the decision-making process, not just an afterthought in response to conflict. The final regulation condition is designed to ensure that these conditions are met in practice and are not just aspirational.<sup>135</sup>

As an example of how these 'accountability for reasonableness' criteria can be applied in practice, Daniels considers the case of publicly-funded contracts with private sector health care providers to treat vulnerable people with mental health problems.<sup>135</sup> In Massachusetts, Medicaid mental health services were provided by the for-profit company ValueOptions. The contract between the two parties specified that ValueOptions would be financially rewarded for meeting 22 performance standards. These performance standards were decided through extensive and public consultation with service users, community groups, researchers and other stakeholders, and this process, in Daniels' view, met his Publicity and Relevance conditions. There was also a process of continuous quality improvement of the program through responsiveness to feedback from a consumer advisory council and a consumer-developed survey. As a result of this feedback, some program guidelines were changed and Spanish-language services improved. This responsiveness to feedback, in Daniels' view, met his Revision and Appeals condition, and the structure of the program as a whole met his Regulative condition.<sup>135</sup>

Norman Daniels provides a sophisticated Rawlsian theory about how to ration health care fairly. He argues that social institutions have a duty to provide health care, as restoring people to normal functioning is an important prerequisite for society to achieve fair equality of opportunity.

## 1.2 The Capability Approach

The Capability Approach is a theoretical framework that can be used to make interpersonal comparisons by focusing on capabilities and functionings. ‘Functionings’ are things that people can be and can do. Examples of ‘beings’ are being well-nourished, being undernourished, being educated, being illiterate, being part of a supportive social network, or being depressed. Examples of ‘doings’ are travelling, caring for a child, voting in an election, taking part in a debate, or taking heroin. As is evident from these examples, the category of functionings, in and of themselves is supposed to be value neutral. This means that conceptually, there are functionings with a neutral or negative value. However, philosophers do not tend to focus on these, but on the distribution of positive and morally relevant functionings.

Capabilities are a different, but related concept, in that they are a person’s real freedoms or opportunities to achieve functionings. Thus, while travelling is a functioning, *the real opportunity to travel* is the corresponding capability. Capability indicators are intended to capture whether people have certain genuine freedoms, not whether they in fact exercise these functioning in practice. For example, a person may have the capability of being well-nourished if they have easy access to a range of nutritious food. They retain this capability even if the person does not choose to eat any of this food, as they are fasting for religious reasons. However, in practice, the level of certain functionings can be a very good indicator of people’s capability sets. For example, it is unlikely that large groups of people would freely choose to fast to the extent of severe malnourishment or would freely choose not to access health care even though they have a treatable and life-threatening disease. In these cases, the fact that people do not have the functionings of being well-nourished or accessing health care is a strong indicator that they do not have the relevant capabilities either, and that social institutions should look to addressing the barriers which prevent them from having these capabilities.

Capabilities and functioning can be used as a framework to guide empirical work. For example, there are significant bodies of literature using capabilities and functionings to measure and compare aspects of societies in public health, development economics, and environmental policy. Capabilities and functionings can also be used in normative theories – such as evaluating social institutions and public policies or creating theories of distributive justice.

There are a number of advantages to using capabilities and functionings as important metrics in a theory of justice. One advantage is that focusing on capabilities can enable people to assess societies in different, and perhaps more intuitively appropriate ways. For example, in the early 1980s, GNP per

capita in Brazil and Mexico was more than seven times that of India, China and Sri Lanka, however, this did not predict these countries' performance on life expectancy, infant mortality and child death rate indicators.<sup>194</sup> Capability theories, with their focus on what people could do and can be in practice, rather than on the resources that were in theory available to them, was in a better position to focus on these indicators as a matter of priority. Capability theories have been influential in the design of the Human Development Index (HDI). The HDI is a composite of life expectancy, education, and the purchasing power and amount of people's incomes. Sen's ideas inspired the development on the HDI through his emphasis that development should not be primarily measured by people's level of resources but on a broader range of factors which have significant impact on well-being. Capability theories are also useful in analysing inequality within countries, communities and households. A focus on overall resources, such as level of household income, can be seriously misleading if it is not accompanied by an analysis of the distribution of work (such as unpaid childcare, housework and elder care), power and ability to function *within* the household unit.<sup>195</sup>

Capability theories also allow people to capture different dimensions of the effects of public policy. For example, Jonathan Wolff and Avner De-Shalit discuss the effects of clearing a slum and moving the people who previously lived in the slum into newly built tower blocks. Capability theories would be able to capture both the advantages of this policy (such as in improved hygiene and shelter) but also possible negative effects on people's well-being, as the social networks that are important to people's lives may not transfer neatly to the new tower blocks.<sup>194</sup> Policies and systems are complex, and it can be helpful to compare them in a way that considers different capabilities separately. There are significant bodies of literature on people's capabilities and functionings in public health, health economics, environmental policy and disability and educational studies.

One benefit of a focus on capabilities and functionings over an account that focuses on equality of resources, is that it recognises the fact that people have different abilities to turn resources into functionings. 'Conversion factors' are what determines the extent to which a person can turn a resource into a functioning. Different people need different levels of resources to achieve the same functionings. For example, a person with paraplegia might need an expensive wheelchair to achieve the same level of mobility as a more able-bodied person. However, capabilities theories recognise that there is an important normative sense in which the person with paraplegia isn't getting 'extra' over and above the able-bodied person. They might be getting different levels of resources, but what matters is that they are equal in the relevant evaluative space, which is that of the capability of mobility. Capability theorists argue that theories of distributive justice that focus on resources have



trouble accommodating people who need more resources to achieve the same capabilities in a way that is both intuitive and fair.

Capability theorists argue that, unlike theories that focus on equal well-being or preference satisfaction, they avoid many of the intuitive problems with adaptive preferences. An adaptive preference is a preference that is not what people actually prefer, but an adjustment to a sub-optimal situation. As they would want something different if this was a realistic possibility, their current preferences and subsequent expressed subjective well-being should not be taken as an indicator to how badly off they are, or as a guide to resource distribution. For example, imagine a woman who has never had any real opportunity to learn to read. However, she may say that she is perfectly happy with this situation and express a preference for being illiterate. She may well have adapted her preferences to adjust to the situation that she has been in – her expressed preferences do not mean that public policy shouldn't make free adult education available to her if possible. Capability theories are able to take these intuitions into account more naturally than a theory focusing on equality of well-being or preference satisfaction would be able to.

Martha Nussbaum, a prominent capability theorist, cites some striking examples of the extent that adaptive preferences and ingrained social expectations can affect people's sense of their own well-being.

'in 1944, the year after the Great Bengal Famine, the All-India Institute of Hygiene and Public Health did a survey in an area near Calcutta, including in the survey many widows and widowers. Among the widowers, 45.6% ranked their health as either, "ill" or, "indifferent." Only 2.5% of widows made that judgment, and none at all ranked their health as, "indifferent" (as Sen notes, a more subjective category than, "ill"). This was in striking contrast to their real situation, since widows tend to be a particularly deprived group with regard to basic health and nutrition... One can also make a remark in the other direction: privileged people get used to being pampered and cared for, and may feel an unusually high level of discontent when the one that did the pampering isn't around any longer.'<sup>195</sup>

These distortions, to Nussbaum, mean that subjective preferences and self-report are an unacceptable basis for social choice, and adjudicating claims of entitlements and social justice.

Related to this, capability theories also claim to be able to avoid some of the problems with using subjective well-being as a metric to make interpersonal comparisons. To illustrate this, Amartya Sen cites an example of a person who needs a wheelchair for mobility and also happens to, for temperamental reasons, always be very happy, happier than other people. It is counterintuitive to

think that because of the fact that this person has higher subjective well-being than other people, that they are not entitled to the wheelchair as a matter of justice. Capability theorists tend to take an example like this to argue that they're interested in the way that capabilities and functionings contribute towards their well-being as defined objectively, not subjectively.<sup>196</sup>

A further benefit is that capabilities are able to be realised in a number of different ways, which takes into account the diversity of people and their experiences. For example, the capability of mobility could be realised through a person being able to drive a private car in some circumstances, and in other circumstances it could be through affordable and reliable public transport. This is important for a moral theory which from its beginning has been applied internationally. This pluralism about how capabilities can be realised also attempts to avoid paternalistic or patronising attitudes. Nussbaum also notes that (within certain parameters) countries may have special histories and circumstances that makes different realisations of these capabilities appropriate. Nussbaum gives as an example that a free speech right that suits Germany well might be too restrictive in the different climate of the United States.<sup>75</sup> Thus, the breadth and abstraction with which capabilities are described can be seen as a strength of Capability Theories.

As capabilities theories have focused on the diversity of human beings and the importance of embodiment and individual differences, it's not surprising that capability theories have been applied to health care and justice. Nussbaum sees health as a distinct capability within a set of ten basic capabilities, within what she calls a 'partial theory of justice': Nussbaum's ten capabilities are:

1. Life. Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to be not worth living.
2. Bodily Health. Being able to have good health, including reproductive health; to be adequately nourished; to have adequate shelter.
3. Bodily Integrity. Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction.
4. Senses, Imagination, and Thought. Being able to use the senses, to imagine, think, and reason – and to do these things in a “truly human” way, a way informed and cultivated by an adequate education...
5. Emotions. Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude, and justified anger. Not having one's emotional development blighted by fear and anxiety..

6. Practical Reason. Being able to form a conception of the good and to engage in critical reflection about the planning of one's life...
7. Affiliation.
  - A. Being able to live with and toward others, to recognize and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another...
  - B. Having the social bases of self-respect and nonhumiliation; being able to be treated as a dignified being whose worth is equal to that of others...
8. Other Species. Being able to live with concern for and in relation to animals, plants, and the world of nature.
9. Play. Being able to laugh, to play, to enjoy recreational activities.
10. Control Over One's Environment.
  - A. Political. Being able to participate effectively in political choices that govern one's life; having the right of political participation, protections of free speech and association.
  - B. Material. Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure...<sup>75</sup>

According to Nussbaum, people are entitled to a sufficient threshold level of all of the ten basic capabilities.<sup>75</sup> Nussbaum justifies people's entitlements to these ten basic capabilities by emphasising that everyone is valuable and worthy of respect, and should be regarded as an end in themselves. She sees these ten basic capabilities as a baseline for a life that has the dignity that all people are inherently entitled to.

Nussbaum's list of basic capabilities has been influential, and other theorists have helped to draw out how the capability of health is in fact implicitly included in all these basic capabilities as well as forming an explicit, stand-alone capability. For example, health status clearly affects life expectancy (Nussbaum's capability 1), but it also affects people's ability to move freely from place to place (capability 3). Some health problems (especially in childhood) can lead to impaired intellectual and emotional development and the chance of receiving a good education (capabilities 4 and 5), and chronic diseases are likely to affect opportunities to make friends and develop a professional network (capability 6).<sup>197</sup>

Further discussions and extensions of Nussbaum's work have been provided by Sridhar Venkatapuram. The main focus of Venkatapuram's work is to define health within a capability

framework and then to draw implications for global justice. Venkatapuram sees health as a 'meta-capability' – the capability to develop other capabilities, a prerequisite to achieve a list of basic capabilities similar to Nussbaum's.<sup>198</sup> In this way, Venkatapuram sees health as not just the absence of disease, but a positive cluster that gives people the abilities to be and do things. As Venkatapuram writes:

The core argument is that a person's health is most coherently conceptualized as her abilities to be and do things that make up a minimally good, flourishing and non-humiliating life for a human being in the contemporary world. Such an argument expressly advances a definition of health that is ethical and rejects others which are focused on disease, and aim to be scientific or statistical. Furthermore, because a person's health is an assessment of her abilities to be and do some basic things, a person's capability to be healthy can be understood as being a meta-capability; an overarching capability to achieve a cluster of basic capabilities to be and do things that make up a minimally good human life in the contemporary world. This meta-capability is based on the concept of a 'cluster-right' as articulated by Judith Jarvis Thomson; it is a right which includes multiple and diverse entitlements to goods, liberties, powers, privileges and immunities (Thomson, 1990). Just as with rights to life, liberty or property, each of which we currently recognize as a cluster-right with diverse claims and correlative duty-holders, we should similarly treat a right to the capability to be healthy.<sup>198</sup>

Venkatapuram emphasises the link between the capability to be healthy and social conditions. Social conditions not only determine who in a society gets medical care and what sort of care they get, but a broad set of other factors that affect to what extent people become unwell in the first place, such as their level of nutrition, the work they do, their exposure to environmental pollutants and their housing conditions. Venkatapuram also connects the moral claim to capability to be healthy with the language of rights. The capability to be health can be seen as a 'cluster right'. While he acknowledges that this moral claim to the capability to be healthy may not be immediately fully realisable, and it may not always have clear duty-bearers, he argues that these do not invalidate the argument that the capability to be healthy is still a right.<sup>198</sup>

The argument for protecting people's health within Capability theories have been succinctly summarised by Lasse Neilson:

- '(1) The aim of justice is to secure people an adequate level of valuable capabilities.
- (2) Valuable capabilities are identified using an objective criterion independent of subjective preferences.
- (3) According to this objective criterion, health is a valuable capability.'<sup>199</sup>

While philosophers within the Capability Approach may disagree<sup>29</sup> about how to secure people's capabilities in practice, or how health-related capabilities relate to other morally important capabilities, Neilson provides a good overall summary of the place that health-related capabilities have within the Capability Approach.

To the extent that this is discussed at all, Capability theorists often ascribe a very limited or no role for individual responsibility in rationing and protecting capabilities (including health-related capabilities). For example, to the extent that Nussbaum specifies who bears the moral duty for expanding and protecting people's capabilities, she argues that the world's governments, not individuals, bear this responsibility.<sup>200</sup> Ingrid Robeyns, in summarising the state of the capability approach literature, writes that:

‘There is a remarkable absence of any discussion about issues of responsibility in the capability literature, in sharp contrast to political philosophy and welfare economics where this is one of the most important lines of debate.’<sup>200</sup>

Robeyns explains this lack of discussion of the question of individual responsibility by emphasising that many capability theorists focus their work on problems in developing countries, and that it would be outrageous to even seem to suggest that the world's poorest people bear any responsibility for their poverty.<sup>200</sup> Another reason that the question of individual responsibility has been so little discussed within capability theories may be that some theorists see it as largely irrelevant. What matters to distributive justice, they might argue, is that a person should have a certain set of capabilities available to them. The way that they choose to use or not use these capabilities would *then* be a matter for individual freedom and individual responsibility. As capability theories tend to focus on analysing situations in which people do not yet have all basic capabilities, the question of individual responsibility does not yet arise.

Capability theorists often focus on developing countries with significant shortages of resources, and thus are acutely aware of the problems caused by scarcity. Despite this, there has been little direct attention of how to allocate scarce health care resources fairly within the Capability Approach. There are a variety of different rules that could be used to make allocations under scarcity. For example, one aim would be to prioritise the worst off, or to try to ensure that everyone ends up with strictly equal amounts of the good in question (in this case the good of capabilities). Nussbaum and a

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<sup>29</sup> Some philosophers within the Capability Approach may prefer a weaker formulation than Neilson provides in (1). Nussbaum describes her theory as a *partial* theory of justice and does not imply that there are no other issues of justice (for example procedural issues of justice) than securing people's capabilities.

number of other Capability theorists argue that in a just society people will all have at least a threshold level of all the ten basic capabilities described previously.

Nussbaum briefly discusses situations in which people have to choose between or prioritise some capabilities over others, which she describes in the language of 'tragic choices'.

'Sometimes social conditions make it seem impossible to deliver a threshold amount of all ten capabilities to everyone: two or three of them may be in competition... In such a case the economist's natural question is "How do we make trade-offs?" However, when capabilities have intrinsic value and importance (as do the ten on my list), the situation produced when two of them collide is tragic: any course we select involves doing wrong to someone. The situation of *tragic choice* is not fully captured in standard cost-benefit analysis: the violation of an entitlement grounded in basic justice is not just a large cost; it is a cost of a distinctive sort, one that in a fully just society no person has to bear.'<sup>201</sup>

Nussbaum goes on to note that in situations where the whole list of basic capabilities has been properly crafted and the thresholds for sufficiency set at a reasonable level, there is usually an appropriate intervention point such that the tragic conflict between basic capabilities does not affect people in the future. Such an intervention point in low-income countries might be to institute flexible school hours and a nutritious mid-day meal so that parents are not forced to choose between the capability of education for their children and the income for food that the children would otherwise bring in. Another way to approach these tragic conflicts is to consider the best policies to move people closer to the threshold sufficiency level, even if they are not able to achieve it immediately. For example, a government might be able to provide equal and universal access to primary school education, even if they are not able to also do this for secondary school education.<sup>201</sup> Overall, Nussbaum emphasises the importance of bringing as many people as possible above the capability threshold, as her Capability Approach 'strive[s] to make a threshold level of capability available to all the world's people.'<sup>195</sup>

As a practical example of using Capability Theories in situations of resource shortages, Denuilin and colleagues<sup>197</sup> analyse the interaction between health and other capabilities, most notably education. They conclude that many effects of health deficits acquired at an early age, such as malnutrition and iodine deficiency, are irreversible in adulthood and have a substantial effect on future poverty and educational attainment. They therefore conclude that the best use of limited resources to protect and promote capabilities is to focus on childhood and preventative health care, so that people are

protected from health problems which are likely to have permanent and multifaceted effects on their well-being.<sup>197</sup>

## 2. The central insight of the functionings and capabilities view

There are many differences<sup>30</sup> between Norman Daniels' theory and Capability theories. However, for the purpose of this thesis, the most important feature of these accounts is what they have in common, which I will call the 'functionings and capabilities view'. Both Daniels' theory and Capability theories see health care as valuable because of the extent to which it affects what people can do and can be. Daniels focuses on this in the context of its importance to achieving fair equality of opportunity, and argues that normal functioning has a profound influence on people's abilities to develop, revise and achieve their life plans. For Capability theorists, the ability to function in good health is intrinsically valuable because it constitutes (or provides the pre-requisites for) valuable freedoms in what people can do and can be. By focusing on the space and capabilities and functionings, Daniels and Capability theorists agree about *what* aspects of health and health care are morally important.

I agree with this central insight from Daniels' account and Capability theories. I believe that an important reason why social institutions should provide health care to people who need it is because health care protects and improves morally valuable functionings and capabilities. This view also provides a partial answer to the question of how social institutions can ration scarce health care resources. The strength or weakness of a person's claim to health care should be partly determined by how likely it is that the health care will protect or improve their morally relevant capabilities and functionings. Note that for my view, I do not need to take a position about whether health itself should be most accurately classified as a 'basic capability' (Nussbaum's view), a 'meta-capability' (Venkatapuram's view), or should fall under some other system of classification. I also do not need to take a position about whether capabilities and functionings are intrinsically important (Capability theorists' view) or whether they are important because of the contribution that normal functioning makes to fair equality of opportunity (Norman Daniels' view). What matters for my view is that part

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<sup>30</sup> One difference is in the grounding of these theories. Norman Daniels aims to provide an extension of Rawls' theory, and grounds his justification for the importance of health care in its role in providing fair equality of opportunity for all citizens. Like Rawls, Daniels argues that the proper metric for egalitarians to make interpersonal comparisons is that of resources, though resources are understood here to mean something broader than income and wealth. Resources include the basic liberties, fair equality of opportunity, income and wealth and the social bases of self-respect. In contrast, Nussbaum's theory and other Capability theories disagree that resources, even using this broader definition, should be the primary space in which interpersonal comparisons are made in theories of justice. In the view of some Capability Theorists, to focus too heavily on resources is to be guilty of a kind of 'fetishism'. By this they are referring to a misplaced emphasis on things that people don't think are *intrinsically* important but are important as a means to what we actually care about, which are capabilities and functionings and the way in which they constitute objectively determined well-being.

of what makes health care important is that it contributes to protecting and improving people's capabilities and functionings.

However, as I will argue in the rest of this chapter, the focus on capabilities and functionings is not sufficient for a plausible view about health and health care rationing.

### **3. Why the functionings and capabilities view isn't enough: the problems of terminal illness and chronic pain**

An important reason why Capability theories and Daniels' theory are insufficient is that there are many cases in which health care seems morally required, and yet this health care is unlikely to result in better capabilities or functionings.

An important example of where health care seems morally required is in the case of people suffering from an incurable terminal illness. Most people believe that it is a moral responsibility for the health care system to provide care, such as palliative care, to people who are likely to die in the near future. Most people do not see this palliative care as expenditure that should be more efficiently spent on other patients, such as people with non-terminal illnesses for whom it is likely to provide an improvement in functioning and capabilities, and who are more likely to have a chance to fulfil their life plans. This attitude implies that there is more to the moral value of health care than improving people's functioning and capabilities.

It could be objected here that there could be other types of capabilities and functionings that are provided by palliative care. For example, in a passage often cited by Sen, Adam Smith describes the importance to people of the capability of being able to 'appear in public without shame'. Perhaps palliative care, by providing care for people for people who are increasingly unable to look after themselves, provides them the ability to interact with others in a dignified manner. For example, many people would feel ashamed to interact with others while emitting an unpleasant odour, and palliative care would enable them to shower more regularly than they would be able to do without assistance. Even though palliative care may not provide any improvement to people's other capabilities and functionings (as their terminal illness makes the decline of their capabilities inevitable) it may help them interact with others without the shame that they would otherwise feel.

Another possibility is people value being in a dignified state at the end of their life particularly highly, as this is important to a sense of closure and completion about their life plans. People may consider that the end of their life has a special significance for the interpretation and meaning of their life as a



whole. For example, people may care a lot about the last memory that their family have of them, and how this may colour other aspects of the family relationship. If people value this highly enough, this may be an explanation of why people value providing palliative care even where it doesn't improve other capabilities and is in conditions of resource scarcity.

However, it seems unlikely that the *primary* reason for palliative care is to be able to interact with others without shame. For example, the progression of terminal illnesses vary, and it is possible that a patient may be able to interact with other people in a dignified manner but still be in a significant amount of pain. It seems that palliative care for this patient to relieve suffering would still be worthwhile, even if it did not affect their relationships with others in any way. Another problem with this account is that it requires a substantive view about the structure of the life span that weights some types of functioning at the end of life very heavily. As this is controversial, an account that does not require this set of assumptions should be preferred.

A further reason why this account of health care that focuses on functioning and capabilities is insufficient is that it does not adequately explain the intuition that people in chronic pain should be entitled to care and treatment as a matter of priority. At first this argument may seem strange. Wouldn't being pain-free be considered an intrinsically valuable functioning?

Daniels' theory and Capability theories both make a distinction between the extent to which a person experiences normal functioning or capabilities and that person's subjective well-being. They do not base their view about a person's health care entitlements on subjective utility. For example, someone with paralysis is entitled to a wheelchair, even if the person's naturally happy disposition means that they would experience greater utility than other people whether they receive the wheelchair or not. However, people suffering from chronic pain are in the reverse situation of the happy paraplegic. Someone in chronic pain who has the same functionings as others would be *not entitled* to pain relievers on the grounds that the just distribution of health care resources isn't based on improving someone's direct utility or subjective well-being. This seems to be counter to our moral intuitions.

It is worth noting that this exclusion of chronic pain from capability and functioning-based accounts is a problem no matter which distributive rule is used to guide the allocation of capabilities under conditions of scarcity. For example, Capability theorists may aim for equality of capabilities, or a sufficiency threshold of capabilities, or priority for the least advantaged. However, if capability and functioning-based theories cannot incorporate the claims of people in chronic pain and terminal

illness, focusing on the distribution of capabilities under scarcity risks excluding the claims of these people.

#### **4. The problems of terminal illness and chronic pain: Potential responses from the functioning and capabilities view**

##### **4.1 Response: The plausibility of achieving capabilities and life plans while suffering chronic pain?**

One response to this could question to what extent it is plausible that people could be both experiencing chronic pain as well as achieving morally valuable capabilities at threshold level. This objection could point to debilitating aspects of chronic pain, such as decreased mobility, crushing fatigue, decreased capacity for sustained attention, and substantially increased risk of psychological conditions such as major depression and anxiety. This response queries whether actual chronic pain patients are able to achieve as many of their life plans as others and demonstrate a threshold level of all of Nussbaum's capabilities, such that they would not be entitled to priority treatment under capability theories or Norman Daniels' theory. Given the scope and goals of capability theories and Norman Daniels' theory, concerns about chronic pain patients being deprioritised from health care would be a weak objection if it did not apply to anyone in the real world.

However, there are numerous examples of people experiencing severe, ongoing pain, who are also able to function in a way which is compatible with having threshold-level capabilities. For example, Abby Norman worked full-time processing medical records in a hospital, managed her own household, was economically self-sufficient, maintained valuable relationships with her partner and family friends, and engaged in hobbies such as reading. At this time, she also experienced crushing pain for years from (then) undiagnosed endometriosis causing chronic inflammation in her appendix and adhesions twisting and sticking her appendix to other organs. As Norman writes in her memoir:

‘The fact that I got a job didn't exactly lend any credibility to my assertions that I felt wretchedly ill. But beyond the simple fact that I had to earn money, I was desperate for my life to have something in it besides illness. It's worth noting that the job I undertook didn't ask much of me: I sat at a desk most of the day, had reasonable hours, plus paid vacation and sick days, and it was an elevator ride to the ER if things got particularly bad.’<sup>202</sup>

There are numerous other examples of this kind, including people who achieved significant career success and were able to achieve many of their life plans. For example, Hilary Mantel has become a popular novelist and won the prestigious Man Booker Prize while suffering for decades with poorly controlled endometriosis.<sup>203</sup> Anastacia Palaszczuk has been Premier of Queensland for four years while suffering from the same condition.<sup>204</sup> When psychological pain (which has significant

neurological similarities to physical pain<sup>205</sup>) is included, there are many other people with flourishing careers and capabilities while suffering from severe conditions. For example, Abraham Lincoln is generally considered to be one of the most respected Presidents in American history. Lincoln achieved this even though he suffered from severe major depression throughout his adult life, including during a demanding political career.<sup>206</sup> Winston Churchill's ongoing major depression is also well-documented.<sup>207</sup>

A Capability theorist might object here that these are examples of unusual and exceptional individuals, and that their experience does not hold true for the vast majority of people in chronic pain. They may argue that it is enough for principles of rationing health care to give intuitively acceptable answers in the majority of cases, not for every single individual. While some very unusual people may be able to maintain threshold levels of objective capabilities while in chronic pain, most people will not be able to do this, and will thus qualify for health care under Capability theories. In this way, Capability theories will not generally lead to refusing health care to people with chronic pain, even under conditions of scarcity.

However, these cases, while not the experience of all chronic pain patients, are also far from being exceptional. While it is difficult to find studies comparing people with and without chronic pain in regard to a range of capabilities, some data from epidemiological studies can provide indications of people's capability levels. For example, a Norwegian study compared the population and outcomes of people with and without chronic pain. They found that while people with chronic pain were less likely to be employed than those without, a majority of people with chronic pain were still employed<sup>208</sup> (the study did not distinguish between full- and part- time employment). A study in the United Kingdom surveying people with chronic neuropathic pain found that only 17.9% of the sample judged themselves to be unable to work due to their pain.<sup>209</sup> An Australian study estimates that one in six working adults are affected by chronic pain, and to the extent that the pain affects their work, the primary effect is lowered work productivity, rather than being unable to attend work at all.<sup>210</sup> While not conclusive, these studies indicate that for many people, having chronic pain does not prevent them from having other capabilities, such as ongoing employment.

How are people able to have threshold level capabilities while also experiencing chronic pain? There is some evidence that certain cognitive and temperamental characteristics are correlated with the ability to function despite the pain. For example, for some people an almost 'fatalistic' attitude towards the pain, such as giving up the hope or expectation of significant pain alleviation, is actually associated with better functioning than those who still hope for pain reduction.<sup>211</sup> Remaining stoical

in the face of severe pain is also associated with particular cultural backgrounds, socioeconomic statuses, gender identities and personality types.<sup>212</sup> It is worth noting that the ability to function successfully through ongoing pain is likely to be in many ways an unchosen and arbitrary characteristic. Personality traits have a significant genetic component, and people rarely choose their socioeconomic background or culture.

#### **4.2 Response: Incorporating the effect of chronic pain into non-basic capabilities?**

Another potential response is to concede that people can be in chronic pain while possessing key basic capabilities and functionings, but to point to other capabilities and functionings which are also important. For example, while a person in chronic pain may be able to have basic capabilities, they may not be able to achieve their full potential, or flourish in the way that they would have without the pain. For example, a person might be able to hold down a standard full-time job and maintain fulfilling relationships. However, if this person had not been in chronic pain, then they may have been able to take on a much more demanding job in scientific research and eventually win a Nobel Prize. While this person currently has achieved basic functionings and capabilities, there is a substantial gap between this and what they would have been able to achieve without suffering from chronic pain. Perhaps this gap can be the basis for people's claims to health care, even if they meet standard levels of functionings.

However, one immediate problem is that given scarcity of resources, societies are going to have trouble ensuring that everyone has achieved a minimum level of even basic capabilities and functionings. Claims based on non-basic capabilities seem likely to be relegated to very low priority. It is counterintuitive to many people that the needs of chronic pain patients should be downgraded to such a low priority in this way.

Another reason to reject this response is it is not compatible with previous commitments made by Daniels' theory and by Capability theories. Capability theories focus on how natural and social factors interact to create capabilities and functionings without privileging one or the other. A person with a range of intellectual and physical disabilities is neither more nor less entitled to morally important capabilities than any other person, it is just that they may need different social accommodations in order to be able to receive an education and have independent mobility. Likewise, the person with very high natural talents is not therefore entitled to a higher level of capabilities or achievements than anyone else. Their abilities may mean that they require different or fewer social accommodations than the average person in order to be able to receive an education. If an individual

has achieved threshold levels of basic capabilities then, if they cannot flourish or achieve their 'natural' potential, it does not seem that this would be the basis of a claim within Capability Theories.

For different reasons, Daniels' theory would also be unable to accommodate this gap between normal and exceptional functioning as a basis for a moral claim to health care. Daniels' focus on how health care affects opportunity is about people's *options* as defined by population standards, not about the extent to which a disease or disability in fact affects different individuals. A person's claim to health care is not based on what they individually could have been or done otherwise, but about their ability to function as determined by being within the bounds of normal human functioning. If a person can already function normally, it is difficult to see how they could have a claim to health care based on not being able to achieve at an exceptional level.

#### **4.3 Response: Incorporating chronic pain within Capability theories?**

Another potential response is to argue that being pain-free is itself an inherently valuable capability. However, the intuition that pain relief is intrinsically important is more difficult to accommodate in the capability and functioning view than one might think. Given the emphasis that Capability theorists and Norman Daniels place the *objective* nature of morally important capabilities (which is important to avoid the problem of adaptive preferences) it seems difficult to incorporate the experience of chronic pain within Capabilities Theories. This is because there is a subjective element to pain which makes it implausible to try to reduce to behavioural patterns and physical aspects.

It is important to differentiate the experience of being in chronic pain per se, with the effect that chronic pain might have on other functionings or capabilities (such as the ability to get out of bed). While pain is often correlated with objectively discernible physical manifestations, such as tissue damage, this is not either a necessary or sufficient condition for a person to suffer pain. For example, it is possible to experience significant tissue damage without experiencing pain. This can occur in situations of severe trauma, such as car accidents or for soldiers in combat. Carlen, Noordenboos and Wall studied cases of Israeli soldiers whose combat injuries from the Yom Kippur War were so severe as to require amputation. The majority of these soldiers did not experience pain for some time after their injuries, and this was the case even though the soldiers were not in an unusual frame of mind, not in a state of shock, and not expecting the injury.<sup>213</sup> In another example of severe tissue damage without the experience of pain, Lorimer Moseley, a physiotherapist and pain researcher, writes about his clinical training:

'The most remarkable patient was the last one. He came in through the emergency department, having been driven there by the thrower of the hammer. That same hammer

was now inserted through the side of his neck. It looked filthy – the tips of the curly bit were just poking out of the front of his neck, having entered from the rear. As he walked across the waiting area, he held the handle of the hammer out at right angles. There were groans and moans from the rest of us as we watched him – he, on the other hand, was as happy as Larry.<sup>214</sup>

Just as people can experience severe tissue damage without pain, people also experience intense pain in situations where there is no clear physical correlate or manifestation. For example, people can also experience chronic pain even though no pain signals are being sent to the brain. This can happen in cases where the person has experienced acute pain such that the brain has learnt to create the experience of pain even in the absence of any signals from the body.<sup>215</sup> People can also experience pain in the absence of physical due to anticipating the experience. Mosely writes that:

‘Researchers convinced subjects to put their heads in what they called a ‘head stimulator’. When the researchers turned up the intensity knob, the subjects reported that their head started to hurt. What’s more, pain ratings related to the intensity settings. That might not seem surprising, except that the stimulator wasn’t real – it wasn’t even connected to the control knobs!’<sup>214</sup>

It would also be difficult to create an objective capability to capture the experience of pain based on observing people’s behavioural patterns. People can be experiencing pain despite no behavioural indicators of this. As an example, Patrick Wall writes that:

‘in the 1930s, Grantley Dick-Read was a colonial doctor in the Tulkarm region of northern Kenya. He wrote of witnessing childbirth in local women who were quiet, calm, dignified, and conversing with their tribal neighbors. He was inspired by this and wrote the book *Childbirth Without Fear*, which was to have a revolutionary effect on prenatal training classes and the education of mothers-to-be in the West. For him, the Kenyans showed that pain did not occur in the absence of fear, anxiety, tension, and ignorance. He set about showing that a mother who was transported by herself and others into a “natural” setting benefited greatly. So far so good. But, fifty years later, a female anthropologist who could speak Tulkarm witnessed a similar scene to that which had so changed Dick-Read and the nature of prenatal training. She asked the woman after the delivery whether it had hurt. The woman answered that the pain had been great. She was then asked why she had not said so and replied: “That is not the custom of my people.”’<sup>213</sup>

In this example, the behaviour of women in childbirth experiencing severe pain was externally indistinguishable from people who were not experiencing pain at all, to the extent that an observer made the mistake of believing that they had found a way to give birth in a pain free manner. Another reason that it would be difficult to create an objective indicator from people's behaviours is that different people can experience different levels of pain in response to the same stimulus, as their pain levels are related to their past experiences and the context in which they put the situation.

Could an acceptable indicator simply consist of asking people whether or not they are in pain? I think that the best course of action within health care is in practice to do this, as this is both the easiest and most respectful way to attend to a person's felt suffering. However, this does not fit easily with other commitments made by capability theorists. As Nussbaum has forcefully argued, it would be entirely unacceptable to simply 'take someone's word for it' when considering how they fare in other aspects of well-being. For example, Nussbaum gives numerous examples of poor women in India who lack a sense of themselves as equal citizens whose rights are being violated, despite suffering domestic violence, discrimination and lack of access to education and opportunity.<sup>195</sup> The fact that these women would not describe themselves as suffering from discrimination would not be reason to conclude that they are not discriminated against. Conversely, if people who have been privileged in the past lose these privileges, Nussbaum would not therefore accept their subjective claims to now being oppressed. This focus on subjective self-report has been systematically rejected in capability theories and it seems somewhat ad-hoc to re-introduce this for a new capability based on the experience of pain.

Our moral intuitions seem to be based on the sense that people are entitled to pain relief, not on the grounds to improving their capabilities and functionings, but because their suffering is bad in and of itself. This then implies that improving capabilities and functionings is not the only point or value of health care.

#### **4.4 Response: Incorporating chronic pain within Norman Daniels' theory?**

Could Daniels could incorporate the desirability of avoiding pain and suffering in his account by stating that it is an implicit part of everyone's plan of life that their lives are pain-free? If Daniels' expanded his concept of fair equality of opportunity to include pain, this would not be in keeping with Rawls' rationale behind this principle. The original Rawlsian principle of fair equality of opportunity is not about guaranteeing equal opportunity for jobs and offices to everyone per se, but only about ensuring properly meritocratic competition among people of equal talent. Rawls' reasons for making the principle of fair equality of opportunity lexically prior to the Difference Principle

include to check economic inequalities allowed by the Difference Principle, to promote greater efficiency through meritocratic competition for jobs, and providing equal access to financial benefits, self-esteem and personal growth that may result from one's career. None of these reasons are directly relevant to people's desire to live a pain-free life as such.

Another reason why it would be difficult to incorporate the importance of avoiding pain into Daniels' account is that Daniels rejects the importance of subjective well-being in theories of justice in order to avoid the problem of 'expensive tastes'. A standard example of the problem of expensive tastes is of a person who is only satisfied with expensive champagne, whereas everyone else is equally satisfied with inexpensive beer. Should social institutions spend extra resources on the champagne drinker so that he can have the same level of subjective well-being from his drink as the beer drinkers? Or is this subsidisation of the champagne drinker an unacceptable and unfair subsidisation of people with expensive preferences?<sup>216</sup> Consistent with his Rawlsian approach, Daniels rejects the claim that people with expensive tastes should be subsidised, and sees the problem of expensive tastes as a compelling reason not to admit subjective well-being as a way of making interpersonal comparisons within a theory of justice. As Daniels writes:

'This intuitive argument points to the unacceptable risks of social hijacking when (A) we think that those who are worse off have some claim of justice for assistance from society and (B) we measure who is better and worse off for purposes of justice using a scale of welfare or satisfaction... If having less welfare than others is a reason to assist or compensate people, as (A) asserts, then unhappy people with extravagant tastes have a claim on us. But it seems unjust to deny more moderate people equal claims on further distributions simply because others have been extravagant. Rather, it seems reasonable and fair to hold people responsible for their unhappiness when it results from extravagant preferences, which could have been otherwise. This judgment about fairness leads to conclusion (C): Reject the claims of dissatisfied extravagant people.'<sup>14</sup>

However, this rejection of subjective well-being as a reason to assist or compensate people also creates a problem for Daniels' account in accommodating the role of chronic pain in health care. If, as I have argued above, chronic pain has an essentially subjective component, and cannot be reduced to external, objective functionings, then this means that it would be difficult to incorporate the importance of treating chronic pain in Daniels' theory, given his prior commitments.



#### 4.5 Response: Intuitions about chronic pain versus capabilities

Another potential response is to point to different intuitions about how social institutions should prioritise restoring people's capabilities, as compared to alleviating chronic pain, in situations of scarce resources. For example, Hilary Mantel in some ways exceeds normal thresholds of capabilities and functionings. This is demonstrated by her achievements as one of the most successful novelists in the English-speaking world. Some people might argue that in a situation where social institutions need to decide between providing pain relief for Hilary Mantel and some intervention that will bring another person up to a basic functioning threshold, that they should give lower priority to Mantel's claims until the other person is above the threshold.

I would reject the idea that very successful people such as Hilary Mantel should receive lower priority for health care on the grounds that they have high levels of (at least some) capabilities and other people who do not have basic levels of capabilities should be treated first.

The first thing to note is that the state of having particularly high capabilities in one or more areas should be distinguished from the state of being conspicuously successful. There are many people who have very high capabilities in one or more areas (such as having an exceptional talent for writing) without achieving conspicuous success (such as one's books becoming bestsellers or winning the Man Booker Prize). For example, Hilary Mantel might have written exactly the same books (thus demonstrating the same amount of writing talent) but if there had been no interest in novels about the Tudor period her books may never have been published. Similarly, there are people who achieve public success and financial resources in their chosen field without having particularly high capabilities at all, for example people who achieve career success from their unchosen relationships to others. The point here is simply that while some people like Hilary Mantel have *both* particularly high capabilities in one or more areas, and financial resources resulting from substantial career success, these can and often do come apart.

One problem with giving lower priority to people who have particularly high capabilities in one or more areas (and at least threshold level of all capabilities) is that it assumes that the value of each increment in capabilities gained is either of the same value as previously gained increments, or at least does not diminish in value too markedly. It is not at all clear that this is the case. For example, imagine a capability such as being able to communicate in writing. Each improvement in writing skill may be valuable up until a threshold is reached, and then each improvement in writing ability beyond this threshold may diminish rapidly in value. Perhaps very basic literacy is of profound value, then each increment of additional writing ability continues to be of benefit until a person is able to

write clear and grammatically correct sentences of reasonable complexity (threshold level). It is not at all clear that writing ability beyond this point (such as the ability to write clever sonnets full of puns and double entendres) has substantial value in and of itself. Writing sonnets may be an enjoyable hobby for some people, but it seems counterintuitive that the ability to write sonnets, in and of itself, should make someone count as privileged enough to lose priority for health care if they experience chronic pain.

Writing ability beyond the threshold point may, of course, have substantial *instrumental* value, in the sense that it might enable people to achieve career success, which is then rewarded with additional financial resources. Greater income and wealth also tend to increase people's capabilities further. Having greater financial resources means that people are more able to pay for security, housing, private medical care, transport, education, social events, and the chance to spend time in the natural world, all of which would be likely to directly enhance a person's morally relevant capabilities as defined by Nussbaum. In this situation I think that it would be both easier and fairer for successful people to be taxed at a higher marginal rate to enable more health care resources to be available for everyone. This already occurs in some form in many countries, such as in Australia where higher income earners are charged an additional levy to fund Medicare.<sup>31</sup> Note that this does not result in directly penalising or relegating people with higher levels of capabilities to lower priority, but only requiring them to contribute more towards medical care if their higher capabilities result in higher earnings.

To illustrate the intuition behind this point, suppose that Hilary Mantel had a sister,<sup>32</sup> who experienced identical endometriosis and pain as Hilary Mantel, as well as identical levels of writing talent and other capabilities. However, suppose that Mantel's sister's novels were all rejected by publishers, meaning that she had no career success and a low income. I do not find it intuitive that Mantel's sister in this case should receive lower priority for endometriosis pain relief because of her unappreciated writing ability. Considering the difference between the cases of Hilary Mantel and Mantel's hypothetical sister indicates that any intuitions about lower priority for people with very high capabilities are in fact about career success, income and wealth, not about capabilities per se.

In certain rare situations, there may be a case for providing higher priority to people of lower socioeconomic status on the grounds of their lower capabilities. For example, suppose a country's

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<sup>31</sup> The situation in Australia is made more complicated by the fact that Australian residents do not have to pay the Medicare levy if they have a specified level of private health insurance cover. There is much weaker egalitarian justification for the current form of this Australian health care policy.

<sup>32</sup> In real life, Mantel has two younger brothers and no sisters.

national health service had a shortage of a certain medication, and more money from higher income earners would not make more medication immediately available (this sort of situation might be caused by a short-term pharmaceutical supply chain problem). In this situation, there may be justification for the health service to give priority to lower income people for this medication. This might be both on the grounds of lower income earners having fewer capabilities and options available to them, as well as these people being in greater need due to the social gradient of health. But in the standard case, intuitions about people with higher capabilities receiving lower priority should best be addressed through redistributive taxation, which would make more health care resources available to everyone.

## 5. Conclusion

In this chapter, I have described two philosophical approaches with applications to health care rationing: Norman Daniels' Rawlsian theory and the Capability theories of Martha Nussbaum and Sridhar Venkatapuram. These theories are similar in that they emphasise the importance of health care for improving or preserving people's morally relevant capabilities or functionings. I agree with the central insight that these theories share, and believe that this insight provides a partial answer to the question of how social institutions can ration scarce health care resources. The strength or weakness of a person's claim to health care should be partly determined by how likely it is that the health care will protect or improve their morally relevant capabilities and functionings.

However, I argue that Daniels' theory and Capability theories' *exclusive* focus on objectively measurable capabilities and functionings means that they are unable to account for the importance of pain relief and alleviating suffering as part of the value of health care. There is a subjective element to the experience of pain which is difficult to measure in terms of its impact of objective capabilities.

In the following chapter, I go on to argue that when policymakers are making decisions about how to allocate scarce health care resources, they should consider to what extent a health care intervention is likely to improve a person's subjective well-being, as well as considering to what extent the intervention is likely to improve the person's capabilities and functionings.

## Chapter 7: Health Care and Subjective Well-being

1. What is subjective well-being?
2. How could we give more weight to subjective well-being in distributing scarce health care resources?
3. Making health care priority decisions on the basis of both capability deficits and low subjective well-being
4. Objections and responses
  - 4.1 Objection: Can we make valid interpersonal comparisons on the basis of subjective well-being?
  - 4.2 Objection: the many influences on subjective well-being
  - 4.3 Objection: Adaptive preferences
5. Conclusion

In the previous chapter, I argued that a focus on capabilities and functionings is insufficient to justify providing pain relief when institutions have limited health care resources. As I argued in Chapter 6, due to the subjective nature of the experience of pain, many patients have threshold levels of basic, objectively defined capabilities while also suffering from chronic pain. Health care's effects on capabilities and on subjective well-being should *both* make a difference to how we ration health care in conditions of scarcity.

In this final chapter, I survey some of the empirical and philosophical research about the concept and measurement of subjective well-being and suggest a number of ways in which subjective well-being could be used in making decisions about health care prioritisation. I consider three objections to using subjective well-being measurements in public policy: whether it is valid to make interpersonal comparisons using subjective well-being metrics, the concern that many factors which influence subjective well-being cannot be directly affected by public policy, and the claim that reports of subjective well-being are affected by adaptive preferences. I argue that none of these objections should deter policymakers from taking into account both subjective well-being and capabilities when allocating health care resources in conditions of scarcity.

### 1. What is subjective well-being?

Subjective well-being is a person's evaluation of their quality of life from their own perspective.<sup>217</sup> It can be contrasted with 'objective' definitions of well-being, which focus on aspects of life which are

considered to be important to well-being regardless of how the individual who experiences these evaluates them.<sup>217</sup> One way to think about the difference between subjective and objective well-being is through the question of whether an individual can be mistaken about their well-being. For example, suppose an individual honestly reports a high level of happiness and sense of satisfaction with their life, but is unable to walk. If being able to walk is an essential criterion for well-being under a particular objective theory, then that theory would say that this person is simply mistaken about their own well-being because they do not meet the criteria of what well-being consists in. Under a subjective theory of well-being, on the other hand, a person's evaluation of their own experience constitutes a person's subjective well-being, and thus it is not possible to tell someone that they are mistaken about their own subjective well-being by referencing some external criteria.

It should be noted that this is not the same as being able to *accurately predict* how a particular set of circumstances will impact on people's subjective well-being. People frequently over- or underestimate how an event or a change in circumstances will affect them, or inaccurately predict how they will feel in the future. For example, people at age 30 tend to predict that the happiness of the average adult will decrease over time, such that they are likely to be less happy at 70 than they are at 30. In fact, based on self-report, older adults appear to be happier than younger adults.<sup>218</sup> This type of mistaken prediction is common but is not relevant to this discussion, as in this context people are asked to report about their subjective experience as it is in the present, and not ask them to remember the past or make predictions about the future.

An important reason to include a person's assessment of their own subjective well-being is because it is widely agreed that pain relief and the relief of health-related suffering is an important goal of health care. As discussed in the previous chapter, given the complex relationships between pain and external behaviours and indicators, if policymaker focus entirely on externally observable, 'objective' indicators such as capability sets, they will often result in excluding chronic pain patients. An exclusive focus on objective criteria for well-being such as capability sets gives us few reasons to treat patients with chronic pain (except to the extent that their pain affects their externally defined capabilities), let alone give them any sort of priority in a situation of scarce health care resources. Furthermore, even if there were externally observable capabilities which were reliably correlated with the subjective experience of pain, then it would be still the subjective experience of pain which is the focus of our concern. It is the subjective experience of suffering pain which is the focus of relief efforts, regardless of whether this subjective experience is caused by, is the cause of, or is correlated with external indicators, capabilities or behaviours.

## 2. How could we give more weight to subjective well-being in distributing scarce health care resources?

What information would we need to be able to use judgements about subjective well-being in health care policy decision-making? One immediate issue would be whether to make priority decisions on the basis of population-level data or to make it on a case-by case basis, using data from each individual patient. I believe that any viable mechanism for including subjective well-being in public policy decision-making would need to use group-level rather than individual-level information. An important reason for this is that individual-level subjective well-being would have obvious issues with incentives, as individual patients would have an incentive to exaggerate the suffering that they are experiencing in order to get higher treatment priority. Another reason is that health care systems and health policies must be designed for large groups of people, which means that it cannot have the necessary information and flexibility to be able to be fully responsive to individual differences. This issue with individual differences would apply to any health care policy which affects populations or large groups of people.

Another important issue with using subjective well-being in health priority-setting is the issue of measurement. Strictly speaking, each person only has direct access to their own individual subjective experience. This raises the question of how valid interpersonal comparisons can be made. To properly incorporate information about subjective well-being in policymaking, we would need accurate and reliable measurements of people's subjective well-being. We would also need accurate and reliable information about how health conditions affect subjective well-being on average. While there are a number of current problems with quality of the empirical evidence on subjective well-being, there are heuristics, surveys and other techniques which we can use to (imperfectly) measure people's subjective evaluations of their own experiences. For example, one heuristic is to use a person's self-report that they are in pain as a reasonable indicator that they are having a painful experience. There are a variety of different types of self-report measures that can be used. One measure is through evaluative questions on surveys which ask people what they *think* about their life or health such as 'Overall, how satisfied are you with your life?'. Another type of measure is affective and asks people what they *feel* about their lives, such as 'How worried or sad do you feel right now?'. There is evidence that some activities, such as working or taking care of children do not rank highly on affective measures (i.e. people do not experience high amounts of positive emotion while taking part in these activities) but give people a sense of fulfillment and thus rank more highly on evaluative measures.<sup>219</sup> Many advocates of using subjective well-being measures in public policy, such as the Global Council for Happiness and Wellbeing, support using both evaluative and affective measurements of people's subjective well-being.<sup>220</sup>

The constraints of this thesis do not allow me to make detailed recommendations about how a metric of subjective well-being should be constructed and how this metric should be used to measure the effect of health conditions on subjective well-being. This is partly because of limits of space, and partly because creating a metric is a complex empirical question. A properly constructed metric needs to be both valid (it actually measures the phenomenon that it is attempting to measure) and reliable (the test consistently produces the same results in the same circumstances).<sup>221</sup> Creating such a metric would require extensive research on the relationships between responses on different questions about subjective well-being. For example, how do people interpret questions about life satisfaction and positive or negative emotion? Are these questions (and the concepts that they reference) interpreted consistently across different demographic groups and different contexts? To what extent do people find the same activities to cause both greater evaluative life satisfaction and greater immediate positive emotion? Is it possible, via statistical analysis, to reduce a broad range of questions about subjective well-being in a survey to a small number of common factors?<sup>33</sup> Current research provides only partial answers to questions such as these.

Creating a proper metric of health-related subjective well-being would also require a detailed analysis of the existing literature, which would further require evaluating the quality and reliability of psychological studies of subjective well-being. While there have been decades of research on subjective well-being, many earlier studies used small sample sizes, such that each experimental condition only had 10-20 participants. Small sample sizes mean that the sizes of the effects from these studies are likely to be systematically overestimated.<sup>222</sup> These methodological shortcomings mean that some researchers repeating these experiments have been not been able to replicate their results.<sup>217</sup> As an example, Lucas describes the case of a much-cited study about to what extent transient factors can affect subjective well-being:

‘Schwarz and Clore (1983) called separate groups of undergraduates either on a warm and sunny day (specifically, the first warm and sunny day of a cold spring in a cold climate; Schwarz and Clore 2003) or a cold and rainy day soon after. Participants reported dramatically higher life satisfaction on the nice day than on the rainy day, and the effect sizes were larger than what is typically found for just about any objective predictor of life satisfaction, including employment status, widowhood, or disability... [However] a number of large-scale replication studies have been conducted, some of which have thousands or even

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<sup>33</sup> This would be similar to the way that five main personality traits have been consistently found in different detailed personality questionnaires such as in the Minnesota Multiphasic Personality Inventory II (MMPI-2), a widely used personality questionnaire. As far as I can tell, no one has performed this type of analysis on different types of survey questions about subjective well-being.

over a million respondents. These studies find very little support for the idea that the original weather effect is robust.<sup>217</sup>

A detailed proposal of how to measure health-related subjective well-being would be likely to require extensive new experimental, statistical and analytical work that is beyond the scope of this thesis.

I tentatively suggest that health-related subjective well-being should be measured using *both* evaluative and affective survey questions, and that policymakers should use surveys of life satisfaction and mood paired with different health condition types, to see what difference particular health conditions make (on average) to subjective well-being. A broad range of questions in a survey on subjective well-being would reduce the risk that, due to question wording or interpretation, only part of a complex concept was being measured. Another reason for including both a general life satisfaction measure and a measure of more short-term affect is that it would accord with the intuitive belief that alleviating *both* temporary and pervasive health-related suffering should be important priorities within health policy.

Despite the limitations of current research into subjective well-being, there are a number of findings that policymakers could use from the literature. Current psychological research suggests that people demonstrate greater or faster adaptation to some types of health conditions than they do to others. In some circumstances, people appear to experience complete adaptation to disability. For example, a study<sup>34</sup> investigated the life satisfaction of German men with a disability over time. This indicates that, on average, incurring a disability results in significantly lower life satisfaction than that experienced in previous years, but men adapt to pre-disability levels of life satisfaction after approximately six years of living with the disability.<sup>223</sup> Measuring a different aspect of subjective well-being, an American study measured the mood and affect (at different points during the day) of patients with end-stage renal disease undergoing haemodialysis. They found that the moods of these patients were indistinguishable from those of a group of health control study participants, suggesting that they had largely adapted to their condition.<sup>224</sup>

In contrast, some patients experiencing health conditions experience limited adaptation. Perhaps the clearest case of people with continuing negative emotion and limited life satisfaction are people suffering from persistent, ongoing depression. The connection between depression and low subjective well-being is almost a matter of definition. A substantial component of commonly used

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<sup>34</sup> There is some disagreement among researchers about the extent of adaptation to disability. I have chosen to side with Pagan-Rodriguez's account rather than Lucas' earlier analysis of this dataset, as I think that Pagan-Rodriguez's definition of disability is likely to be more relevant to real world conditions.



diagnosis criteria sets for depression, such as the Beck Depression Inventory,<sup>225</sup> include asking patients to what extent they feel sad and feel guilty, are discouraged about the future and get little satisfaction out of life.<sup>226</sup> These questions in the Beck Depression Inventory have considerable overlap with the questions people are asked in surveys of affect and life satisfaction. Furthermore, a program of research is investigating to what extent ongoing major depression is caused by the failure of brain mechanisms which (in non-depressed people) regulate negative emotion and result in hedonic adaptation.<sup>227,228</sup> Major depressive disorder is a relatively common health condition. In 2015 it was estimated by the World Health Organisation to affect 4.4% of the world's population (or 322 million people), with higher frequency among women and among those aged 55-74 years.<sup>229</sup> Given these factors, a health care system which prioritises improving people's subjective well-being would be likely to give greater attention to the prevention and treatment of depression, and particularly high priority to research into persistent depression.

There has been little research about the direct<sup>35</sup> effect of chronic pain on subjective well-being,<sup>36</sup> but there is a considerable body of research indicates chronic pain and major depression tend to be co-morbid conditions.<sup>233-237</sup> Health policy that prioritises conditions with ongoing effects on subjective well-being would be likely to emphasise the importance of treatment for major depression, chronic pain, and the interaction of these two conditions.

Other factors also affect to what extent people adapt to health conditions and disabilities. For example, some research indicates that uncertainty is a barrier to successful adaptation in the case of disability. Patients whose disability was potentially reversible reported lower subjective well-being than those whose (similar) condition was irreversible, when this was measured at the same length of time after incurring the disability.<sup>238</sup> However, this finding cannot necessarily be generalised to the case of chronic pain. Swedish research suggests that continuous chronic pain results in lower life satisfaction than intermittent pain.<sup>239</sup> Further research is needed into how and to what extent patients adapt to different health conditions, and which factors are likely to lead to faster and more complete adaptation. A health care system which prioritises improving subjective well-being could give priority to addressing health conditions to which patients are less likely to completely adapt. It may also give special priority to sub-populations of patients who, due to demographic or historical

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<sup>35</sup> For research about the effect of pain on quality of life (not always the same as subjective well-being, though a related concept), see: 230. Wang XS, Cleeland CS, Mendoza TR, et al. The effects of pain severity on health-related quality of life. *Cancer* 1999; **86**(9): 1848-55., 231. Katz N. The Impact of Pain Management on Quality of Life. *Journal of Pain and Symptom Management* 2002; **24**(1, Supplement 1): S38-S47, 232. Choi S-M, Kim BC, Jung H-J, et al. Impact of pain and pain subtypes on the quality of life of patients with Parkinson's disease. *Journal of Clinical Neuroscience* 2017; **45**: 105-9.,

<sup>36</sup> It is likely that researchers think that the causal link between chronic pain and low subjective well-being is too obvious to be worth systematically investigating. Some researchers discuss pain as a conceptual part of low subjective well-being.

reasons, are less likely to experience adaptation and reversion to previous levels of subjective well-being.

How should health systems make priority decisions when a patient suffers from more than one chronic illness? My suggestion in this case would be to simply ask patients who suffer from both conditions which one they would want to be addressed first. Would most patients prioritise getting treatment for hearing loss or for interventions for Crohn's disease? It is true that this approach may not be possible for all condition pairs (it is unlikely that anyone has experienced both prostate cancer and endometriosis). However, a database could be built up of different condition pairs showing which treatments people would prioritise, and this database could help policymakers to extrapolate to other condition pairs. For example, data collected about the priorities of Crohn's disease patients could also be used to inform policy on ulcerative colitis (a similar painful gastroenterological condition). While asking patients about their preferences is, strictly speaking, different to asking them about their subjective well-being, this kind of question is related to subjective well-being and could provide some guidance in how to set priorities given very different types of health conditions. An approach such as this may at least provide a starting point to compare different health conditions in deciding how to set priorities in the health care system.

### **3. Making health care priority decisions on the basis of *both* capability deficits and low subjective well-being**

Using two factors in health care priority setting (such as in assessing the value of the health care by its effects on improving capabilities *and* improving subjective well-being) necessarily raises questions about how policymakers should weigh these two factors relative to each other. There are a number of ways in which policymakers could use two factors to set priorities in health care. For example, they could use one factor as a tie-breaker only, they could weight one factor using the other, or they could consider both factors separately and weight them equally. In this section, I provisionally sketch how health policy could use *both* subjective well-being and people's capabilities in order to make decisions about resource allocation. I suggest that in some types of choices, policymakers could give more priority to treating capability deficits which (on average) cause lower subjective well-being than others. In some types of choices, they could consider the factors of improving subjective well-being and improving capabilities separately. The details of how this should be worked out in practice can be left to the democratic political process, as long as this process respects all citizens equally.

One type of decision that a policymaker may face is if they need to choose between prioritising treatment for a health condition that affects (on average) both subjective well-being and capabilities,

as compared to a condition which just affects capabilities (to the same degree). For example, compare a condition such as *myasthenia gravis*, which causes fatigue, muscle weakness and other capability deficits (but usually without substantial pain), to a condition such as *fibromyalgia*, which also causes muscle problems and fatigue, but typically with widespread chronic pain as well. In this sort of comparison (assuming that myasthenia gravis and fibromyalgia patients affect capabilities to the same extent, and assuming similar treatment cost) my principles of health care resource allocation would lead to prioritising fibromyalgia patients. This is because the fibromyalgia patients in this example are likely to suffer greater pain and lower subjective well-being with similar capabilities to the myasthenia gravis patients. While this case may seem like an unrepresentatively straightforward example of prioritisation in the health care system, it provides an improvement to using capabilities and functionings alone for making health care prioritisation decisions. As argued in the previous chapter, philosophical accounts which focus exclusively on objective capabilities and functionings do not take account of subjective factors in making interpersonal comparisons – only objectively measurable capabilities make a difference when deciding how well or badly off a person is for the purposes of a theory of justice. As these theories do not take account of the subjective character of a person’s chronic pain, it would be likely to rate these conditions as being of the same importance, with the added suffering of the fibromyalgia patients making no difference to their priority in the health care system.

Another kind of decision that a policymaker may face is whether to prioritise patients with a health condition which affects their objectively measurable capabilities but not does not affect subjective well-being, as compared to patients with a condition which affects subjective well-being but does not affect objectively measurable capabilities. It may not be immediately obvious which set of patients is more in need of health care, given conditions of resource shortages. For example, would a health system choose to prioritise a group of people with painless hearing loss<sup>37</sup> if this hearing loss leads to a substantial reduction in their capabilities, or would it choose to prioritise a group of people with Crohn’s disease (a painful gastroenterological condition) if these Crohn’s patients are still able to have normal capabilities?<sup>38</sup> In situations such as these, low subjective well-being and capability deficits would need to be considered as separate factors.

The most common type of decision that policymakers are likely to face is about how to make priority decisions between two conditions, in cases where both conditions affect both capabilities and well-being, but to different extents. One way to incorporate both factors in these situations is to partially

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<sup>37</sup> In this scenario I assume that the painless hearing loss does not cause lower subjective well-being.

<sup>38</sup> In the real world, many people with Crohn’s disease are unable to have anything like normal levels of capabilities, and many people with painless hearing loss may have accommodations which enable them to function at a high level.

weight capability deficits by their expected effect on subjective well-being. What I mean by this is that policymakers should prioritise capability problems that (on average) have a substantial effect on subjective well-being and should relegate to a lower priority those which do not usually have this effect. This may mean making some surprising decisions about which patients to prioritise in the health care system. For example, some preliminary research has found that moderate anxiety has a greater effect on subjective well-being than many other conditions, such as moderate levels of problems with mobility and self-care.<sup>240</sup> This is the case when the researchers surveyed people's level of life satisfaction as well as when they measured people's affect throughout the day.<sup>240</sup> A possible reason for this kind of result is that problems with mobility do not seem to be the focus of people's attention and experience to nearly the extent that anxiety and related mental health issues are. A metric which weights capability problems by the extent to which they affect subjective well-being may give higher priority to mental health problems and lower priority to mobility problems than many current health care systems do.

These considerations raise the further question of *to what extent* capability deficits should be weighed against subjective well-being in decisions where some patients face capability deficits but not low subjective well-being, and some patients experience low subjective well-being but not capability deficits. Also, *to what extent* should capability deficits be weighted by their likely effect on subjective well-being? I argue that this can be at least partially determined through the democratic political process. Governments can (and should) create a freely accessible website, which would enable citizens to directly refer to the scientific papers on subjective well-being used by policymakers, how decisions about metrics were made, and how these metrics are being used in health policy. This publicly available information could facilitate public debate and enable citizens to influence policy decisions through the political process. Citizens could influence to what extent the health care system emphasises improving capabilities as compared to emphasising improving subjective well-being. Citizens could also influence to what extent health care resources are used to cause the largest overall increase in subjective well-being, and to what extent resources should be targeted to benefiting those with the lowest subjective well-being.

However, there should be limits to what extent public debate and the democratic process can affect this health care priority-setting process. Public debate should not enable the health care system to benefit some people and not others, solely on the basis of their membership of a particular demographic group. For example, public debate should not be able to allow the health care system to prioritise addressing the pain of men over the pain of women, if this prioritisation was on the basis that men's pain was inherently more important than women's pain. This is different to a policy having

disparate impacts on different populations due to evidence-based health reasons. For example, if a country experienced a high incidence of prostate and testicular cancer but a low incidence of ovarian, endometrial and cervical cancer, then it may be justified to spend a larger proportion of the cancer budget on men than on women. But in the latter scenario, spending more money on men's health than women's health would be based on evidence and situational contingencies, not beliefs and judgements which are incompatible with respecting and treating all citizens equally. The health care rationing principles that I propose are compatible with reasonable transparency and justification of public policy to citizens, and with normal democratic processes.

A potential result of using subjective well-being in health care priority-setting is a greater emphasis on investigating the contexts in which health conditions occur and the beliefs that patients have prior to developing a health condition, regardless of whether these factors have a direct effect on capabilities. For example, prior beliefs which lead patients to assume that pain is always an indicator of tissue damage are associated with worse experiences of pain. Educational interventions, such as Lorimer Moseley's *Explain Pain* course, teach patients that chronic pain disorders frequently occur in the absence of ongoing tissue damage, and this improved patient knowledge is associated with better pain management.<sup>241</sup> Perceived control over pain and the patient's environment is itself associated with less experience of pain.<sup>242</sup> Other contextual factors such as the level of sunlight<sup>243</sup> and noise<sup>244</sup> in health care facilities are also thought to affect pain perception and painkiller usage. More attention to patient education and the health care context are likely to decrease the experience of pain and improve subjective well-being even in the absence of better treatments for capability deficits. These types of interventions are likely to receive greater attention in a health care system which prioritises improving subjective well-being.

#### **4. Objections and responses**

##### **4.1 Objection: making valid interpersonal comparisons on the basis of subjective well-being?**

One objection that may be raised here is whether it is valid and meaningful to compare different individuals' reports of their subjective well-being. How do we know that these are not just 'apples to oranges' comparisons, which would make any metrics comparing or aggregating these self-reports meaningless?

The first thing to note here, as James Griffin has commented, is that this objection can be seen as a particular application of the classic philosophical 'problem of other minds'.<sup>178</sup> The philosophical problem of 'other minds' often takes the form of asking how I can know or justify the belief that other beings exist who have thoughts, feelings, and other mental states.<sup>245</sup> In this case, the problem

would be asking how I can know or justify the belief that other people experience relevantly similar states which can all be meaningfully described as 'well-being'. Exploring the broader problem of other minds is beyond the scope of this thesis, however I think that we have good reason to believe that 'well-being' can be compared and measured across different people.

One immediate reason to think that it is possible to make meaningful interpersonal comparisons of well-being is that all people have a shared evolutionary history. While well-being does not have to be defined as synonymous with the presence of pleasure or the absence of pain, it would be a strange theory of well-being in which these concepts played no role. In evolutionary history, natural selection is likely to have had a substantial effect on what people found painful or pleasurable. People who found it pleasurable to stick their arms and legs into fires are likely to have left fewer descendants than those who found this painful and so treated fire with appropriate caution. People who preferred to live entirely alone, without the support of any family or wider group were also likely to be more vulnerable to disasters than those who stayed with their group, and thus this was unlikely to be a successful reproductive strategy. Through evolutionary history, some traits, such as preferring some level of social interaction, have gone to fixation throughout the whole human population. This provides a reason for assuming that there will be some factors which will make a difference to almost everyone's well-being. Deliberately burning a person's limbs or keeping a person in solitary confinement for any significant length of time are almost universally considered to be forms of torture. Our shared evolutionary history gives us reason to assume that there are at least some similarities in factors which promote or detract from different people's well-being, and so give us reason to think that we can make some basic interpersonal comparisons of well-being.

A different version of the objection from interpersonal comparisons has been raised by Daniel Hausman in his book *Valuing Health*.<sup>246</sup> Hausman expresses scepticism about whether individual well-being can be measured, compared and aggregated in the way that incorporating it in public policy decision-making would require. Note that this is somewhat different to the question of whether a factor exists which makes people's judgements about their own or other people's well-being true or false. Hausman is sceptical that we can make valid interpersonal comparisons of well-being in practice for a number of reasons. Firstly, he argues, well-being is too heterogeneous. As Hausman puts it:

'The good life for some people consists in adventure, in others it lies in serenity. Some people thrive by cultivating their aesthetic sensibilities. Others live well by taking care of others.'<sup>246</sup>

One important reason behind this heterogeneity is that what is good for a person depends heavily on who they are: on their identity, goals and values.

A further problem for Hausman is the holistic nature of well-being. Hausman argues that well-being is primarily thought about in terms of whole lives, and our interpretation of a person's life and well-being during a particular period often depends on what their life is like before and after that period. Another aspect of the holistic nature of well-being is that well-being requires the integration of many factors. As Hausman notes:

‘assembling a good life is like cooking a good dinner; more of some delicious ingredient does not necessarily improve a dish... More of some specific element that contributes to someone's well-being may make her life worse, because it is less integrated, harmonious, or coherent... As a consequence, increasing a good such as pleasure, without diminishing other first-order components of well-being such as friendship or accomplishment, may diminish relational aspects of well-being. A person's well-being depends on how the various goods that contribute to well-being are combined, not on how many of them the person has.’<sup>246</sup>

This complexity is increased, in Hausman's view, by the issue that different ‘mixtures’ of goods may be best for different people. While it may be possible to make some kinds of very basic interpersonal comparisons of well-being, Hausman argues that well-being is too heterogenous to be able to make valid interpersonal comparisons for the purposes of public policy.

In response to this, I do not believe that Hausman's objections are enormous obstacles to measuring and making interpersonal comparisons of *subjective* well-being. This is because to the extent that contextual factors are important in assessing well-being, they would be automatically included in the person's assessment of their own well-being. For example, if one person experiences adventure as being essential to their well-being, they will not rate their well-being very highly if they are restricted to a very sedentary and predictable lifestyle.

Another reason be less sceptical than Hausman about the viability of measuring well-being is that researchers have been able to measure, compare and aggregate other complex and multifaceted phenomena reliably enough for their measures to be useful in public policy. For example, there are many aspects involved in human intelligence, and a person may have excellent verbal skills but low ability to solve quantitative problems. There is also a contextual element, such that people may feel more confident to solve problems in certain situations than in others. However, psychologists have been able to construct intelligence tests that take this heterogeneity of cognitive abilities into

account and can infer a general factor of intelligence from a person's performance on a range of specific sub-tests. This measurement of intelligence can be accurate enough to be able to predict children's later academic performance using the results of an intelligence test conducted at the age of 5 (before they started school).<sup>247</sup> While there are many ongoing problems with measuring intelligence and the results of intelligence tests are far more accurate on a population than an individual level, they can still be reliable enough for some public policy uses. I see no reason why the heterogeneity of well-being should mean that it cannot be measured accurately enough to make interpersonal comparisons for use in public policy.

#### **4.2 Objection: the many influences on subjective well-being**

One objection to using subjective well-being in health care priority setting is that there are many factors which influence subjective well-being other than health status. For example, employment<sup>248,249</sup> and marital status<sup>250,251</sup> have consistently been found to have a significant effect on subjective well-being. Personality traits, such as a person's level of extraversion, are substantially heritable, and have a strong influence on a person's baseline subjective well-being as well as on their adaptation to negative or positive events.<sup>252</sup> This objection questions whether subjective well-being can be a good way to make decisions about priority-setting in health care given that subjective well-being is heavily influenced by factors outside health care, especially as some of these factors (such as genetic inheritance) are not under the direct control of public policy.

However, just because there are factors which affect subjective well-being and are outside the control of health policy, it does not follow that therefore subjective well-being should not be used in the health care priority-setting process. As an analogy, consider life expectancy estimates<sup>39</sup> and mortality rates. There are many factors outside health policy which affect life expectancy, such as the risk of political violence or trade policy affecting food availability. However, this does not mean that changes in life expectancy or mortality rates should not be taken seriously in evaluating health policy. For example, the recently reported rise in mortality rates among white Americans without a university degree<sup>253,254</sup> has prompted a valuable reconsideration of health policy around addiction and opioid prescriptions. This is the case even though the rise in US mortality rates from 1993 to 2013 is small compared to the rise in mortality rates between 1940 and 1945 in the Soviet Union (where the Soviet mortality rise was caused by World War II).<sup>40</sup> In a similar way, even though many

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<sup>39</sup> Life expectancy at birth estimates represent the average number of years that a newborn baby could expect to live, assuming that they experience current age-specific death rates through their lifetime. An age-specific death rate is the number of deaths divided by the population in a particular age group.

<sup>40</sup> On Soviet WWII death rates, historian Catherine Merridale writes: 'Of the generation of young men that was born in 1921, the conscripts who had been called up in time for the battles of Kiev and Kharkov, or for the calvary of Stalingrad itself, up to 90 per cent were dead.' 255. Merridale C. *Ivan's War: Life and Death in the Red Army, 1939-1945*: Macmillan; 2006.



factors that are outside the control of health policymakers can cause low subjective well-being, this does not mean that subjective well-being should not be used in the priority-setting process.

#### **4.3 Objection: Adaptive preferences**

A different objection that could be made here is that subjective quality of life data is subject to adaptive preference formation, and thus is inappropriate to help determine fair shares of health resources. An adaptive preference is a preference that people hold because they have come to prefer an option from the diminished set that was (due to sub-optimal circumstances) available to them. As this option is not one that they would otherwise choose or prefer but is the result of a psychological adaptation to difficult circumstances, adaptive preferences are thought to give strong moral reasons for discounting some of the testimony of people in certain circumstances.

To give an example of why adaptive preferences are thought to be so problematic, consider the example of Jayamma from Martha Nussbaum's book *Women and Human Development*:

‘When women were paid less for heavier work at the brick kiln and denied chance for promotion, Jayamma didn’t complain or protest. She knew that this was how things were and would be... When her husband took his earnings and spent them on himself in somewhat unthrifty ways, leaving Jayamma to support the children financially through her labor, as well as doing all of the housework, this didn’t strike her as wrong or bad, it was just the way things were, and she didn’t waste time yearning for another way... Jayamma seemed to lack not only the concept of herself as a person with rights that could be violated, but also the sense that what was happening to her was a wrong.’<sup>195</sup>

Although Jayamma experienced a number of different forms of oppression, such as highly inequitable treatment at work and at home, she was so used to experiencing these forms of oppression that she did not experience dissatisfaction or report low well-being on account of them. Jayamma’s reaction to her circumstances is not unusual, and is likely to be an adaptation to enable her to function without experiencing frustration from unmet desires. However, her adaptation is also a reason to put less weight on her report of her own subjective well-being. It would seem counterintuitive and unjust to deny Jayamma extra resources at work and at home because she did not express dissatisfaction about her circumstances.

It could be argued that when people with disabilities express high subjective well-being that they have merely psychologically adapted to the circumstances that they have found themselves in. As they would want something different if this was a realistic possibility, their current preferences and

subsequent subjective well-being should not be taken as an indicator to how badly off they actually are, or as a guide to resource distribution. In many cases, having a physical disability is thought to constitute the absence of some basic goods (such as physical health or bodily integrity) which are commonly considered to be a fundamental part of any reasonable conception of well-being. It could be argued that it is so implausible that people with certain physical disabilities are in fact experiencing high well-being that their testimony to this should be considered to be evidence for adaptive preference formation, and it would be unjust to include this in an assessment to guide health care resource distribution.

I have a number of responses to this concern about adaptive preferences. Firstly, I agree that in some circumstances, adaptive preferences mean that subjective wellbeing may be misleading as to how well-off someone actually is. This is one of the reasons for including an 'objective' measure of functioning as a way to determine a person's needs for health resources. However, I do not think that concern about adaptive preferences are a good reason to reject including information about subjective well-being in health care priority-setting.

One aspect to note is that in some situations discounting a person's preferences due to adaptive preferences seems more plausible, but in other types of situations it seems much less plausible. For example, many people would think that it was very implausible that Jayamma was experiencing high levels of well-being and would not want to use her testimony of this as evidence of how badly off she actually was. On the other hand, there are many possible situations in which attributions of adaptive preferences seems paternalistic and simply wrong. For example, in the past, gay and lesbian people who reported experiencing a high quality of life may have been taken as experiencing adaptive preferences. When gay and lesbian people reported that they had satisfying and enriching relationships and did not prefer to be heterosexual, this testimony may have been interpreted as an adaptive response to missing out on the basic human good of heterosexual relationships.<sup>173</sup> Much of the philosophical literature on adaptive preferences tries to find a test or a principle which will reliably distinguish cases like Jayamma's from cases such as gay and lesbian people who experience high subjective well-being.

One possible test is to look at the consistency of people's preferences and beliefs to assess whether their testimony or preferences should be discounted for the purpose of applying theories of distributive justice. For example, suppose a woman who experienced domestic violence from her spouse thought that domestic violence *in general* was morally wrong, but that it was not unjust when *she* suffered from domestic violence. This kind of arbitrary exception from a general rule may be

good evidence that a person is experiencing adaptive preference formation. Polly Mitchell gives another example of conflicting preferences: ‘a patient with chronic kidney disease who reports minimal change in quality of life despite having to attend twelve hours of haemodialysis per week would exhibit adaptive preferences...if he also reports a strong preference for time spent out of hospital over time spent in hospital’.<sup>256</sup> However, while considering whether a person has inconsistent preferences and beliefs may illuminate some individual cases, it is also not a very widely applicable test in the real world. For example, it is entirely possible a woman such as Jayamma might believe that domestic violence towards women in general was an unalterable feature of the world and not morally wrong. Also, it is very common for people in general to have some degree of conflicting preferences or irrational beliefs, and we do not therefore think that *all* testimony is unreliable. It seems too narrow to only focus on the consistency of people’s preferences and beliefs in order to determine whether their preferences are adaptive in this sense.

A different suggestion is to adopt a procedural test for adaptive preferences. For example, Elizabeth Barnes argues that:

‘Warrant for adaptive preferences can only be gotten in cases which involve a general social distortion.

By social distortion I mean things like: abuse of power relationships, exertion of dominance, forcible removal by one party of another party’s resources or freedoms, etc. Notice first that this criterion for diagnosing adaptive preference behavior gets the paradigm cases right.

Abused women and kidnap victims have both been subjected to such social distortions.

Someone had an advantage over them, and used that advantage to keep them submissive and subdued. When they report having benefited from their experience, they are reporting to have benefited from this sort of social distortion.’<sup>173</sup>

Here, Barnes argues that we only have evidence that a person’s testimony is subject to adaptive preferences if their preferences were formed in situations of social oppression. This would provide a way to distinguish the cases of Jayamma and gay people. The structure of Jayamma’s situation would be very different if her employer and husband did not abuse their power and treat her unjustly. In contrast, gay and lesbian people have been part of every society, regardless of whether or not their society discriminated against them for their sexual orientation. As Barnes puts it:

‘You can’t be an abused spouse or a kidnap victim unless someone acts against you. But you can certainly be female or gay without someone acting against you—you can be female or gay on a desert island.’<sup>173</sup>

The problem with this kind of procedural account is that it seems to aim at the wrong target. Why should the fact that phenomenon (such as domestic violence) is ‘socially’ caused mean that a person’s preferences regarding it are unreliable and ‘adaptive’, whereas preferences regarding a ‘naturally’ caused phenomenon (such as disability) are an accurate account of a person’s well-being and are non-adaptive? This also seems to be an unhelpful test to apply in the real world. Most cases of illness and disability have complex and interacting social and natural causes, and it is not always clear whether, or to what extent, a given illness or disability can be said to be caused by a ‘social distortion’. Barnes’ account does not seem to help in identifying problematic adaptive preferences.

In identifying problematic adaptive preferences, I think that it is important to note that there are phenomena that may superficially look like adaptive preferences but are in fact conceptually distinct. One of these cases is of incomplete information. For example, consider a person, Anne, who has never had any kind of disability or illness. Anne then develops a headache as a result of a cold. Suppose that Anne then visits a doctor and reports that her pain is ‘10 out of 10’. Compare this case to Rosemary, who has a chronic pain disorder. Rosemary only reports that her pain is ‘10 out of 10’ in situations where she is in hospital and intravenously administered ketamine<sup>41</sup> does not even take the edge off her pain. While both Anne and Rosemary are sincerely describing their internal experiences, the incomplete information and lack of scale context would lead us to overestimate Anne’s claim to health care resources. This case should be distinguished from that of adaptive preferences. Neither Anne nor Rosemary experience adaptive preferences in this case – but their reports of their experiences are relative to what they have experienced in the past, which can lead to misleading comparisons. A more detailed questionnaire about their pain would be more likely to more accurately describe Anne and Rosemary’s subjective experiences.

A related case is that of inaccurate information. Polly Mitchell describes the case of ‘severely malnourished women in Andhra Pradesh, prior to the efforts of a government consciousness raising program, didn’t consider themselves to be malnourished, or their conditions to be unhealthy’.<sup>256</sup> Having grown up in extreme poverty, these women had always experienced malnutrition and so did not know that their health would improve if they had been able to eat a properly balanced diet. This type of case is also not properly an example of adaptive preferences – when the women had more information about health and nutrition, they were able to more accurately describe their situation to people from outside their village, and their preferences did not change. However, this type of case is

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<sup>41</sup> Ketamine is a medication primarily used as a tranquiliser and anaesthetic. Due to the likelihood of severe side-effects including psychosis, it is only used when other pain relief treatments have failed.

rarely experienced by people with illnesses or disabilities, as most people have experienced being able bodied in the past.

A different case which should also be distinguished from that of adaptive preferences is that of *unfamiliar* preferences, which are in fact compatible with well-being. In many cases, as Barnes writes ‘the experience of living with an impairment is not what many non-disabled people imagine it to be, and it does not leave most disabled people pining to have their bodies normalized’.

I think that many of the purported cases of adaptive preferences related to illness and disability are actually cases of unfamiliar preferences. One clue that a person actually has unfamiliar preferences might be that they describe their experience as having *different* options or experiences rather than *diminished* ones. For example, Barnes cites the experience of Rebecca Atkinson:

‘Losing your sight is not like just shutting your eyes. The loss is so gradual that as one sense dies others grow. Suddenly you can smell the world and sense when someone is standing out of your line of vision. Your brain grows on the inside and things on the outside start to matter less. I get to live my life twice over in two different bodies (the sighted one I used to have and the partially sighted one I now have), and with that comes the privilege of spying on the world and its intricacies from multiple vantage points...If this experiment of going blind has taught me anything, it is that what you lose in one place you gain elsewhere, and while a blind life is different to a sighted life, it is not lesser.’<sup>173</sup>

Another clue that people are experiencing unfamiliar preferences might be that they describe their new life with a disability as a change that has resulted in learning more about their goals and the many ways in which they can be achieved. This is not the same as developing lower expectations. It may just be an experience of learning more about their own preferences and about the world. For example, a person might initially believe that he would be very unhappy if he could not play cricket, but after experiencing an injury finds that what he really enjoyed about the cricket was being outside with his friends, and that he can still experience this.

It is also worth noting that everyone is to some extent constrained by their circumstances. We do not consider a person’s testimony of having high well-being unreliable because they cannot fly to Mars or become immortal. Also, no single individual can have the full range of human experiences. By growing up in Tamworth, NSW, I was unable to have the experience of growing up in Auckland, or on Long Island, or in Madrid. Yet it would be strange to say that I experienced adaptive preferences in my childhood for that reason. It is important not to inadvertently discount the testimony of disabled people as unreliable, while ignoring the ways in which everyone adapts their preferences

As Elizabeth Barnes notes, a high bar of evidence should be required before deciding that someone's stated view about their own well-being is actually an adaptive preference, as this overturns the general truth that an individual is more likely to be a reliable source of knowledge about their own well-being than another person is.<sup>173</sup> In general, surprising reports of high well-being should be a call to understand and find out more, not to dismiss the testimony of people with disabilities.

## **5. Conclusion**

In this chapter, I have explored how policymakers could make greater use of subjective well-being in allocating scarce health care resources. I summarised some of the empirical research findings in this area, such as that different health conditions on average have different effects on people's subjective well-being, and that people tend to adapt more quickly and completely to some conditions than to others. I have suggested that policymakers could also give greater priority to treating conditions to which people experience poorer adaptation (such as ongoing major depression), subject to input from the democratic political process. I responded to concerns about the validity of interpersonal comparisons with regard to subjective well-being, about the many influences on subjective well-being and adaptive preferences and have argued that these objections should not prevent policymakers from including subjective well-being in the priority-setting process.

Ultimately, to treat people with respect is, in most cases, to take seriously their experiences, preferences and autonomy, and to attend to the suffering that people experience. These considerations should lead policymakers to include subjective well-being in setting health care priorities.

## Conclusion

No modern society can avoid the question of how to allocate health care resources when there is a gap between the amount of health care that people want and the health care resources that are available. This problem is only likely to grow more pressing in the short to medium term. Medical science and technology continue to improve, making a greater range of health care interventions possible, while at the same time aging populations and an increasing rate of chronic non-communicable illnesses increase the demand for health care. This means that it is important that social institutions have principles that enable them to choose between competing health care needs and to set priorities in a way that is consistent and fair.

In this thesis, I have argued that social institutions should allocate health care resources on the basis of two factors: to what extent a given health care intervention is likely to improve people's morally relevant capabilities, and to what extent the health care intervention is likely to improve people's subjective well-being. I have argued for this view through a critical engagement with the literature.

The purpose of Part 1 is to argue that people's responsibility for damaging their health should not play a part in determining the strength of their claim for health care. In Chapter 1 I described and explained how luck egalitarian principles could be applied to the question of health care rationing. I focus on luck egalitarianism in Part 1 as I take this to be the most promising and well-developed set of principles for allocating health care resources in a way that is sensitive to individual responsibility.

In Chapter 2, I discussed the Abandonment Objection, which argues that luck egalitarian principles lead to objectionably harsh treatment of people who are considered to have caused their own condition through recklessness or imprudence. While the philosophical literature on the Abandonment Objection is too extensive to address entirely in one chapter, I considered those luck egalitarian responses that I take to be most relevant to the applied ethical question of health care rationing. I argued that even the most promising luck egalitarian responses to the Abandonment Objection are problematic and that this raises significant questions about whether luck egalitarianism can be a plausible moral account of allocating health care resources in conditions of scarcity.

In Chapter 3, I considered the question of whether luck egalitarian principles could be applied to health care policy in the real world. I argued that those luck egalitarian accounts which aim to provide guidance for health policy face a dilemma. They can focus on making priority for health care

dependent on people's actual health behaviours, or alternatively they can make priority for health care dependent on measurable health outcomes as a proxy for health behaviours. If they focus on health behaviours directly, then this is likely to have negative consequences outweighing its intended benefit and further penalise the socioeconomically disadvantaged. If on the other hand, advocates of responsibility-sensitive health care policy focus on health outcomes as a proxy for health behaviours, then they face the problem that it is not possible to reliably infer detailed information about people's health behaviours given their health outcomes. For these reasons I reject luck egalitarian principles as applied to the question of how to set health care priorities.

Having argued against responsibility-sensitive health care, I considered a number of responsibility-insensitive systems of allocating health care resources in Part 2, culminating with developing and defending my own view in Chapters 6 and 7.

In Chapter 4, I considered the claim that health care resources should be allocated by the free market without government intervention. I argued that, due to structural problems, it is necessary for governments to intervene in the health care and health insurance markets for these markets to be able to provide health insurance to everyone. I rejected the arguments of Nozick and other libertarians that government intervention is always impermissible.

In Chapter 5, I considered two metrics which may at first glance seem to be promising methods for allocating scarce health care resources. Quality Adjusted Life Years (QALYs) and Disability Adjusted Life Years (DALYs) aim to measure the value of health states and health interventions. They incorporate estimates of to what extent a health intervention is likely to affect a person's quality of life and lifespan into a single measure. However, I argued that these metrics are seriously flawed and should not be used in public policy. This is because QALYs and DALYs use inaccurate assumptions about people with disabilities, obscure issues of distributive justice, and inappropriately conflate the goods of additional lifespan and quality of life.

In Chapter 6, I moved on to explain and argue for my own view about how scarce health care resources should be allocated in practice. I draw out and concur with the central insight of Norman Daniels' theory and Capability theories about the moral importance of capabilities and functionings. I believe that this provides a partial answer to the question of how social institutions can ration scarce health care resources. The strength or weakness of a person's claim to health care should be partly determined by how likely it is that health care will protect or improve their morally relevant capabilities and functionings. However, I argue that an *exclusive* focus on objectively measurable



capabilities and functionings is insufficient for setting health care priorities fairly. This is because there is a subjective element to the experience of pain which is difficult to measure in terms of its impact on objective capabilities.

In Chapter 7, I provided the other part of my view. I argued that policymakers should include measures of subjective well-being, in addition to capabilities, in considering which health care interventions to prioritise in situations of scarce resources. I suggested that policymakers could give greater priority to treating conditions to which people experience poorer adaptation (such as ongoing major depression), subject to input from the democratic political process. I responded to potential objections about adaptive preferences and the validity of interpersonal comparisons and argue that these concerns should not deter policymakers from including subjective well-being in the priority-setting process.

In this thesis I have only sketched the beginnings of an answer to the question of how social institutions should allocate scarce health care resources in practice. A broad program of interdisciplinary research would be needed to provide more detailed policy recommendations. For example, philosophers, psychologists, medical researchers and epidemiologists can all contribute to the project of providing more wide-ranging and rigorous research into the nature of subjective well-being, how subjective well-being can be measured, and how subjective well-being is affected by different health conditions and medical treatments. Philosophers, medical professionals, economists and political scientists can consider in more detail how to make health care priority decisions while aiming to improve people's both capabilities and their subjective well-being. There is also a role for citizens to contribute to health care priority setting through the political process.

I hope that through greater interdisciplinary research and political engagement, social institutions can do a better job of allocating health care resources in a way that is fair, consistent and principled, with improved outcomes for people's capabilities and quality of life.

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