

In a democracy, what should a healthcare system do?

A thesis submitted to the University of Manchester for the degree of PhD in Bioethics
and Medical Jurisprudence in the Faculty of Law

Year: 2013

Candidate: Malcolm Oswald

Department: Centre for Social Ethics & Policy

List of Contents

ABSTRACT	4
1. INTRODUCTION.....	6
THE THESIS QUESTION.....	7
OTHER THEMES EXPLORED.....	7
THESIS STRUCTURE AND CONTENT.....	8
2. CHOOSING A RESEARCH QUESTION.....	12
THE CONTEXT: A SUMMARY OF RELEVANT LITERATURE ON RESOURCE ALLOCATION	13
<i>Analysis by economists.....</i>	<i>13</i>
<i>Analysis by philosophers and bioethicists.....</i>	<i>15</i>
<i>Theory into practice: the international experience.....</i>	<i>19</i>
HOW I CHOSE MY RESEARCH TOPIC.....	20
DECIDING HOW DEEP TO GO.....	21
SAYING SOMETHING ABOUT A SUBJECT THAT MATTERS.....	21
PAPER 1: IT’S TIME FOR RATIONAL RATIONING.....	22
WHY I CHOSE THE CONTEXT OF A MODERN REPRESENTATIVE DEMOCRACY.....	26
PAPER 2: SHOULD POLICY ETHICS COME IN ONE OF TWO COLOURS: GREEN OR WHITE?	29
3. WHY IT IS A QUESTION OF PUBLIC POLICY.....	45
WHAT A HEALTHCARE SYSTEM IN A DEMOCRACY SHOULD DO IS A PUBLIC POLICY QUESTION.....	46
PAPER 3: WHAT HAS THE STATE GOT TO DO WITH HEALTHCARE?.....	47
4. LOOKING TO PHILOSOPHICAL BIOETHICS FOR AN ANSWER.....	66
PHILOSOPHICAL BIOETHICS AND DEMOCRATIC DECISION MAKING.....	67
PAPER 4: HOW CAN ONE BE BOTH A PHILOSOPHICAL ETHICIST AND A DEMOCRAT?...	71
5. LOOKING ELSEWHERE FOR AN ANSWER.....	86
WHY LOOK BEYOND BIOETHICS?.....	87
PUSHING AT THE “IS/UGHT DISTINCTION”.....	87
WHY I HAVE CHOSEN A MULTI-DISCIPLINARY APPROACH.....	89

RELEVANT ARGUMENTS FROM OTHER DISCIPLINES	91
<i>Economics</i>	91
<i>Social policy</i>	96
<i>Political philosophy and political science</i>	97
<i>Law and jurisprudence</i>	100
<i>Systems theory</i>	104
6. A GOOD AND FAIR ANSWER	108
TWO ARTICLES ADDRESSING THE QUESTION OF WHAT A HEALTHCARE SYSTEM IN A DEMOCRACY SHOULD DO	109
WHY GOOD AND FAIRNESS ARE SEPARATE CONSIDERATIONS.....	109
A PARTIAL ANSWER	110
PAPER 5: ACCOUNTABILITY FOR REASONABLENESS: AS UNFAIR AS QALYS?.....	111
PAPER 6: IN A DEMOCRACY, WHAT SHOULD A HEALTHCARE SYSTEM DO? A DILEMMA FOR POLICYMAKERS	147
7. CONCLUSION	192
SAYING SOMETHING ORIGINAL	193
SAYING SOMETHING USEFUL TO POLICYMAKERS	193
CONCLUSIONS.....	194
OPPORTUNITIES FOR FURTHER RESEARCH.....	196
APPENDIX A: BIBLIOGRAPHY	198
APPENDIX B: OTHER PUBLICATIONS AND PRESENTATIONS LINKED TO MY PHD THESIS.....	216
APPENDIX C: ACKNOWLEDGEMENTS	218

Word count: 65,319

Abstract

University Name: The University of Manchester

Candidate Name: Malcolm Leslie Oswald

Degree Title: Doctor of Philosophy (PhD)

Thesis Title: In a democracy, what should a healthcare system do?

Date: 15/07/2013

In a democracy, what should a healthcare system do? It is a question of relevance to many disciplines. In this thesis, I examine that question, and add something original to the existing debate by drawing on, and synthesizing, thinking from several disciplines, and especially philosophical ethics, economics and systems theory.

Paper 6 in this thesis, entitled “In a democracy, what should a healthcare system do?”, tackles the thesis question directly. The central conclusion of that paper, and of this thesis, is that a healthcare system in a democracy should do as much good as possible, although sometimes some overall good should be sacrificed for the sake of fairness, as John Broome has argued. However, what counts as the good of healthcare, and when good should be traded off for fairness, depend on your *weltanschauung* (or worldview). Political pluralism is normal, and every democracy has institutions and processes for making policy when people disagree because their worldviews differ. Ultimately, elected policymakers are accountable for making decisions.

This analysis is complemented by paper 5, entitled “Accountability for reasonableness – as unfair as QALYs?”. It assesses the vulnerability of three theories of resource allocation to injustice. It concludes that Daniels and Sabins’ accountability for reasonableness approach is vulnerable because it does not require evidence of costs and benefits. Maximising quality-adjusted life years can also lead to large-scale injustice because it is concerned only with health gain, and not with fairness. I conclude that a “good and fairness framework”, which is drawn from the writing of John Broome, is the least vulnerable to large-scale injustice.

There are four other papers in this thesis. “What has the state got to do with healthcare?” (paper 3) makes the case for an important assumption underpinning this thesis, namely that the question of what a healthcare system should do is a question of public policy. Paper 1, entitled “It’s time for rational rationing” argues that efficiency gains are not inexhaustible, and to continue with its austerity programme, policymakers should assess whether the NHS in England could do more good with the same money by doing different things. I explore how philosophical ethics can contribute to policy, and the importance of context when writing papers about policy, in: “Should policy ethics come in one of two colours: green or white?” (paper 2) and “How can one be both a philosophical ethicist and a democrat?” (paper 4).

These latter two papers, and much of the narrative within this thesis, explain how my thinking has developed during the course of my PhD, and why I have looked within and beyond philosophical ethics for an answer to my central research question.

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

Copyright

The author of this thesis (including any appendices and/or schedules to this thesis) owns any copyright in it (the “Copyright”) and s/he has given The University of Manchester the right to use such Copyright for any administrative, promotional, educational and/or teaching purposes.

Copies of this thesis, either in full or in extracts, may be made only in accordance with the regulations of the John Rylands University Library of Manchester. Details of these regulations may be obtained from the Librarian. This page must form part of any such copies made.

The ownership of any patents, designs, trade marks and any and all other intellectual property rights except for the Copyright (the “Intellectual Property Rights”) and any reproductions of copyright works, for example graphs and tables (“Reproductions”), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property Rights and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property Rights and/or Reproductions.

Further information on the conditions under which disclosure, publication and exploitation of this thesis, the Copyright and any Intellectual Property Rights and/or Reproductions described in it may take place is available from the Head of School of Law.

1. Introduction

The thesis question

It is not just clinicians who discuss the nature of healthcare and healthcare systems. Philosophers and bioethicists debate whether health and healthcare has special moral significance, and who should get what out of a healthcare system. Lawyers and political scientists seek rules on who should get what healthcare, and how that can be decided. Management scientists and systems theorists consider how a healthcare system can be designed and improved. Economics, psychology, sociology and many other disciplines are also concerned with health and healthcare.

Many of the academic debates in these fields lead back to the central question of what a healthcare system should do. Unless one knows what a healthcare system should do, how is it possible to determine who should get what healthcare, or what counts as an improved system? It is a question of fundamental importance, of relevance to many disciplines, and to the people funding, providing and receiving healthcare across the world.

Many disciplines offer important insights to help answer this question. However, most debates take place within disciplines rather than across disciplinary boundaries. Few people attempt to synthesise thinking from several fields. The aim of this thesis is to add to collective knowledge by drawing on arguments from several disciplines, and put forward a basic framework for determining what a healthcare system within a functioning democracy should do. It is a broad topic for a Ph.D., especially when tackled from the viewpoint of more than one discipline. The setting of a democracy has been chosen partly in order to limit scope.

Other themes explored

There are other reasons for choosing the context of democracy. I am interested in exploring the relevance of ethical thinking and argument to real-world policy-making in a functioning democracy like the United Kingdom. Much is written in academic journals on policy questions of ethical concern, but few of the important arguments made by philosophical ethicists appear to find their way into the policymaking process. If more was done to connect philosophical ethics to policymaking, surely both ethicists and policymakers would benefit, and better policies would result? However, the pursuit of philosophical truth is a very different activity to the craft of

policy-making in a democracy. The differences between these two enterprises raise a potential obstacle to connecting philosophical ethics and policymaking, and I explore in this thesis how that obstacle could be overcome.

Thesis structure and content

Bioethics and Medical Jurisprudence is a structured Ph.D. Programme at the University of Manchester – a thesis must be structured around a set of papers that are published or publishable in peer-reviewed journals. This thesis contains six papers. At the time of writing, three have been published (papers 1, 2 and 4), two have been accepted by journals and are awaiting publication (papers 3 and 6), and one is under review by a journal (paper 5):

- “It’s time for rational rationing” was published in the July 2013 issue of the British Journal of General Practice (paper 1 in section 2);
- “Should policy ethics come in one of two colours: green or white?” was published in the Journal of Medical Ethics April 2013 special issue on infanticide (paper 2 in section 2);
- “What has the state got to do with healthcare?” has been accepted by the Manchester Review of Law, Crime and Ethics, and will be published in the 2013 edition of that journal, due out in August 2013 (paper 3 in section 3);
- “How can one be both a philosophical ethicist and a democrat?” has been published online by Health Care Analysis but not yet incorporated within an issue of that journal (paper 4 in section 4);
- “Accountability for reasonableness: as unfair as QALYs?” is currently under review by the Journal of Health Politics, Policy and Law (paper 5 in section 6);
- “In a democracy, what should a healthcare system do?” has been accepted by the journal Politics, Philosophy and Law (paper 6 in section 6).

The remainder of the thesis should provide the narrative that links together, and fills the gaps between, the articles. In order to achieve this, this thesis has been structured into seven sections followed by three appendices.

Following this introduction, section 2 explains how and why I chose my Ph.D. topic. That choice was shaped by existing literature, and a summary of the literature reviewed is provided. Section 2 also explains why I consider the subject interesting and important. It recognises the value and also the inherent risks of a multi-disciplinary Ph.D. Section 2 elaborates my reasons for setting the context of a functioning democracy, and introduces and includes papers 1 and 2, each of which is relevant to my choice of Ph.D. topic.

Paper 1 is entitled “It’s time for rational rationing” and is a very short opinion piece. It questions whether health service efficiency should be the only tool for implementing financial austerity, and illustrates the relevance and importance of healthcare rationing – a major theme of this thesis. Paper 2, entitled “Should policy ethics come in one of two colours: green or white?”, develops the distinction used by John Harris between a green paper (an unconstrained philosophical exploration of ideas about a policy question) and a white paper (a serious policy proposal). It proposes three essential and two desirable characteristics of a white paper. I argue that authors and editors of all policy ethics papers should make clear in advance whether a paper is “green” or “white”, and that had Giubilini and Minerva classified their controversial paper on infanticide as “green” before it was released, the authors and editors would have been better placed to defend the publication of the paper (Giubilini and Minerva, 2012a).

The arguments developed in this thesis rest on the assertion that determining what a healthcare system in a democracy should do is a matter of public policy. Some people, such as staunch libertarians, would dispute this claim. In section 3, I back up this claim with paper 3, entitled “What has the state got to do with healthcare?”. This paper, which is written as a dialogue, draws on thinking from philosophy, economics, law and elsewhere. It argues that even for an ethical libertarian, the state has an important role to play in at least the regulation and funding of healthcare, and thus a democratic government must be concerned with what a healthcare system should do.

In exploring the literature, it became clear to me that many philosophical ethicists were sceptical about important aspects of democratic policy-making. For example, some reject compromise, and others see ethical policymaking as a job for experts rather than ordinary citizens. Furthermore, the business of philosophical reasoning and pursuit of truth require very different skills to the craft of democratic

policymaking. I explore these issues, and how philosophical ethicists can contribute constructively to democratic policymaking in section 4, where I introduce and include paper 4: “How can one be both a philosophical ethicist and a democrat?”.

The question of what a healthcare system in a democracy should do is not just a matter for bioethics. Other disciplines can provide useful insights. Section 5 explains why I have chosen a multi-disciplinary approach, and draws out arguments relevant to the question of what a healthcare system in a democracy should do from economics, social policy, political philosophy and political science, law and jurisprudence, and systems theory.

My answer to the question posed by this thesis is built upon the thinking of John Broome, and specifically his notions of good and fairness. I begin section 6 by explaining why good and fairness are separate considerations. Section 6 includes the two long articles that are central to this thesis, and which together provide my response to the thesis question.

Paper 5, entitled “Accountability for reasonableness: as unfair as QALYs?” assesses the vulnerability of three competing theories to large-scale injustice. Using a recently-reported case of large-scale injustice against mentally-ill people in England as an example (Mental Health Policy Group, 2012), the article considers how likely it is that such injustice could occur under accountability for reasonableness, quality-adjusted life years, and a good and fairness framework based on the writing of John Broome. Even though accountability for reasonableness is a theory of procedural justice, I conclude that it is vulnerable (and at least as vulnerable as quality-adjusted life-years) to grave injustice, partly because it does not attempt to value the healthcare to be distributed. Quality-adjusted life years were designed to measure and maximise benefit, but not to prevent injustice. I argue that accountability for reasonableness takes insufficient account of the good of healthcare, and maximising quality-adjusted life years takes insufficient account of fairness, and that the good and fairness framework is least vulnerable to large-scale injustice because it provides a means of valuing the good to be distributed, and is also tempered by fairness.

Paper 6 is entitled “In a democracy, what should a healthcare system do?”, directly addressing the question posed by this thesis. It draws on theory from philosophy and

economics, and looks to system theory for an account of the nature of systems. The paper argues that a healthcare system in a democracy should do as much good as possible, although good may be traded off for reasons of fairness. Although based on a particular account of good and fairness, it leaves open some questions about both good and fairness. The answer to these questions depends on your worldview, and it is for accountable individuals and institutions within a functioning democracy to make policy in the face of competing worldviews.

Section 7 summarises the main conclusions from this thesis. It also explains why this thesis adds something original to existing literature that could be useful to policymakers.

There are three appendices. The bibliography in Appendix A lists in alphabetical order all of the works cited in the thesis (including the references within the six papers). Appendix B describes other relevant publications and presentations I have produced during the course of my Ph.D. The final appendix acknowledges the support I have received.

2. Choosing a research question

The context: a summary of relevant literature on resource allocation

Before choosing a research question, it is important to understand what has already been written on a subject area. The research question I have chosen is primarily concerned with resource allocation in healthcare. The existing literature on this subject sets the context for choosing a specific research question. I provide a summary of the literature below, concentrating on the main contributors: economists, philosophers and bioethicists. It is followed by a brief account of the extent to which economic and philosophical theories have been put into practice internationally.

Analysis by economists

Economic theory suggests that a competitive market is the most effective mechanism for allocating resources for a private good (like, say, office stationery) but that markets may fail to operate effectively for other goods including healthcare (Arrow, 1963, Hsiao, 1995). Whether healthcare is funded publicly or through private insurance, public or private policy makers must decide between alternative health programmes and interventions, and they require some means of determining which treatments should be funded. Economists have developed different forms of analysis to assess and compare costs and benefits of alternative courses of action. Costs and benefits may be assessed in monetary and/or non-monetary terms, and weighed against risks. Where money is not the measure, another measure of value or utility is used.

In the 1980s and 90s, economists elaborated the concept of quality-adjusted life years (QALYs) as a measure of the utility, expressed in healthy years of life, to be gained from healthcare. (Williams, 1985) (Culyer, 1989) (Williams and Kind, 1992) (Brock, 1993) One QALY represents a healthy year of life, so a healthy year of life for two years would be two QALYs, and a year of life at 70% of full health would be worth 0.7 QALYs. At its simplest (and there are many variants, interpretations and applications), the QALY was proposed as a means to assess which healthcare treatments yield the greatest benefit for the money, and thus a means of allocating scarce resources.

Since the development of QALYs, economists have continued to identify and refine formulae for maximising outcomes, or minimising poor health, from the finite

resources devoted to healthcare.(Gold et al., 2002) For example, in addition to the QALY, years of life lost (YLL) aims to minimise the years of healthy life lost per dollar or pound spent. A variation of YLL adopted by the World Health Organisation is the disability-adjusted life year (DALY). A DALY combines YLL with years of “suffering” from disability, implying that years of life lived with a disability is a loss comparable with loss of life. The greater is the severity of the disability, the greater is the DALY score.

Like QALYs, DALYs may be refined to take account of discounting over time (where a year of life starting today is worth more than a year of life starting tomorrow) and other factors(Rushby and Hanson, 2001). Although the World Health Organisation claims they are based on “egalitarian principles”(World Health Organisation, 2011), DALYs are based on questionable ethical assumptions. Like QALYs they can be criticised for being ageist, but with greater force, as DALYs place no value on the lives of older people who live beyond a fixed target age. Furthermore, DALYs explicitly value a year of life led by a person with disabilities less highly than that of an able-bodied person, and imply that a disabled person has a weaker claim to healthcare than an able-bodied person(Arnesen and Nord, 1999). The World Health Organisation use the DALY as a means of assessing and comparing the burden of disease and disability disease in populations across the world, and although it has been criticised as being a poor indicator of disability it may have more potential for that purpose than as a means of prioritising the use of scarce resources. (Grosse et al., 2009) (Kothari and Gulati, 1997)

Economists have given considerable attention to assessing the validity of QALYs, and QALY maximisation. It has been recognised that the simple concept of health gain, measured in expected health improvement multiplied by the number of years of improvement, may not capture the full goals of a health service. Some theoretical arguments have been put forward in favour of weighting or otherwise adjusting the QALY to take account of various factors including:

- Age and life expectancy(Tsuchiya, 2000);

- The contribution, and potential loss of productivity due to lost health, to society from the individual (e.g. as an employee, a parent, a tax payer)(Brouwer et al., 1997);
- The severity of an individual's health condition prior to treatment(Nord, 1993);
- The size of the health benefit(Culyer, 1997); and
- The duration of health benefit and discounting over time.(Nord, 1999, p. 50-57)

These questions of how to value health benefits (which economists sometimes refer to as “social value”) have also been addressed by economists and social scientists in numerous public surveys. Many hundreds of such surveys have been carried out, and useful summaries of that empirical data have been published(Dolan et al., 2005, Schwappach, 2002). One interesting result is that a significant minority of people surveyed are either not prepared to make choices or refuse to accept any kind of prioritisation of health care(Schwappach, 2002, p. 217-218), or are not prepared to prioritise according to cost(Nord et al., 1995). Other social scientists have also become interested in assessing the social value of healthcare.(Clark and Weale, 2012) (Littlejohns et al., 2012)

Analysis by philosophers and bioethicists

Academic philosophers and bioethicists have also been concerned with how resources should be allocated and prioritised in healthcare. But, unlike economists, their primary concern tends to be on justice rather than efficient resource allocation. Thus writers like Norman Daniels have tried to apply John Rawls's book “A Theory of Justice”(Rawls, 1999) to healthcare(Daniels, 1985, p. 36-57), where justice implies protecting the needs of the worst off in society. Ronald Dworkin, another political philosopher, begins his analysis of a “prudent insurer” model for healthcare from his (somewhat different) conception of justice rooted in equality of resources (Dworkin, 2002, p. 307-319).

Because of this concern for justice, there have been many objections to QALYs from bioethicists, philosophers and others, leading to debate (e.g. (Mooney, 1989), (Cubbon, 1992)). For example, one major criticism is that QALYs are unfair, and in

particular, that they discriminate against the elderly and others with a short life expectancy, and against disabled people (who have less health to gain under QALY ratings). For example, where considering life-saving treatment, QALYs give a person who can expect to live thirty more years thirty times the priority of a terminally ill patient who would gain an extra year from the same treatment. Even most health economists and supporters of QALYs recognise that QALYs may violate societal notions of fairness.(Culyer, 2001) (Nord, 1999, p. 24) (Schwappach, 2002, p. 210)

More generally, some philosophers and bioethicists reject utility-maximisation approaches and have concluded that it is not possible to agree a fair and publicly-acceptable rationale for allocating healthcare resources.(Holm, 1998) (Daniels and Sabin, 2008) They argue that there is too much disagreement on the numerous ethical questions that arise when making these difficult life-and-death decisions (for example, should we fund expensive cancer treatment for very elderly people?). Indeed the disagreement is not only on how to distribute resources fairly, but more fundamentally over what a healthcare system should aim to achieve. For example, is it maximising good-quality life years, as QALYs suggest? Is it life-saving first, and restoring bodily functioning second? Does it include preventing future ill-health and death? The competing answers to such questions reflect deeper disagreements on social justice that can be traced back into political philosophy. As Amartya Sen says, “there may not indeed exist any identifiable perfectly just social arrangement on which impartial agreement would emerge”.(Sen, 2009, p. 15)

Because of this lack of consensus, Norman Daniels and James Sabin propose that the only reliable guidance that can be given to policy-makers is that they use fair, transparent and accountable processes to justify their resource allocation decisions. They propose four conditions of “accountability for reasonableness”:(Daniels and Sabin, 2008, p. 43-6)

- **Publicity:** rationing decisions made, and their rationale, must be made public;
- **Relevance:** the rationale on which decisions are made must be reasonable (i.e. based on evidence and relevant reasons), taking account of how the organisation provides value for money and meets varied health care needs;
- **Revision and appeals:** there must be a mechanism for individuals to challenge and dispute decisions, and for the organisation to learn and revise its policies; and

- Regulation: there must be either external or self-imposed mechanisms for enforcing the first three conditions above.

Some philosophers and bioethicists have supported and worked to develop and refine the “accountability for reasonableness” fair processes proposed by Daniels and Sabin. For example, in 1998, Soren Holm agreed with Daniels and Sabin that the point had been reached where the prioritisation problem would not be “solved” because an agreed set of rules could not be found, and that it was time to move on to considering fair processes.(Holm, 1998) With Andreas Hasman, Holm later argued that accountability for reasonableness needed to be elaborated further in order for it to be applied effectively by policy makers.(Hasman and Holm, 2005) Several writers have described how to apply the accountability for reasonableness framework in specific settings, including Jennifer Gibson, Douglas Martin and Peter A. Singer. They apply it to Canadian health services, drawing on the experience of case studies in a variety of settings(Gibson et al., 2005a), and publish criteria, processes and parameters found to be successful by participants(Gibson et al., 2004). The authors also argue that their experience suggests that a fifth condition of “empowerment” ought to be added to the accountability for reasonableness framework in order to optimise participation and minimise power differences in the priority-setting process(Gibson et al., 2005b).

In recent years, Daniels has become particularly interested in adapting accountability for reasonableness to developing countries where healthcare budgets are especially tight (Daniels, 2008, p. 274-312, 333-355), and in developing a rights-based approach to health (Gruskin and Daniels, 2008) (Daniels, 2008, p. 313-332) that integrates with his theories of priority-setting.

Although “accountability for reasonableness” has been widely cited, and applied in practice in many organisations in several countries (Daniels and Sabin, 2008, p. 149-210), the debate on fairness in resource allocation has continued. It would be oversimplistic to claim that bioethicists now accept that a procedural solution, like the one proposed by Daniels and Sabin, is necessary because no agreement can be found on the numerous ethical questions that arise. Many philosophers, bioethicists, economists, clinicians and others have continued to write about the rights and wrongs of the rationing debate.

The following list illustrates some of the many contentious ethical questions on which authors have continued to publish in recent years:

- Does a “rule of rescue” impose a moral duty to prioritise life-saving when allocating resources? (Cookson et al., 2008) (McKie and Richardson, 2003)
- Is it ethically justifiable to discriminate according to age or life expectancy?(Harris, 2005) (Giordano, 2005)
- Is it ethically justifiable to favour people according to their contribution to society (for example, employees over the unemployed, parents over single people)? (Ram-Tiktin, 2011) (Schneiderman, 2011)
- Is maximising aggregate health benefit a relevant goal in allocating resources? (Broome, 1988) (Cookson and Dolan, 2000)
- Should there be a decent minimum level of healthcare to which everyone should be entitled?(Schneiderman, 2011) (Paris, 2011)
- Who should pay for healthcare? (Bloor, 2008) (Paris, 2011)
- Does justice require that the disadvantaged within society have a greater claim to healthcare resources?(Rosa Dias and Jones, 2007) (Dworkin, 2002)
- Should we give priority to those in greatest health need? (Cookson and Dolan, 2000)
- Ought those whose lifestyle has caused or contributed to their ill-health have a lower priority? (Cappelen and Norheim, 2005) (Brudney, 2007)

Thus many bioethicists and philosophers look beyond a procedural solution like accountability for reasonableness, and continue to offer policy advice on the substantive ethical issues that arise in resource allocation. Richard Ashcroft goes further, arguing that to resort to recommending a procedural solution, rather than an ethical justification grounded in substantive moral principles, “amounts to a serious dereliction of intellectual duty on the part of the bioethics community”.(Ashcroft, 2008, p. 3)

Economists and other social scientists have continued to survey public opinion on difficult ethical issues such as those listed above. (Schwappach, 2002) (Dolan et al., 2005) Cookson and Dolan urge philosophers to develop theories of justice for rationing healthcare that accord more closely with the moral values of the general public.(Cookson and Dolan, 2000, p. 329)

Theory into practice: the international experience

Explicit priority-setting processes, based to a varying degree on “accountability for reasonableness”(Sabik and Lie, 2008), have been deployed in Norway, Denmark, New Zealand, Israel and elsewhere. In some of these countries, policy-makers have sought to engage the public in the process of establishing principles or making decisions about what healthcare should be prioritised (Sabik and Lie, 2008).

In general, countries have favoured fair processes over cost-effectiveness approaches like QALYs. A notable exception is Oregon, USA where a QALY-like approach in the early 1990s led to controversial conclusions (e.g. prioritising pills for headaches for the many over life-saving operations for the few) before it was changed in favour of an approach rooted in public consultation(Sabik and Lie, 2008, p. 5) (Hadorn, 1991)

In the UK, QALYs have been, and still are, used by bodies such as the National Institute for Health and Care Excellence (NICE) to make resource allocation decisions on new medications and other technologies. However, NICE has claimed that it also applies accountability for reasonableness, and this claim has been backed by Daniels and Sabin who cites NICE as an example to which other organisations and countries can aspire.(Daniels and Sabin, 2008, p. 180) However, Michael Schlander has questioned whether NICE puts effectively into practice the conditions necessary for accountability for reasonableness (Schlander, 2006) (Schlander, 2008). Keith Syrett sees judicial review in the courts as a potential mechanism for applying accountability for reasonableness conditions, and thus a potential source of legitimacy for the resource allocation processes of NICE, but concludes that the courtroom is not as yet an appropriate forum for public deliberation and debate about values, especially in the context of judicial review (which is rooted within administrative law) (Syrett, 2008, p. 139-140).

How I chose my research topic

“A Ph.D. thesis should be narrow and deep”.

That was the advice of my brother, a time-served academic, when I first spoke to him about doing a Ph.D. At that time, I knew that I wanted to explore whether there was a way of fairly allocating resources to healthcare that drew on the thinking of both the utility-maximising economists, and the fair-minded bioethicists. Since beginning my Ph.D., I have pursued many questions around this theme, some broad, some narrow, often drafting pieces and then sometimes discarding them, including:

- How do we test whether a universal answer to a difficult ethical question is valid/true/justified?
- Do policy-makers really need universal answers to difficult ethical questions if healthcare systems are for a specific democracy at a specific point in time?
- Could bioethicists offer something more helpful to real-world commissioners than fair procedures for rationing?
- What should we maximise (if anything)?
- What are the purpose(s) of a healthcare system?
- What does a democracy require of a healthcare system?
- How can legitimacy be achieved with a population of millions?
- Who should decide what is fair when allocating the resources of a democracy?

I have gradually refined and restricted the scope of my research throughout the course of my Ph.D., and settled finally on the question of “in a democracy, what should a healthcare system do?”. It could not be described as a narrow research question. However, I will attempt to demonstrate in this thesis that the analysis is of sufficient depth.

Deciding how deep to go

What is evident from the literature is that the disagreement about how to allocate resources to healthcare, and about what a healthcare system should do, is fundamental. There is a lot of debate about many relevant ethical issues like whether people who contribute more to society should be given prioritised access to healthcare; Shepley Orr and Jonathan Wolff provide a useful analysis of many such issues.(Orr et al., 2011) I could attempt to provide an answer to many of those questions, but that would double the length of this thesis – it would be both deep and wide.

Rather than that, I aim to address the fundamental differences in thinking between economists and philosophers, and provide a basic theoretical framework for resource allocation in healthcare, and more specifically what a healthcare system in a democracy should do.

Saying something about a subject that matters

I was drawn to this research question because I think it is of great importance to try to find a good and fair way of allocating resources to healthcare, when budgets are limited, as they invariably are, and when there is not enough money to do all of the possible good things for all of the people. It remains a contentious and topical subject here in the United Kingdom, and is likely to continue to remain contentious and topical here and across the world.

The recent policy move to freeze real spending on NHS funding will increase the attention on, and importance of, fair healthcare rationing. Various reports issued in December 2012, prompted me to write and publish a short article on healthcare rationing, and its relevance to the debate on NHS spending and efficiency savings.(National Audit Office, 2012) (Roberts et al., 2012) (Lawton and Silim, 2012) Paper 1, published in the British Journal of General Practice in July 2013, is entitled “It’s time for rational rationing”, and is reproduced below.

Paper 1: It's time for rational rationing

“Ask me my three main priorities for the NHS, and I tell you: efficiency, efficiency, efficiency”.

No government minister said this, at least not yet. Of course, the government wants quality too, but its war is on spending, and efficiency is its weapon. NHS spending power is set to remain stable at best for the foreseeable future. Unprecedented 4% productivity gains for at least five years are now demanded by the government.(Roberts et al., 2012)

And this is in the face of a relentless increase in the demand for healthcare, throughout modern history, and across the world.(Lawton and Silim, 2012, p. 14-15) December brought news of a rising UK population, and that across the globe we live longer but are sicker, so increasing demand for NHS care seems certain to continue.(Horton, 2012)

December's National Audit Office (NAO) report told us that the NHS in England met its first year target mainly by plucking the low-hanging fruit. The NAO is doubtful about prospects for large year-on-year efficiency savings until 2015, let alone beyond. It also examined the government's only alternative to efficiency savings - “demand management”:(National Audit Office, 2012)

“The aim is to control demand without inappropriately restricting patients' access to care, but the Department has no way of routinely gaining assurance that this is being achieved.”

The NAO is drawing a distinction between appropriate and inappropriate “demand management”. However, like the government, it offers no indication of how to distinguish between the two. This comes as no surprise as neither the government nor the NAO has explained how to judge what healthcare should, and what should not, be provided by the NHS.

“Demand management” is a euphemism for what might more honestly be called healthcare rationing. Almost all academic writers recognise that rationing is inevitable, even in private healthcare systems where treatments are either included or excluded from insurance policies. However, “rationing” is not a word the public likes

to hear. In a society where maximising consumer choice and spending are ideals, it should be no surprise that the word “rationing” has been expunged from politicians’ vocabulary. English courts have placed significant demands on primary care trusts to ensure that they follow processes to justify refusing treatment to individuals, but courts too are wary of getting involved in rationing decisions.(Newdick, 2007)

This culture has prevented the creation of what the BMJ proposed twelve years ago: a Committee for Honest and Open Rationing (Smith, 2000). But now its time has come.

Rationing is not a bad thing, as some have suggested.(Paton, 2010) The roots of the word are “reasonable” and “ratio”. Our reasoning allows us to allocate good and fair ratios of healthcare. It lets us choose the healthcare that will do the most good, and distribute it fairly.

Currently, we have no idea whether we are choosing the healthcare that does the most good with the money available. We have some idea how much different treatments cost. But other than NICE assessments of new medicines and other technology, and the occasional assessment done by commissioners of specific cases like in vitro fertilisation, the NHS does not attempt to assess, and take into account, the relative good done by the thousands of different types of things it does, from hip operations to health checks.(MacAuley, 2012) The NHS attempts to monitor outcomes by healthcare organisations, but not assess the good done by different types of treatment. Collecting that information is a big task, to be done systematically, and for efficiency, to be done once centrally.

However, first there needs to be some measure of the good of healthcare. NICE uses the quality-adjusted life year (QALY), seeking to maximise the years of good quality health from available resources. An important criticism of QALY maximisation is that it is unfair to older people and others with short life expectancy.(Harris, 1991) When resources are limited and we cannot do everything, fairness is relative. Fairness means some healthcare for everyone, and more to those with the strongest claims. The QALY was not designed to be fair but to measure the good of healthcare.

The NHS budget should be used to do as much good as possible, whilst being fair. This is easier said than done. The writing of economist and philosopher John Broome explains how good and fairness can be balanced, as outlined in the RCGP’s Ethical

Commissioning Guidance.(Broome, 1999, Broome, 1994) However, our values differ on what is good and fair, and so the government needs to engage the public openly and honestly in the difficult choices that face us, as done in some other countries.(Sabik and Lie, 2008)

The government cannot continue to pretend that the only thing that the NHS needs is a good dose of efficiency. Efficiency gains are not inexhaustible. As more people seek more, and more expensive, healthcare, we must also decide what healthcare the NHS should provide, and not provide, and to whom. That requires much better information, and more systematic analysis, of the relative good done by healthcare. We should aim to do as much good as possible, whilst being fair. We won't all agree on what is good and fair, so honest and open consultation is needed. You might call that rational rationing.

References

BROOME, J. (1994) Fairness versus doing the most good. The Hastings Center Report, 24, 36-39.

BROOME, J. (1999) Ethics out of Economics, Cambridge: Cambridge University Press.

HARRIS, J. (1991) Unprincipled QALYs: a response to Cubbon. Journal of medical ethics, 17, 185.

HORTON, R. (2012) The Global Burden of Disease Study 2010. The Lancet, 380, 2053 - 2260.

LAWTON, K. & SILIM, A. (2012) Pressures and Priorities: the long-term outlook for Britain's public finances [Online]. Institute for Public Policy Research. Available: http://www.ippr.org/images/media/files/publication/2012/09/pressures-and-priorities_Sep2012_9633.pdf [Accessed 15 Dec 2012].

MACAULEY, D. (2012) The value of conducting periodic health checks. BMJ: British Medical Journal, 345.

NATIONAL AUDIT OFFICE. (2012) Progress in making NHS efficiency savings [Online]. Available: www.nao.org.uk/publications/1213/nhs_efficiency_savings.aspx [Accessed 14 Dec 2012].

NEWDICK, C. (2007) Judicial Review: Low-Priority Treatment and Exceptional Case Review. *Medical law review*, 15, 236.

PATON, C. (2010) We should eschew UK style rationing here too. *BMJ*, 340.

ROBERTS, A., MARSHALL, L. & CHARLESWORTH, A. (2012) A decade of austerity? [Online]. Nuffield Trust. Available: <http://www.nuffieldtrust.org.uk/publications/decade-austerity-funding-pressures-facing-nhs> [Accessed 16 Dec 2012].

SABIK, L. M. & LIE, R. K. (2008) Priority setting in health care: Lessons from the experiences of eight countries. *International Journal for equity in health*, 7, 4.

SMITH, R. (2000) The failings of NICE. *BMJ*, 321, 1363.

Why I chose the context of a modern representative democracy

It should be clear from the literature review above that economists tend to be interested in maximising cost-effectiveness, whereas bioethicists and philosophers are more concerned with what is fair. These different concerns provide one explanation for the very different advice they offer to those engaged in real-world resource allocation. There is no agreement on principles of justice, and the fair processes proposed by philosophers like Norman Daniels are helpful, but provide little guidance to help the policy makers, clinicians and others to make the rationing decisions. The utility-maximising rationale of economists provides practical advice that can be implemented to allocate resources, but little defence against claims of unfairness.

Most writers, both economists and bioethicists, seek universal solutions to what is a universal problem of resource allocation. But should we be seeking a universal answer? Is searching for a universal answer a reason why philosophers and bioethicists conclude that we cannot agree on a rationale for resource allocation? Policymakers are not trying to answer an abstract question of “how should resources be allocated?” or “how should resources be allocated fairly?”. They are trying to identify how they should allocate resources in their own context, and for many policymakers, the context in which decisions are made is that of a modern representative democracy. They are making decisions at a particular time, and for a particular society. They do not require an answer for all time, and for all the world. This is one reason why my research question relates specifically to a modern representative democracy.

Another reason I have chosen to set the context of a modern representative democracy is that it can help in finding an answer to my research question. With so much disagreement about what should be done, and whose values count, the context of a modern representative democracy provides a framework for resolving disagreement, or at least for making decisions. Furthermore, functioning democracies share some underlying principles, such as the notion that every citizen matters, and that elected representatives are accountable to citizens for their decisions, and these undisputed principles are useful when so much else is disputed.

The scope of the thesis is functioning modern representative democracies -the “polyarchies” described by Robert Dahl, and identified by Tatu Vanhanen.(Dahl, 2000, p. 44-61) (Vanhanen, 2003) I do not mean one of the many ideal notions of democracy proposed in the literature.(Barber, 1984) (Bohman, 1997) (Caspary, 2000) (Fishkin and Laslett, 2003) (Fischer, 2009) (Habermas, 1996) (Kim et al., 2009) (Raz, 1988) (Rehg and Bohman, 2002) This choice of scope is deliberate. I am interested in writing about what real world policymakers should do, given the constraints under which they work.

One could also challenge whether democracy is the most ethical way to organise a society. I would suggest that it is, all things considered. History suggests that, compared to the alternatives, democracy brings the best consequences, as Robert Dahl argues. He identifies ten significant benefits of democracy, including the prevention of tyranny.(Dahl, 2000, p. 44-61) An important conclusion of Amartya Sen’s analysis of famines was “the remarkable fact that, in the terrible history of famines in the world, no substantial famine has ever occurred in any independent and democratic country with a relatively free press”(Sen, 1999, p. 7-8). Sen sees democracy being of universal value, having intrinsic importance in human life, and being central to the very idea of justice.(Sen, 1999) (Sen, 2009, p. 324-337)

It is also legitimate to ask whether policy ought to be made by the people that make it, and whether it should be made in the way that it is made in modern representative democracies.

However, such questions are outside the scope of this thesis. Democratic states exist, and policymakers in democratic states across the world have to consider what their healthcare system(s) should do. That is the scope and context for this thesis. I do not attempt to identify in this thesis what a healthcare system should do in a non-democratic state (for example, in theocracies and oligarchies), partly for reasons of expediency, and partly because less is known about policymaking in such societies.

If writers publishing in academic journals seek to influence policy in a particular context (be it a nation state, democracies in general, or some other setting), then they are most likely to succeed if they explicitly make that context part of the terms of reference for their publication. I elaborate this thinking, and argue that all policy

ethics papers that seek to influence policy should have a fixed real-world context, in paper 2 that follows directly below, entitled: “Should policy ethics come in one of two colours: green or white?”. It was published in a Journal of Medical Ethics special issue on infanticide in April 2013.

Paper 2: Should policy ethics come in one of two colours: green or white?

ABSTRACT

When writing about policy, do you think in green or white? If not, I recommend that you do. I suggest that writers and journal editors should explicitly label every policy ethics paper either 'green' or 'white'. A green paper is an unconstrained exploration of a policy question. The controversial "After-Birth Abortion" paper is an example. Had it been labelled as 'green', readers could have understood what Giublini and Minerva explained later: that it was a discussion of philosophical ideas, and not a policy proposal advocating infanticide. A serious policy proposal should be labelled by writer and editor as 'white'. Its purpose should be to influence policy. In order to influence policy, I suggest three essential, and two desirable, characteristics of any white paper. Most importantly, a white paper should be set in the context in which the policy is to be made and applied.

DO ETHICISTS THINK IN GREEN AND WHITE?

In response to the recent controversy and reported outrage about “After-Birth Abortion”(Giubilini and Minerva, 2012a), Alberto Giubilini and Francesca Minerva explained “we are not policy makers, we are philosophers, and we deal with concepts, not with legal policy”. (Giubilini and Minerva, 2012b)

Cited as a defender of infanticide(Savulescu, 2012), John Harris clarified his position in a BMJ Group Blog: (Brassington, 2012a)

“I have always drawn a clear line between what I call “Green Papers” and “White Papers” in ethics. Green papers are intellectual discussions of the issues, white papers are policy proposals. I have never advocated or defended infanticide as a policy proposal.”

Harris had elaborated the distinction between green and white papers in an earlier interview , in relation to his “survival lottery”(Westerman, 2005)

“In England... the government issues green papers and white papers. White papers are proposals for legislation. Green papers are something that is much short of that; green papers are discussion documents putting forward ideas seriously but not necessarily for implementation in legislation. I think of the survival-lottery as a green paper, not as a white paper.”

For Harris, a green paper may include a philosophical defence of an idea, but that is quite different from advocating it as a policy solution. He has suggested to me that “An ethically defensible market in organs”(Harris and Erin, 2002) could be an example of a ‘white paper’, not literally a detailed proposal for government legislation of course, but nevertheless something that is intended to inform or shape policy. It advocates a policy proposal for a regulated market with a single purchaser of organs. Contrast that paper with his survival lottery. The survival lottery is a philosophical discussion of acts and omissions and the sanctity of life, exemplified through a scenario in which a living person, chosen by lottery, would be sacrificed, broken down into her spare parts, and allocated to those needing organs, resulting in net life-saving. He mounts a philosophical defence for that imaginary lottery, but he is not

seriously encouraging governments to begin slaughtering and harvesting people. It is a green paper.

Do all philosophers and ethicists write about policy questions in either green or white? If so, then it is not evident in their publications, just as it is not explicitly stated in articles by Harris. Nevertheless, perhaps all ethics papers on matters of public policy should be classified as either “discussion green” or “proposal white”. I pursue that idea in this article.

I am concerned only with articles that relate to a public policy question. For example, a recent essay from Harris discusses what it’s like to be good.(Harris, 2012) It poses a philosophical question, not a policy question (although of course good may have a bearing on policy). Few would seek to prevent, or constrain, Harris from saying whatever he believes it is to be good. His article is outside the scope of this paper.

IS THERE A NEED FOR POLICY GREEN PAPERS?

However, infanticide and organ donation are different: both matters of public policy, addressed by legislation across the world. Arguably, “After-Birth Abortion” caused harm in the form of public distress (Biegler, 2012), and by portraying ethicists as out of touch with reality, it may have damaged the reputation of academic ethics and ethicists.(Curtis, 2012) If such harm could be caused, should ethicists write papers on policy questions like infanticide or organ donation that are not serious proposals? Why write about a policy question other than to make a serious contribution to the policy debate, especially if such an article has the potential to cause harm? Do such policy green papers have any place in the ethics literature? If, as Derek Parfit says, “the fundamental question of ethics is: ‘what should I, ought I, or must I do?’”(Parfit, 2011, p. 415), then why would ethicists write articles on public policy questions that do not address the question of what policymakers should, ought, or must do? Do papers like “After-Birth Abortion” help to answer the policy question about what should, ought, or must be done about abortion or infanticide?

I would expect Giubilini and Minerva would answer that their paper can help, for example by highlighting the difficulty in making a clear moral distinction between a foetus and a new-born child. This is surely a valid test of a green paper on policy, or indeed of any ethics publication: whether it contributes something of relevance to thinking on the subject. As long as it does, then in the interests of academic freedom and better policy development, there should be a place for a green paper where an ethicist can write freely on a policy question. Some writers may decide to take account of the potential harms associated with publishing, weighing these against the benefits of publishing, and as a result constraining what they write, even in green papers. But that is a matter for the writer: marking a paper as ‘green’ would alert readers that the piece explores, but does not necessarily propose a solution to, a policy question. It would make clear to lay readers that the author does not propose some potentially shocking policy like infanticide (although limited infanticide could be, and indeed has been, put forward as a serious policy proposal).

Some readers will not notice the green label, or fail to understand it (even if clearly explained by the journal), so controversy and potential harm could still ensue from green papers on policy questions. Nevertheless, by marking the paper as ‘green’ and

by explaining the meaning of ‘green’ to readers, both authors and academic journal editors would be doing what they could to set the context for the published article, and reducing the risk of harm from an article like ‘After-Birth Abortion’. They would be making clear their intentions to other academics, to the public, and to policymakers, who could then choose whether, and if so in what light, to read the paper.

Green papers may still have an important bearing on policy thinking, especially those containing fundamental philosophical argument. For example, ‘Animal Liberation’ (Singer, 1995) might not be considered a policy proposal, but few would doubt that it has had a significant influence on the public, and public policymaking, in many countries. Pure research in any field can lead to (often unforeseen) real-world applications of significant benefit.

So there is a legitimate place for policy green papers, explicitly labelled as green.

IS THERE A NEED FOR POLICY WHITE PAPERS?

Few contributors to, or readers of, this journal would doubt that philosophy and ethics can make an important contribution to policymaking. If applied effectively, philosophical thinking can inform and improve policy, leading to better, and more just, laws and policies, thereby benefiting many lives. Some writers argue that, rather than social sciences like economics, it is normative ethics based on philosophical principles that should drive policy:

“Contrary to a popular misconception, economics alone cannot decide what policy changes we should make. Economics, at its best, can tell us the effects of pursuing different policies; it cannot, without the guidance of normative principles, recommend which policy to pursue.”(Lamont and Favor, 2007)

So philosophical thinking has an important potential contribution to make to policymaking. But how can academic ethicists contribute effectively? Good policy is not made by simply applying normative principles to a given problem. Indeed, some writers argue that good policy is not grown from philosophical principles or theories.(Arras, 2010) One means by which academic ethicists can contribute to the policymaking process is by writing articles that directly address a policy question in a peer-reviewed journal: what Harris describes as a white paper. To be successful, a white paper should be designed to directly influence policy and the policymaking process.

Those shaping and making policy (for example, government, public officials, and the public) do not necessarily look to academic journals for arguments. Few papers in academic journals, however well-structured and written, have much influence on policy. Policymakers typically have insufficient time to carry out a literature review, and are more likely to be drawn to journals widely-read by the public, than those read primarily by a small target audience of academics. Nevertheless, if serious policy proposals were all classified as white papers, and had the characteristics that policymakers sought in a serious policy proposal, then those that shape policy might be more likely to look for, and more likely to find, white papers on a given policy topic. This is one reason to distinguish white papers from green.

Thus, there is a need for policy white papers, explicitly labeled as white. They have a clear purpose: to influence policy. To achieve that purpose, I propose a number of characteristics that all white papers should share.

WHAT WOULD A PAPER NEED TO BE WHITE?

In his introduction to public policymaking, James Anderson paints a picture of a policy environment: (Anderson, 2010, p. 29)

“Policymaking is “political”; it involves “politics”. That is, its features include conflict, negotiation, the exercise of power, bargaining and compromise – and such nefarious practices as deception and bribery. There is no good reason to resist or disparage this conclusion...quite reasonable people can disagree on policy issues because they have differing interests, values, and affiliations. Politics is the way a democratic society resolves such differences.”

How different this sounds to academic scholarship, and to philosophical thinking in particular. It bears little resemblance to the process outlined by Lamont and Favor, where policy is made from normative principles. It aligns more closely to Dan Brock’s experience as a philosopher in a policy world:(Brock, 1987, p. 787)

“...those who directly participate in the formation of public policy would be irresponsible if they did not focus their concern on how their actions will affect policy and how that policy will in turn affect people. The virtues of academic research and scholarship that consist in an unconstrained search for truth, whatever the consequences, reflect not only the different goals of scholarly work but also the fact that the effects of the scholarly endeavor on the public are less direct, and are mediated more by other institutions and events, than are those of the public policy process. When philosophers move into the policy domain, they must shift their primary commitment from knowledge and truth to the policy consequences of what they do. And if they are not prepared to do this, why did they enter the policy domain? What are they doing there?”

These observations from Anderson and Brock suggest that contributing to a policy debate is very different from philosophical argument in pursuit of truth. As Soren Holm said, “attempting to reach a legitimate public policy in a morally pluralistic liberal democracy is not a social activity of the same kind as trying to win a philosophical argument”.(Holm, 2005, p. 1) If a policy white paper is to be effective,

it has to influence policy and policymaking in a particular context. To achieve this, I propose three essential, and two desirable, requirements of a white paper.

Essential characteristics

1. Has an explicit target policy context

A white paper must be intended by the writer to be a serious policy proposal for one or more particular policy 'jurisdictions'. So it might be targeted at a policy body like England's National Institute for Health and Clinical Excellence, the state of Mississippi, a nation state like Australia, a group of nation states like the European Union, or even something less tangible like modern representative democracies, or biobank organisations around the world. Stating explicitly this policy context would help readers understand the scope of the proposal.

2. Is constrained by the policy question and context

The policy context should be fixed, including its existing laws, institutions, history, culture etc. This is no retreat into relativism, but rather recognition that the context for policy is given. The question is always: 'from where we are now, what should be done?' It is not: 'in an ideal world, where everything could be changed, what should be done?' The context for most policy ethics writers is a particular democracy, or democracies in general. In modern representative democracies (or polyarchies), (Dahl, 1971a) the policymaking process is largely determined, and this can provide an important and useful constraint when assessing a policy question. So, in resource allocation policy, where academic writers cannot agree on ethical principles, (Daniels and Sabin, 2008, p. 2) and cannot agree on an ethical decision-making process, (Rid, 2009) the constraint of democratic context can assist in resolving debates. The laws and institutions of most modern democracies largely determine decision-making responsibilities and processes, and so proposing a policy where resource allocation priorities are set by public surveys, or exclusively by deliberations amongst citizens, is likely to be irrelevant. I am not suggesting that ethicists should never criticise democratic institutions and processes, but that it is something to be done in a separate paper, and not when making specific policy proposals about some other matter of ethical concern like resource allocation. Specific policy proposals should not rely on arguments that demand a different policymaking context.

Committees set up to examine policy are given externally-imposed terms of reference. They work within that fixed context. Ethicists publishing policy proposals are given no such constraints. I am proposing that, if they seek to influence policy, writers should impose their own terms of reference.

3. Identifies consequences

As Brock argues, policymakers will always be concerned with consequences. In a democracy, they have a responsibility to consider the impact that policies will have on different people, the economy and the environment. Whether or not a writer is a consequentialist, if she wishes to influence policy, she must consider the impact of a policy proposal and its alternatives.

Desirable Characteristics

1. Recognises arguments from outside philosophy and ethics

Philosophers and ethicists are particularly prone to developing philosophical arguments to reach interesting but extreme positions on policy questions (like infanticide). To a policymaker unused to this practice, it appears, at best, out of touch and irrelevant (which is how “After-birth abortion” appeared to some commentators).(Curtis, 2012) Jonathan Wolff explains why this problem may arise:

"In science and social science research a researcher makes his or her name by presenting a view that others find attractive or useful and build upon. By and large the situation in philosophy is the reverse. Philosophers become famous for arguing for a view that is highly surprising even to the point of being irritating, but is also resistant to easy refutation. The more paradoxical, or further from common sense, the better. Philosophy thrives on disagreement, and there is no pressure to come to an agreement. Indeed agreement is unhelpful as it cuts discussion short. In public policy, however, a report must be written, or a recommendation made, or a law or policy drafted, just as in science and social science a practical outcome is sought.”(Wolff, 2011, p. 3)

In the context of public policy, arguments are more likely to be influential if they recognise other perspectives and attract consensus.

Almost all policy issues of concern to ethicists are also policy concerns for other disciplines; for example, doctors also write articles on abortion policy. Policymakers are interested in experts from different disciplines, and in the views of the general public. They also listen to, and address, arguments in the public domain from non-academics such as politicians and media commentators. They do not weigh up arguments in abstract, but must decide which arguments to trust. (Hobson-West, 2010, p. 49) If policy ethics white papers recognise and discuss the arguments prevalent in the policy debate, and better still draw on, or synthesise, arguments from other disciplines, they are more likely to persuade those that shape and make policy.

2. Is written for a wide audience

It is obvious that white papers are more likely to be effective if they are written in a way that is understandable, and of interest, to policymakers, journalists, commentators, experts, and lay readers. The perspective of the policymaker, and their role of listening to, if not satisfying, many diverse interest groups, is particularly important.

In practice, which papers would be white?

In practice, published policy ethics papers range from the deepest green to the brightest white; many meet some, but not all, of the above white paper requirements. Consider three articles that Harris sees as white papers.

‘An Ethically Defensible Market for Organs’ (Harris and Erin, 2002) ticks all the boxes: it has an explicit reference to the intended policy context (nation states, or a bloc of states); it addresses a particular policy question; it identifies consequences (and safeguards against bad consequences); it considers arguments from economics and the writing is accessible to a wide audience. It pays little attention to the constraints of the policy context, but the policy context is intentionally broad (any nation state), and it does not rely on arguments or claims that clash with existing laws or institutions beyond the domain of organ donation.

Another article has a clear policy objective: that cadaver organs should be automatically available. (Harris, 2003) It is aimed explicitly at England, and perhaps implicitly at other policy contexts. This policy would require a change in law (in

England at least) which Harris recognises. He considers some of the consequences, but not how the public might respond to such a change in law, which he might argue is a part of the political process and not his concern. I would argue that if it is to influence policy, it has to consider the context that confronts the policymaker. The public reaction to the Alder Hey Hospital scandal, where organs and tissues from some dead babies were stored without parental consent, suggests that there would have been almost universal outcry in England against such a change in the law. All of the main political parties in the United Kingdom, national newspapers, and the British Medical Association, all spoke out against the “shocking” and “unforgivable” practice of storing organs and tissues without explicit consent from the family.(BBC News, 2011) (British Medical Association, 2001) Therefore, at the time the article was published, two years after the inquiry, the prospect of any imminent change in the law to enable cadaver organs to be automatically available was negligible, if not nil. The article does not make any reference to this policy context. For a policy ethics green paper, it is entirely reasonable to set out strong ethical arguments in support of using cadaver organs without consent, but given that the article did not recognise or address the circumstances in England at the time, this could not be considered a serious policy proposal, and does not meet the requirements I propose above for a white paper.

The third paper reaches conclusions such as: “I believe it is ethical to prevent the births of people with disabilities because it is right to prevent needless harm”.(Harris, 2001, p. 21) They are ethical conclusions, not policy proposals. So it does not meet the essential criteria that I propose here for white papers.

These conclusions on his papers are not surprising; the characteristics I propose are not necessarily the same as those that Harris has in mind for a white paper.

Conclusions

I conclude that John Harris raised an important distinction, and that policy ethics papers should come in one of two colours: green or white. Making this distinction explicit in published policy ethics papers would make clear to readers that green papers, like the recent controversial “After-Birth Abortion”, are not serious policy proposals, but rather present an unconstrained exploration of ideas. Editor and writer would be setting the context in which the article should be read. Explicitly identifying

white papers will help those interested in finding and reading relevant policy proposals and arguments, including policymakers. I see no disbenefits to an explicit bi-colour distinction, nor any reason to have a third colour of ethics policy paper; others may. Rather than constraining writers, I propose that they are explicit about their purposes.

As serious policy proposals, distinct from green papers, white papers should have a clear purpose and distinguishing characteristics. I argue that the purpose of a white paper should be to influence policy, and I suggest some properties that any white paper should possess if it is to influence policy.

Policy is about what someone, or some people, somewhere, should do. It is about asking: ‘given where we are, what should we do?’. Ethics is concerned with what we ought, should or must, do, and so has an important contribution to make to policy. To influence a particular policy question, ethicists are most likely to succeed by beginning from where people are, and not from where people ought to be. They should recognise and accept the context in which policy is made. For some ethicists, writing a policy white paper may mean shifting where they draw the ‘ought/is distinction’.

REFERENCES

- ANDERSON, J. E. (2010) Public policymaking: An introduction, Belmont: Wadsworth Pub Co.
- ARRAS, J. (2010) Theory and Bioethics [Online]. Available: <http://plato.stanford.edu/archives/sum2010/entries/theory-bioethics/> [Accessed 8 Feb 2012].
- BBC NEWS. (2011) The Alder Hey report [Online]. Available: <http://news.bbc.co.uk/1/hi/health/1144774.stm> [Accessed 30 Aug 2012].
- BIEGLER, P. (2012) Symposium on 'after-birth abortion': Public distress as a moral consideration in after-birth abortion. *Monash Bioethics Review*, 30, 48-51.
- BRASSINGTON, I. (2012) John Harris Clarifies his Position on Infanticide [Online]. Available: <http://blogs.bmj.com/medical-ethics/2012/02/29/john-harris-clarifies-his-position-on-infanticide/> [Accessed 9 Aug 2012].
- BRITISH MEDICAL ASSOCIATION. (2001) BMA response to Alder Hey Inquiry Report [Online]. Available: <http://web.bma.org.uk/pressrel.nsf/wlu/SGOY-4TGMER?OpenDocument&vw=wfmms> [Accessed 31 Aug 2012].
- BROCK, D. W. (1987) Truth or consequences: The role of philosophers in policy-making. *Ethics*, 97, 786-791.
- CURTIS, M. C. (2012) 'After-birth abortion': Can they be serious? [Online]. Washington Post. Available: http://www.washingtonpost.com/blogs/she-the-people/post/after-birth-abortion-can-they-be-serious/2012/03/03/gIQADgiOsR_blog.html [Accessed 20 August 2012].
- DAHL, R. A. (1971) *Polyarchy: participation and opposition*, Newhaven: Yale Univ Pr.
- DANIELS, N. & SABIN, J. E. (2008) *Setting Limits Fairly - Learning to share resources for health*, New York: Oxford University Press.

GIUBILINI, A. & MINERVA, F. (2012a) After-birth abortion: why should the baby live? *Journal of medical ethics*.

GIUBILINI, A. & MINERVA, F. (2012b) An Open Letter from Giubilini and Minerva [Online]. Available: <http://blogs.bmj.com/medical-ethics/2012/03/02/an-open-letter-from-giubilini-and-minerva/> [Accessed 20 August 2012].

HARRIS, J. (2001) One principle and three fallacies of disability studies. *Journal of medical ethics*, 27, 383-387.

HARRIS, J. (2003) Organ procurement: dead interests, living needs. *Journal of medical ethics*, 29, 130-134.

HARRIS, J. (2012) What It's Like to Be Good. *Cambridge Quarterly of Healthcare Ethics*, 1, 1-13.

HARRIS, J. & ERIN, C. (2002) An ethically defensible market in organs. *BMJ*, 325, 114-115.

HOBSON-WEST, P. (2010) The role of 'public opinion' in the UK animal research debate. *Journal of Medical Ethics*, 36, 46-49.

HOLM, S. (2005) Bioethics down under - medical ethics engages with political philosophy. *Journal of Medical Ethics*, 31, 1.

LAMONT, J. & FAVOR, C. (2007) Distributive justice [Online]. Stanford University. Available: <http://www.science.uva.nl/~seop/archives/fall2008/entries/justice-distributive/index.html#Strict> [Accessed 28 Nov 2012].

PARFIT, D. (2011) *On what matters*, Oxford: Oxford Univ Pr.

RID, A. (2009) Justice and procedure: how does "accountability for reasonableness" result in fair limit-setting decisions? *Journal of Medical Ethics*, 35, 12.

SAVULESCU, J. (2012) "Liberals Are Disgusting": In Defence of the Publication of "After-Birth Abortion" [Online]. Available: <http://blogs.bmj.com/medical-ethics/2012/02/28/liberals-are-disgusting-in-defence-of-the-publication-of-after-birth-abortion/> [Accessed 20 August 2012].

SINGER, P. (1995) *Animal liberation*: London: Random House.

WESTERMAN, P. (2005) A conversation with John Harris about bioethics [Online].

Available:

http://www.paulinewesterman.nl/documenten/THE_MORALIST_HARRIS.pdf

[Accessed 9 Aug 2012].

WOLFF, J. (2011) *Ethics and Public Policy: A Philosophical Inquiry*, London:

Routledge.

3. Why it is a question of public policy

What a healthcare system in a democracy should do is a public policy question

An assumption that underpins much of the argument in this thesis is that the question of what a healthcare system in a democracy should do is a public policy question for modern representative democracies. It is something that I envisage being resolved ultimately by public policymakers who are accountable to citizens in a democracy. I do not claim that *all* healthcare systems are, or even should be, operated or funded publicly. The question of what privately-funded and privately-owned healthcare systems should do is at least in part a question for private policymakers, such as employees of private insurance companies who determine what is covered, and what is not covered, under the company's healthcare insurance policies. However, I argue that even these companies should (and invariably do) operate within a regulatory framework established by public policymakers. Furthermore, private insurance companies may look to the decisions made by public policymakers when deciding what treatment should be in and out of coverage.

I am making an empirical and a normative claim. Firstly, in most functioning democracies around the world, at least half of the healthcare provided is publicly funded, and therefore what the healthcare systems providing that healthcare should do *is* a matter of public policy. Even in the USA, health insurance is a heavily regulated industry, and about half of all healthcare provided is publicly funded. (Jost and Hall, 2005) (Gostin, 2001, p. 5-11) (OECD, 2011, p. 157) (Woolhandler and Himmelstein, 2002, p. 88) Secondly, I am arguing that the state *should* have an important role in determining what a healthcare system should do. I make, and back up, these claims in paper 3, entitled "What has the state got to do with healthcare?". The paper, which has been accepted by the Manchester Review of Law, Crime and Ethics, and is due to be published in its 2013 issue, follows directly below.

Paper 3: What has the state got to do with healthcare?

Abstract

How should healthcare resources be allocated? Who should pay for it? What is the role of the state? There is little agreement on these questions, and little sign of agreement because differences are fundamental, and often inter-disciplinary. Some writers, typically philosophers and ethicists, begin with a human right to health or healthcare, whilst some pursue equality of capability, or procedural justice. Economists tend to look to maximise health yield from scarce resources. These analyses often rely heavily on state involvement, and state funding. Many libertarians would reject these claims, and seek to minimise the involvement of the state, arguing that, as far as possible, individuals should be responsible for choosing, and paying for, the healthcare cover that they want.

In this article, I draw on thinking from several academic disciplines, and consider what the minimum involvement of the state should be, from the perspective of an ethical libertarian seeking to minimise state involvement and maximise individual autonomy and responsibility. The story that follows is set in a democracy (but no particular democracy), and suggests that even from this position there is much for the state to do, including:

- funding basic healthcare, and many public health activities;
- subsidising (or making the market cross-subsidise) insurance cover for more-than-basic-healthcare for people who would otherwise, through no fault of their own, have high-cost insurance premiums; and
- making law and policy on how decisions about who is entitled to healthcare are made, providing procedural justice, and creating a regulatory framework for governing providers of healthcare products and services.

Beginning

“Great news, John. I have organised a big campaign speech entitled: ‘what has the state got to do with healthcare?’. The TV crews and national newspapers will all be there.”

“Good work, Barney.” The candidate paused. “And what is my policy on healthcare, Barney?”

“Our usual message, John. It’s ‘let’s get government out of healthcare, because we know what’s best for ourselves and our families’. We want consumer-driven healthcare – we each buy the health insurance we want. (Herzlinger, 2004) It’s a fashionable message, in keeping with our other policies, and our supporters will love it. You could add in a bit of nudge policy (Sunstein and Thaler, 2003b) to encourage people to do the sensible thing – but be careful we are not accused of telling people that government knows best.”

The candidate was smart enough to know that the market for healthcare was not as straightforward as the market for soap. “OK, let me talk to a few people.”

But Barney knew what he was thinking. “Not those academics again, John. If you must talk to them, I’m coming along”.

John welcomed them as they arrived: the economist, the political philosopher, the clinician, the bioethicist, and the historian. It was one thing to persuade those who already distrusted the state, and quite another to persuade other more thoughtful and sceptical voters. These academics made him think more deeply about difficult policy questions. He also consulted them because he cared about doing the right thing.

“Ladies, thank you for coming to meet me. We are a refreshingly pluralist democracy, full of people who express freely their differing opinions. But many people share my beliefs: that government is much too big, that each of us is responsible for choosing and finding our own way in the world and making a success of our own life. (Dworkin, 2006, p. 17-21) What counts as a good life for me might not be a good life for you. That adds to the richness and diversity of our society. We must respect others, let them make their choices – good and bad - and live with the results. To interfere with

those freedoms more than we must is wrong; it is unethical. I recognise that we do not all have the same opportunities, and we may be able to do something to level the playing field, especially when people are young, but we cannot legislate away good and bad luck. In general, we should step back and respect the autonomy of individuals.

I recognise that others have alternative ethical convictions. They talk of rights to healthcare, and of equality of one thing or another. We might disagree, but I must listen to their arguments. I am a politician who looks to govern a pluralist democratic state, so I must look to govern those who agree with me and those who do not. I must lay out my thinking, and let people judge me on my values and my policies. If they vote for me, they must know what they are getting.

Few things matter more to people than their own health. So when it comes to healthcare, I want people to make their own choices, according to their own priorities, and for the state to interfere as little as possible. But what is as little as possible? When it comes to healthcare, what are the minimum responsibilities of a state? I know that some libertarians see no role for the state in healthcare (Nozick, 1974, p. 297-334), but I am open to persuasion. Let us leave what we can to the market, but where are we morally bound to intervene? I have brought you here today to ask you these questions.

So let us begin from the position that the state has got nothing to do with healthcare, and identify the minimum that it must do in any decent democratic society”.

Middle

Candidate: “Perhaps we could begin with the general responsibilities of the state.”

Political philosopher: Well, of course there is much disagreement amongst scholars, especially about the characteristics and responsibilities of an ideal democracy (Barber, 1984, Dahl, 2000, Dworkin, 2006). But almost all political philosophers and political scientists would agree that a government in a working democracy (Dahl, 1971b, p. 63-89) has a responsibility amongst other things to:

- protect the safety of the people, an idea dating back to Thomas Hobbes...”;(Hobbes, 1987, p. 128)
- make law to make clear what is right and wrong, and interpret and apply that law, resolving disputes in the courts, as argued by John Locke;(Locke, 2002, p. 57-8)
- when making law and policy, show equal concern for the lives of everyone, even though it is inevitable that laws and policies will affect different people differently;(Dworkin, 2006, p. 144-5)
- listen, respect, and be responsive to, the preferences of citizens(Dahl, 1971a, p. 1), although most would agree that that this does not mean that politicians must always follow the will of the majority.

Candidate: OK, but let’s not forget John Stuart Mill who said that the only justification for the state interfering with our liberty is to prevent harm to others(Mill, 1989). But do the responsibilities you mention mean that the State has to get involved in the healthcare of individuals?

Political philosopher: When we think about the state’s role of protecting safety, we tend to think about national defence, and perhaps the police service. But many of us today, face a greater threat from by viruses, diseases and accidents(Erin and Harris, 1993, p. page 166). Often such threats have been deadly and come from foreign shores.(Chen et al., 1999) How can the state protect our safety without addressing these threats?

Candidate: I agree we all want to be protected from danger. But I want people to take responsibility for their own health and their own lives. It is important that they insure themselves against threats to their health. Markets work; this we know. Let us leave the state out of this, and let the market insure citizens against these threats.

Economist:

“Ideally, the best way to run the economy is to let individuals work, play, and consume what they want without restrictions. The interaction of supply and demand in the market naturally leads to equilibrium in which marginal benefits equal marginal costs. The prices that arise from the exchange in the

market direct individuals to work at jobs where their skills provide the most value to society, to find efficient means of production, to limit the consumption of goods that are most scarce, and to save and invest for the future. Under ideal conditions, the entire economy functions without any central control or direction from the government. However, perfect market conditions...do not occur in the real world. Imperfect market conditions justify government intervention to protect the public's health...A "public good" is a good or service that does not lend itself to market allocation because it costs nothing for an additional individual to enjoy its benefits, and it is generally difficult or impossible to exclude individuals from consuming it. The institutional and technical capacity to respond to disease outbreaks and prevention research are examples of public goods. A fundamental problem with public goods is the difficulty of motivating people to pay for them."(Carande-Kulis et al., 2007, p. 227)

Political philosopher: That suggests that, in order to protect the safety of the people, the government has to intervene, and pay for "public goods" like preventing and controlling epidemics. Otherwise viruses and diseases will develop and spread. These activities cannot be left to the market.

Barney: Why? Let us make it a criminal offence to fail to buy healthcare insurance to pay for this protection.

Political philosopher: That would hardly signal individual autonomy and small government. It would be the state coercing the individual to pay for something the state wants the citizen to have.

Barney: The state need not fund everyone. Those who can afford it can pay for themselves.

Economist: Means testing will mean that some will buy cover and some will not. Cover will not be universal. Public health works by protecting whole populations. Some public health activities economists would call public goods, and some, like vaccination against infectious disease, we would call "merit goods" where there are "externalities" - benefits or costs to others from our economic choices. When I am vaccinated, you benefit from my protection against disease. Externalities prevent

markets from working efficiently where consumers or producers are not compensated for these effects. They can apply to individual healthcare and public health. For example, choosing to see the doctor when I am ill is likely to have a positive impact on other people, such as the people I meet (who otherwise might become infected), my employer who needs me at work, and the economy as a whole. The knock-on benefits of my doctor's visit are not reflected in market prices, and as a result some people will be deterred from visiting the doctor even though the overall benefits justify a visit.

Candidate: I accept that the state has to fund, or at least subsidise, public health activities like vaccination where the population has to be protected so that each individual is protected. Advocates of consumer-driven healthcare like John Goodman also accept your arguments about externalities:

“We don't want a parent to choose not to have her child vaccinated, or an at-risk expectant mother to avoid prenatal care, or a heart patient to eschew aspirin or beta blockers. The reason: there is overwhelming evidence that the social benefits of the care exceed the social cost. Yet instances where we can be absolutely sure that we know which alternative is the right choice are rarer than one might suppose. At the other extreme, there are literally thousands of cases where only the patient can make the right choice.”(Goodman, 2006, p. 4)

He goes on to argue that whether to spend an extra \$800 on a brand-name drug is a decision that can only be made by an individual. Drugs affect different people differently, and different people have different attitudes toward risk. Only when individuals spend their own money will they reveal their preferences. So one person cannot make an informed choice for another.

Lawyer: That of course ignores children and adults lacking the capacity to make decisions for themselves. The state must make law to say who can make decisions on their behalf to protect their interests. Also, when two identical patients are offered two different levels of care, one of superior quality to the other, this could raise some difficult legal questions. For instance, is it acceptable to offer “sub-standard” care to one of the patients? Could that be construed as negligence?(Hall, 2006, p. 176-8)

Clinician: Furthermore, the patients will not know in advance how the drug will affect him. And how well will she know her preferences for chemotherapy treatment if she has never experienced it before? When I buy many goods, like eggs for instance, I know my preferences, but that does not hold true for much healthcare. Thus the individual patient is not especially well-placed to judge either risk or her own preferences.

Economist: Research does suggest that human beings tend to be poor at making decisions that involve the assessment of risk(Tversky and Kahneman, 1981), and indeed at making rational choices in general(Ariely, 2009). Our choices are shaped by how problems are framed.

Candidate: Whatever the evidence of our failings as rational actors, you are not going to convince me that anyone other than me is best-placed to make the important choices that affect my life. However, I accept that the State has a role to play where there are significant wider social benefits from healthcare. But other than that, the consumer buys insurance to protect her own health. Agreed?

Economist: There are difficulties with insurance. Economists know that many people would rather consume today, rather than insure for tomorrow. Younger people, especially those on lower wages, are likely to allocate an insufficient portion of their wages to future healthcare.(Hall, 1994, p. 66) So they are likely to under-insure. These same time-related preferences lead people to consume too much food today, despite the negative impact that this will have on their future health and life expectancy.

Barney: This is where individuals have to take responsibility for their actions. We have options, we make choices, and we must live with the consequences. The state is not there to bail us out for our dumb choices.

Lawyer: But we can at least encourage people to avoid bad choices so that they won't need bailing out. Responsible governments around the world make laws and policies that create incentives for good behaviours, and disincentives for unhealthy or unsafe behaviours (like smoking).

Bioethicist: Yes, the state can be seen as a steward, with a responsibility to guide people towards good choices, and to reduce health inequalities.(Nuffield Council on Bioethics, 2007, p. 18-19)

Barney: The state is not a shepherd guiding us through life!

Candidate: I accept there is a role even for a libertarian government to “nudge” people towards sensible choices(Sunstein and Thaler, 2003a), but not to tell people what to do.

Bioethicist: An ethical government has to do more than nudge people. It has to be there to bail out some people even when they have made bad choices.

Barney: Oh save me from bleeding heart liberals. The state is not a big cash cow to be milked dry by people who make dumb choices and get themselves in a fix.

Bioethicist: We know there will be people who will not buy healthcare insurance. Imagine Al. He is an alcoholic, homeless, and with very little money. Drunk one night, he crosses the road in front of a hospital and is hit by a passing car. He requires basic medical care to clean his wounds and stem the profuse bleeding from his leg. With no money, and no insurance, should he be left to die?

Barney: Al should have stayed off the booze and off the streets. No one forced him to become an alcoholic. He must live or die with the consequences of his decisions.

Bioethicist: How can we know it was Al’s fault that he became an alcoholic? Maybe he had a tendency in his genes. Maybe he was abused as a child and ran away from home. Maybe he failed to get a job after years of trying. Maybe he became depressed because his wife left him and took the kids. How are we in practice to sort out if Al is to blame? And even if he is to blame, are we all to stand by and watch him die? Could we ever call that ethical behaviour? Many would argue there is a moral rule of rescue(McKie and Richardson, 2003) that means we cannot walk on by.

Political philosopher: Whether or not we accept the moral rule of rescue, we are compassionate beings. As Jean-Jacques Rousseau said, “it is this compassion that hurries us without reflection to the relief of those who are in distress” [Discourse on the Origin of Inequality, 76]. He maintained we are naturally sympathetic to others,

and are upset by their suffering. Mencius, an early scholar from the Confucian tradition, argued that humans find suffering in others unbearable, are naturally benevolent, and that benevolence is the strongest motive to moral action.(Lau, 2003, p. xviii - xix)

Barney: So what? Why should we listen to some long-dead Frenchmen and a prehistoric Chinese guy?

Clinician: Because modern science has proven Mencius and Rousseau to be right. Brain research tells us that when a human detects pain in another person, it triggers a response in the observer's brain in the same area of brain circuitry as that of the sufferer – a “compassionate” response. Not only does an observer's brain “mirror” activity in that of the pain sufferer, but his or her empathy varies directly with pain intensity(Saarela et al., 2007).

Candidate: I accept that people are compassionate. But why not leave it to individual compassion? Let each of us choose to give to charities that can help AI.

Barney: Yeah, leave the state out of it.

Political philosopher: We have said already we cannot reliably judge who is to blame for a person's ill-health. If we left it to charity, the state would be failing to protect not only AI's safety, but also the safety of children who suffer harm and disease through no fault of their own, and the disabled or genetically unfortunate who are burdened with chronic ill-health, disability or loss of life. Like AI, they too may have great need but may have little money. The duty to protect safety cannot be abdicated, and left to individual philanthropy. Why should I abide by the coercive laws of the state when it does not protect me? Furthermore, the scale of the philanthropy you envisage would be considerable. Individual autonomy comes with responsibility, and that should not be shirked. The compassionate and generous should not have to pay for AI because the selfish would like to see him saved but would prefer to keep their money for themselves. Each must pay their fair share to the state, so the state can be fair.

Candidate: Remember that the state has already stepped in to protect AI's safety with traffic laws, speeding fines, road signs and so on. There are limits to the state's responsibilities. Nevertheless, I accept the state should fund these catastrophic cases. I

am not persuaded that it is our moral duty, but I am persuaded that my voters are compassionate. But state funding should cover the very minimum necessary to prevent serious harm and protect human life, and only for those cases where basic care brings great benefit. In these cases, our compassion is strong. A clear line needs to be defined and drawn: the state can afford basic care for AI, but coercive state taxes should not be imposed in order to pay for AI to have expensive cancer drugs. Beyond basic care, it is for each of us to decide how we spend our money. We might choose to spend less on houses and hobbies, so that we can spend more on healthcare. No one else can make those trade-offs for us. It would be wrong for the state to prevent some of us from choosing better healthcare.(Engelhardt, 1994) Each chooses, and pays for, his own healthcare insurance cover.

Bioethicist: That sounds fair on libertarian grounds. But pause a moment. You believe in equal opportunities for all - let each of us be given the chances and then make our own luck. So then what do you say to those who are dealt the poor cards: born to a deprived family with a poor diet, or with damaged genes, or with a chronic illness? That makes them unlucky enough to expect poor health, and their ability to earn may be diminished. Are we to add to that by making them pay double or triple the health insurance premiums of the rest of us? We said earlier that when making law and policy, the state has a responsibility to show equal concern for everyone. Equal concern must mean that the state makes the healthy subsidise the unhealthy.

Barney: The insurance companies can look after that if they want. It's not for the state to interfere.

Economist: Unless the state intervenes, the market will charge according to risk. So the unhealthy will pay handsomely. If an individual firm offered to cross-subsidise as you suggest, a rational healthy consumer will simply move to another company with cheaper premiums. Furthermore, if obliged to cross-subsidise by law, and fix prices in favour of one or more groups of consumers, the market will not function efficiently, because the market would not be setting prices according to cost.

Historian: These cross-subsidies may not be efficient economically, but they have been a common way that healthcare has been funded in the past. They have occurred

not only because different people are blessed or burdened with different health characteristics, but because not everyone has the same ability to pay.

“Under ancient Roman law and in Renaissance England, physicians, like barristers, were legally precluded from enforcing ordinary contracts for their fees because this was seen as inconsistent with their status as noble, learned professionals. Instead, physicians and barristers received voluntary honoraria and were expected to serve patients regardless of their ability to pay.”(Hall, 2006, p. 164-5)

Barney: But this is not ancient Rome!

Candidate: We have already said that the state must provide funding to ensure that basic healthcare is accessible to all, to protect their safety, as long as it is not too costly. I do not accept that the state has also to be concerned about ability to pay for insurance for healthcare that goes beyond that basic minimum. However, I do accept that there is argument for subsidies for “more-than-basic” healthcare for those who inherit or are afflicted by serious health problems. However, I see two conditions. Firstly, it must be absolutely clear that ill health is through no fault of their own. If they in any way caused their own ill-health, for example by smoking or eating too much, then they must live with the consequences. Secondly, it normally should apply only to children, because adults can decide for themselves to buy insurance cover before they are struck down with illness or disability. But I accept the state might intervene in some cases, like say for those children born with a disability, either by providing direct subsidies to those affected, or by regulating the insurance market to enable cross-subsidies. But that sounds complex. Can it be made to work?

Economist: Several European systems, including Dutch healthcare, operate with cross-subsidies. The consumers choose their healthcare insurer and insurance package, and consumers who have been assessed as high-risk, high-cost cases are subsidised from a risk equalization fund.(Bevan and Van de Ven) Furthermore, The Netherlands is considered to have one of the most successful healthcare systems(Davis et al., 2010).

Clinician: However, your distinction of people “at fault” and “not at fault” of causing their ill-health, and of children and adults, will be very difficult to apply in practice.

For example, is an adolescent who is brain damaged after falling from a tree “at fault”?

Candidate: I can see difficult policy decisions are required there, but they can be confronted. We have accepted that the state has to intervene to fund public health activities and basic healthcare for individuals, to subsidise (or make the market cross-subsidise) more-than-basic insurance cover for certain individuals who would otherwise, through no fault of their own, have high-cost insurance premiums. Is there anything else the state has to do?

Lawyer: It must make laws and policies. You may not agree that health or healthcare is a human right(Gruskin and Daniels, 2008), or with the role of healthcare in securing equality of capability(Sen, 2002) (Nussbaum, 2001, p. 77-78) (Fabre and Miller, 2003), or even that healthcare has a special moral significance because it protects our equal right to opportunity(Daniels and Sabin, 2008, p. 14-18). But I am sure you accept that healthcare is a very important good – more important than motors and mowers and movies. We may die through lack of it. Who should get it and who should decide who gets it? Those are very important questions, and because they may be matters of life and death, they are ones that the state cannot ignore. The state must make laws and policies to answer these difficult questions, or at least to explain how, and by whom, these questions are to be answered. For example, our discussion today suggests that we need to decide which public health activities should be funded by the state. Similarly, we have said that basic healthcare will be funded by the state – but how, and by whom, are decisions made about what constitutes “basic healthcare”? These are complex questions on which people will disagree depending on their values(Daniels and Sabin, 2008, p. 69-73). And if I am ill, who decides in my particular case whether some or all of my treatment fits within whatever has been defined as “basic healthcare”? As my life may depend on it, justice demands an appeals procedure. The state must provide, or regulate to stipulate who provides, for procedural justice(Daniels and Sabin, 2008, p. 43-66).

Clinician: Yes, psychological research shows that procedural justice engenders trust and legitimacy, so that people are prepared to accept decisions as fair even when they go against them(Tyler, 2006, p. 379-381).

Barney: My head hurts. It was already starting to sound like socialised medicine. Now you are suggesting British death panels!(Barr, 2009)

Candidate: The lawyer is right. There are difficult choices to be made, and because they could be about life and death, the government must either make them, or stipulate who can make them. And individuals must be able to appeal against decisions.

Bioethicist: And what about the insurance companies who provide the more-than-basic healthcare cover? Are they the right people to decide what is covered and what is not? Whether a particular cancer drug is covered by my policy could also be the difference between my life and death.

Economist: The insurance companies will be able to respond to demand, and consumers will be able to choose the insurance cover they want, based on what is included and excluded, and on price.

Lawyer: Nevertheless, the importance of these policies justifies regulation of the insurance companies too. How policy cover is decided, and what action I can take to challenge a decision that my treatment is out of policy - these are questions of public concern. There are also other complex regulatory issues(Jost and Hall, 2005).

Clinician: Patients are often particularly vulnerable when seriously ill, open to exploitation by those who might profit from that vulnerability, and thus in need of protection.

Candidate: Yes, I accept there is a need for regulation of the insurance market too.

Lawyer: And then there are the healthcare providers and clinicians themselves – who is to regulate them? And what about medications, and medical devices that are used to treat us, or are implanted inside us?

Economist: There is an asymmetry of information at work here, and so another type of market failure. The manufacturer knows a lot more than we can about the effectiveness and efficacy of their device or drug. We have relatively little information on which to judge the competence of a doctor, and the value of the healthcare that they offer, and because of their expertise and authority, the patient is

vulnerable to being exploited (Berenson and Cassel, 2009, p. 321). For example, the doctor may sell the patient more services than she needs. Nevertheless, the capability and reliability of a doctor, a medical device, or a drug, to deliver a good outcome is of great importance to us as individuals – it could be the difference between life and death. Asymmetry of information is one important reason to regulate (Garoupa, 2004, p. 4-5).

Candidate: An interesting explanation. Few would doubt the importance of regulating healthcare so that we can have competent, qualified clinicians and can trust that medications and medical devices will do us more good than harm. Either it should be self-regulation, overseen by government with the ground rules laid down in law, or it should be state regulation.

Bioethicist: You have shown a touching faith in the reliability of the market to provide healthcare. What happens to people if market mechanisms break down and we have no healthcare provided? How then could the state protect our safety?

Candidate: I know she has talked about market failure, but I am sure the economist would tell us there is sound theory and empirical evidence that demand for goods and services generates supply. But that is unnecessary because I recognise that, in principle, in order to protect the people, the government has a responsibility to ensure that healthcare services are made available. In the unlikely event that markets were to fail, the government would have to step in, and do something to rectify the problem.

Let us finish here. I am sure there is more that could be said, but I think we have identified the main responsibilities of the state. The state has much to do. It should:

- fund, and ensure provision of, many activities necessary to protect public health;
- ensure basic healthcare – that is, at least lower-cost care that protects safety - is accessible to all, with the state funding either everyone or just those with insufficient means to pay for themselves;
- subsidise, or make the market cross-subsidise, insurance cover for more-than-basic-healthcare for certain people (normally young people) who would otherwise, through no fault of their own, have high-cost insurance premiums;

- oversee, and ensure that there is, continuing provision of a wide range of healthcare;
- make law and policy that specifies
 - how decisions about who is entitled to healthcare are made,
 - systems of procedural justice enabling, for example, appeals by those denied healthcare,
 - the regulatory framework (either self-regulation or state-regulation) governing insurance companies, healthcare professionals, medical devices, and medication.

Barney: John, that message is political suicide.

End

The crowd were raucous and rowdy; this was no sedate tea party. People were chanting: “We hate government! We love John!” Many wore T-shirts declaring: “What has the government got to do with healthcare? Nothing!”. A woman, presumably from the religious right, held up a sign proclaiming: “John stands firm against Johnnies!”

The candidate stood before his faithful crowd and began:

“So...what has the State got to do with healthcare?” A huge roar came from his expectant audience, each one a believer in individual freedom and small government. “My answer is...”. Another pause and another roar. “A lot!”.

The gasps were audible, as shock spread across the faces of the crowd.

Barney had his head in his hands. He was already thinking about his next job.

References

- ARIELY, D. (2009) *Predictably irrational: The hidden forces that shape our decisions*, New York: HarperCollins.
- BARBER, B. R. (1984) *Strong democracy: participatory politics for a new age*: University of California Press.
- BARR, A. (2009) Palin doubles down on 'death panels' [Online]. Available: http://news.yahoo.com/s/politico/20090813/pl_politico/26078 [Accessed 16 Feb 2012].
- BERENSON, R. A. & CASSEL, C. K. (2009) Consumer-driven health care may not be what patients need—caveat emptor. *JAMA: The Journal of the American Medical Association*, 301, 321-323.
- BEVAN, G. & VAN DE VEN, W. Choice of providers and mutual healthcare purchasers: can the English National Health Service learn from the Dutch reforms. *Health Economics, Policy and Law*, 5, 343-363.
- CARANDE-KULIS, V. G., GETZEN, T. E. & THACKER, S. B. (2007) Public goods and externalities: a research agenda for public health economics. *Journal of Public Health Management and Practice*, 13, 227.
- CHEN, L. C., EVANS, T. G. & CASH, R. A. (1999) Health as a global public good. *Global public goods*, 1, 284-306.
- DAHL, R. A. (1971a) *Polyarchy: participation and opposition*, Newhaven: Yale Univ Pr.
- DAHL, R. A. (1971b) *A preface to democratic theory*, Newhaven: University of Chicago Press.
- DAHL, R. A. (2000) *On democracy*, Newhaven: Yale Univ Pr.
- DANIELS, N. & SABIN, J. E. (2008) *Setting Limits Fairly - Learning to share resources for health*, New York: Oxford University Press.

- DAVIS, K., SCHOEN, C., STREMIKIS, K. & FUND, C. (2010) Mirror, mirror on the wall: How the performance of the US health care system compares internationally: 2010 update [Online]. Commonwealth Fund. Available: <http://www.commonwealthfund.org/Publications/Fund-Reports/2010/Jun/Mirror-Mirror-Update.aspx?page=all> [Accessed 28 March 2012].
- DWORKIN, R. (2006) Is democracy possible here?: principles for a new political debate, Princeton: Princeton University Press.
- ENGELHARDT, H. T. (1994) Health care reform: A study in moral malfeasance. *Journal of Medicine and Philosophy*, 19, 501-516.
- ERIN, C. A. & HARRIS, J. (1993) AIDS: ethics, justice, and social policy. *Journal of applied philosophy*, 10, 165-173.
- FABRE, C. & MILLER, D. (2003) Justice and Culture: Rawls, Sen, Nussbaum and O'Neill. *Political Studies Review*, 1, 4-17.
- GAROUPA, N. (2004) Regulation of professions in the US and Europe: A comparative analysis. bepress.
- GOODMAN, J. (2006) Consumer-directed health care [Online]. SSRN. Available: http://papers.ssrn.com/sol3/papers.cfm?abstract_id=985572#PaperDownload [Accessed 18/03/2012].
- GRUSKIN, S. & DANIELS, N. (2008) Process is the point: justice and human rights: priority setting and fair deliberative process. *American Journal of Public Health*, 98, 1573.
- HALL, M. A. (1994) Reforming private health insurance: American Enterprise Institute.
- HALL, M. A. (2006) Paying for What You Get and Getting What You Pay for: Legal Responses to Consumer-Driven Health Care. *Law & Contemp. Probs.*, 68, 159.
- HERZLINGER, R. E. (2004) Consumer-driven health care: Implications for providers, payers, and policy-makers: Jossey-Bass.

- HOBBS, T. (1987) 1651. Leviathan London.
- JOST, T. S. & HALL, M. A. (2005) Role of State Regulation in Consumer-Driven Health Care, *The Am. JL & Med.*, 31, 395.
- LAU, D. C. (2003) Mencius: Chinese Univ Pr.
- LOCKE, J. (2002) *The second treatise of government: and, A letter concerning toleration*: Dover Pubns.
- MCKIE, J. & RICHARDSON, J. (2003) The rule of rescue. *Social Science & Medicine*, 56, 2407-2419.
- MILL, J. S. 1989. On Liberty. In: COLLINI, S. (ed.) *On Liberty and Other Essays*. Cambridge: Cambridge University Press.
- NOZICK, R. (1974) *Anarchy, state, and utopia*, New York: Basic Books.
- NUFFIELD COUNCIL ON BIOETHICS. (2007) *Public Health: ethical issues* [Online]. Available: <http://www.nuffieldbioethics.org/public-health> [Accessed 21 Jun 2013].
- NUSSBAUM, M. C. (2001) *Women and human development: The capabilities approach*, Cambridge, Mass.: Cambridge Univ Press.
- SAARELA, M. V., HLUSHCHUK, Y., WILLIAMS, A. C. C., SCHÜRMAN, M., KALSO, E. & HARI, R. (2007) The compassionate brain: humans detect intensity of pain from another's face. *Cerebral Cortex*, 17, 230.
- SEN, A. (2002) Why health equity? *Health Economics*, 11, 659-666.
- SUNSTEIN, C. R. & THALER, R. H. (2003a) Libertarian paternalism. *American Economic Review*, 93, 175-179.
- SUNSTEIN, C. R. & THALER, R. H. (2003b) Libertarian Paternalism Is Not an Oxymoron. *University of Chicago Law Review*, 70, 1159-1202.
- TVERSKY, A. & KAHNEMAN, D. (1981) The framing of decisions and the psychology of choice. *Science*, 211, 453-458.

TYLER, T. R. (2006) Psychological perspectives on legitimacy and legitimation.
Annual Review of Psychology, 57, 375-400.

4. Looking to philosophical bioethics for an answer

Philosophical bioethics and democratic decision making

From within bioethics, and philosophical bioethics more specifically, I draw on the work of Norman Daniels (including his joint work with James Sabin) which I summarised earlier. His writing on “accountability for reasonableness”, the conclusions that led to this thinking on procedural justice, and his subsequent work on the implementation of accountability for reasonableness in various countries, are highly cited and widely respected by other scholars. His writing is measured and logical, and addresses many difficult resource allocation questions. Unusually for an academic writer, he has taken great interest in testing his theory in different countries¹. I also have some criticisms of his theory of accountability for reasonableness (in paper 5).

Of particular relevance to this thesis is his analysis of the role of citizens in finding just answers to difficult ethical questions. (Daniels and Sabin, 2008, p. 64)

“We believe that compliance with our four conditions will lead to better decisions by limit setting organisations in at least this sense: they will rest on a more coherent set of reasons and arguments that are thought relevant to acceptable limits by fair-minded persons. But are they better in the sense that they are more likely to be just or fair decisions, as judged by some view of justice independent of the process of the decision-making itself?

This deeper and more difficult question goes to the heart of democratic theory. Some theorists (including Plato) suggest that moral authority requires having the moral expertise to make morally correct decisions. Authority comes from getting moral questions right according to these theorists, a process that does not improve the prospects of getting the right answers and laws and policies cannot claim legitimacy.

The problem with this elitist approach, say its critics, including us, is that we should not expect people to surrender moral authority to experts. But if we

¹ However, it is interesting that the second edition of *Setting Limits Fairly* contains several new chapters on the implementation of accountability for reasonableness internationally, but the first 11 chapters where the authors set out their theory, is entirely unchanged from the first edition published six years earlier. This might suggest that they learned no lessons from the additional testing of their theory.

reject the idea of experts, are we reduced to accepting as morally legitimate whatever results from democratic process? We might be happy about democratic process if we have some assurance that exercising it properly and deliberatively added to our chances of getting better laws and policies, where "better" is judged from a perspective independent of the democratic process itself. This problem about whether there is epistemic authority to democracy - whether it helps us get things right - lies at the core of much current debate about democratic authority.”

I agree with Daniels and Sabin that “we should not expect people to surrender moral authority to experts”. However, accountability for reasonableness does not make sufficiently clear who should make these difficult prioritisation decisions. It does not explain whether some fundamental resource allocation decisions can and should be made by government, which would then shape and constrain the decision-making on more detailed questions by other bodies such as health authorities or private health insurers. Given that accountability for reasonableness is advice on procedure, decision-making responsibilities should be clearer, especially when it is grounded in, and partially justified by, the sort of democratic ideals espoused by Daniels and Sabin.

What accountability for reasonableness appears to imply is that the fair-minded people involved in deliberation are the citizens who will be affected by the decisions made. The theory does not recognise that in almost any country, be it a democracy or non-democracy, policy decisions are invariably taken by governments and not by groups of citizens. Conclusions reached through deliberation by fair-minded people sometimes inform government policy but rarely make government policy. This may be because the authors are seeking what ought to be, rather than what is, and they argue that the involvement of citizens in this way gives legitimacy to the process. However, only very small numbers of people can ever be involved such a process, and it is not clear why ordinary citizens ought to be making such decisions, rather than the citizens who are elected through democratic means to represent the public, and who are accountable to the public for the decisions they make. Surely the participation of elected representatives would increase legitimacy.

This kind of debate seems central not just to healthcare resource allocation, but to any fundamental disagreement amongst philosophers, social scientists, and scientists that

concern policy. How ought we to make policy decisions in a democracy where experts disagree amongst themselves, or where they agree amongst themselves but their thinking is at odds with that of the public at large? Many bioethicists and philosophers argue that the “right” answers to moral questions are derived from moral reasoning – that there is a truth to identify, and that it can be found through logical argument. Their job as they see it is to pursue and demonstrate that truth (Brock, 1987), and to distinguish it from the imposters that may be put forward by others. (Holm, 2005, p. 1)

Where public opinion does not recognise and accept this truth, that is of little relevance to some experts, whilst others will use public opinion to back up their arguments (Hobson-West, 2010). Eve Garrard and Stephen Wilkinson argue that following public opinion on ethical matters amounts to moral relativism, which as philosophical bioethicists they reject:

“for while public opinion should sometimes be taken into account when framing policy, there is no necessary connection between what “society thinks” about any given issue and the moral truth of the matter... it would be possible for a “society to think” that sex between adults and children, genocide, and torturing kittens were all morally permissible, even if really such practices were wrong.” (Garrard and Wilkinson, 2005, p. 85)

Although pursuing truths, philosophical ethicists disagree amongst themselves on many fundamental moral questions such as how to value life, and whether morality ought to be judged on actions, or outcomes of actions. Some are sceptical of philosophical truth, or even justified moral belief, and argue that whilst such truths will be built using rational argument, they inevitably will be founded on normative value statement(s) or claim(s) (Sinnott-Armstrong, 2009). As Raz said, ‘ordinary knowledge is fallible’ (Raz, 1988) and, as philosophers John Dewey and William James argued, truth, in whatever sphere, has to be verified and may be temporary – “truth happens to an idea” (Shields, 1996, p. 397).

How can philosophical truths and principles be verified? Dewey argues that it is through experience and experimentation, just as it is in science (Dewey, 1922, p. 210-211) (Caspary, 2000, p. 135). However, principles and truths are working hypotheses

and not immutable; they must be subject to continual evaluation and reappraisal, even where they have been laid down in law (Dewey, 1921, p. 571).

In his book “On What Matters”, Derek Parfit analyses what many eminent philosophers have to say about normative truths. He considers their arguments in detail, and finds many points of fundamental disagreement. For example, in relation to Korsgaard, he writes (Parfit, 2011, p. 419):

“If we cannot convince some people that some answer is true, that is no objection to realism. If there are answers to normative questions, these answers would have to be truths. If there were no truths about what we have reasons to care about, or to do, we could not make better or worse decisions. We might as well act on impulse, toss coins, or do nothing. But there *are*, I believe, such truths. No disagreement could be deeper.”

Even if there are moral truths to be discovered, it does not necessarily follow that policy must be based on those truths. As Soren Holm explains: “attempting to reach a legitimate public policy in a morally pluralistic liberal democracy is not a social activity of the same kind as trying to win a philosophical argument”. (Holm, 2005, p. 1) So just as Garrard and Wilkinson can say that “it is not clear why ethicists should care about the fact that ‘90% of people disapprove of x’” (Garrard and Wilkinson, 2005, p. 85), it can equally be argued that it is not clear why policy-makers should care about the fact that 90% of ethicists disapprove of Y.

With such fundamental disagreements between so many distinguished philosophers, what truths, if any, should policymakers and others draw from the philosophical literature? If there can be no agreement on fundamental philosophical principles, is the right approach to abandon that struggle, and concentrate instead on agreeing fair procedures, as Daniels and Sabin have done? However, even when it comes to fair procedures, there is little agreement within philosophical ethics about the process through which policy decisions ought to be made, and by whom.

It was tensions such as these that prompted me to write paper 4: “how can one be both a philosophical ethicist and a democrat?”. The article has been accepted by Health Care Analysis and published online. It is reproduced below.

Paper 4: How can one be both a philosophical ethicist and a democrat?

ABSTRACT

How can one be both a philosophical ethicist and a democrat? In this article I conclude that it can be difficult to reconcile the two roles. One involves understanding, and reconciling, the conflicting views of citizens, and the other requires the pursuit of truth through reason.

Nevertheless, an important function of philosophy and ethics is to inform and improve policy. If done effectively, we could expect better, and more just, laws and policies, thereby benefiting many lives. So applying philosophical thinking to policy is an important job. However, it comes with substantial difficulties, not least in reconciling, or choosing between, competing philosophical theories. Despite the importance of the task, and the apparent obstacles, there is relatively little literature on how to apply ethics to real-world policy-making.

Democracies need ethicists who can engage in democratic debate and bridge the gap between philosophy and public policy. I offer some tactics here.

INTRODUCTION

In a recent issue of this journal, Iain Brassington makes a case for the role of philosophy within bioethics, and in democratic policymaking.(Brassington, 2012b) I was easily persuaded of his main argument: philosophy has a central place within bioethics. Brassington gives less attention to the role of philosophical thinking in policymaking. I contend that it merits more attention. Many philosophers have provided theories of how citizens ought to contribute to policy in an ideal democracy (Habermas, 1996) (Bohman, 1997), but few have explained how philosophers and philosophical ethicists should participate in the policy process in today's democracies. It is not obvious how they should, or that many do, contribute effectively to policymaking. This is a loss to the philosophical community, but more importantly to the quality of public policy.

I write here about how ethicists and philosophers can bring philosophical thinking to bear on policy problems that arise in today's democracies. By "today's democracies", I am referring to functioning representative democracies that exist today, where each citizen has a voice, but where policy is controlled invariably by officials elected at regular intervals through universal suffrage: something akin to what Robert Dahl calls 'polyarchy'(Dahl, 2000, p. 90). Tatu Vanhanen assessed 102 out of 170 countries in 2001 to be democracies, based on a threshold comprising similar criteria for democracy to those used by Dahl.(Vanhanen, 2003, p. 188) Most articles in the literature that apply philosophical thinking to contemporary policy questions are from writers resident in, and considering policy questions that arise for, such democracies.

Philosophical thinking, with its insights into what is good and fair, has an important potential contribution to make to law and policy in today's democracies. It should enable the making of better and fairer laws and policies, reducing harm and improving life for millions of citizens. However, academics using evidence and reason to pursue truth may find it difficult to adapt to a political environment where policy outcomes are negotiated(Brock, 1987) (Anderson, 2010, p. 29). The process of policymaking is very different to the methods an ethicist uses to develop a philosophical argument. Furthermore, ethicists develop conclusions through reasoning, whereas policymakers may look to the views of the public which may be founded on little more than intuition. To policymakers, philosophy may seem remote from their concerns, and

with so many competing philosophical arguments, they may be ill-equipped or unwilling to choose between competing theories, or bring philosophical ethics into the public sphere. Rather than settling known disputes, philosophy may raise new questions. The two worlds do not easily mix.

So, in this context, how can one be both a philosophical ethicist and a democrat? I grapple with this question in the short story that follows. I have drawn much of the dialogue between the interviewers and the interviewee in the story directly from academic publications. This is deliberate; I want to present (and not misrepresent) something about what it is to be a philosophical ethicist through the words of ethicists and philosophers. Professor Wright's dialogue is drawn from several different academic writers, and has been chosen to represent a particular strand of thinking and combative argument that is characteristic of some writing in the field. The interviewee, Dr. Demos, has a different and more democratic perspective, and her debate with the Professor highlights some of the difficulties of applying philosophical reasoning to policy. She sets out tactics for philosophical ethicists who wish to participate constructively in public policymaking in a democracy. There is, of course, much diversity in philosophical ethics and these characters represent just two perspectives that could be taken.

The President chairs the interview, without taking positions. My own sympathies lie primarily with the interviewee, and some of her arguments are mine. I see a role for philosophical ethicists in public policy, which the interviewee elaborates. It requires particular skills, and may not be a role that everyone would choose.

Direct quotations are shown in double quotation marks, followed by a reference. Some of the arguments made by Dr. Demos are not direct quotations, but are backed by references.

THE STORY

“Next!”

There was a weariness in the voice of the President of the Association of Philosophical Ethicists (APE). He was chairing the interview panel, but his heart was not in it. In recent years, requests from government bodies had grown, and it had been getting more and more difficult to find competent ethicists to represent the association on national policy committees. He had no time, and most of his colleagues were not sufficiently interested in policy to take time off from their academic work. Their university employers and peers valued research publications above contributions to democratic debate. Many of the ethicists and applied philosophers that had participated often became frustrated by the policy-making process.

Joining the President on the interview panel was Professor Wright, an eminent philosopher, who had made his name decades earlier with his first book “Embryos are good, but better with bacon”. He was also known for having stormed out of the Commission for Regulating the Use and Destruction of Embryos shouting “I have explained why embryos are not morally significant, but you seem incapable of recognising and understanding truth”.

And so the Association had decided to recruit an ethicist to sit on policy committees and represent the thinking of philosophical ethicists. Everybody knew that it was a poisoned chalice. For a start, there was so little agreement on all the big philosophical questions that meaningful representation of APE members was not possible. And even where there was a shared understanding and acceptance of philosophical theory, there was no agreement on how to apply that thinking to policy.

The President brightened as he ran his eyes over the curriculum vitae of the next candidate. She was a young and promising bioethicist who already had several publications in top journals. The President smiled warmly as the young woman entered the room, shook hands, and sat down.

President: Welcome. I see you already have experience as a bioethicist on a policy committee looking at the treatment of animals in research. Would you like to tell us a little about that please?

Dr. Demos: Thank you. "My first task was to provide a report explaining the current 'state of knowledge' in ethical thinking. Accordingly I undertook a review of some of the major contributions to the philosophical literature, as well as some surveys. One thing that was obvious from the first glance was that there was no such thing as the current state of knowledge. The debate was divided. At one extreme were those who argued that current practices of eating and experimenting on at least some more complex and developed animals was in principle no different to doing the same thing to human beings, and therefore not just wrong but morally horrific. At the other end of the scale were those views that would apparently have been consistent with finding nothing morally objectionable to cockfighting, bear-baiting and torturing animals for fun, although no one seemed quite ready to draw those conclusions... on the whole, philosophers seem to defend views that were so far from current practice as to seem, to the non-philosopher, quite outrageous. The idea that society could adopt any of the views put forward seemed almost laughable. To put it mildly, from the point of view of public policy the views were unreasonable and unacceptable.

This was a shock. Moral and political philosophy, I had assumed, is made for the analysis of public policy, exploring foundational values, and consolidating them into theories and prototype policies that could, with reasonable adjustment, fit practical needs to improve the moral quality of our public lives".(Wolff, 2011, p. 1-2)

President: So you found it more difficult than the other committee members to report the state of knowledge in your field?

Dr. Demos: Yes. "In science and social science research a researcher makes his or her name by presenting a view that others find attractive or useful and build upon. By and large the situation in philosophy is the reverse. Philosophers become famous for arguing for a view that is highly surprising even to the point of being irritating, but is also resistant to easy refutation. The more paradoxical, or further from common sense, the better. Philosophy thrives on disagreement, and there is no pressure to come to an agreement. Indeed agreement is unhelpful as it cuts discussion short. In public policy,

however, a report must be written, or a recommendation made, or a law or policy drafted, just as in science and social science a practical outcome is sought.”(Wolff, 2011, p. 3) With so many divergent competing philosophical theories, policymakers are liable to reject the whole discipline as divided and unhelpful, with nothing useful to contribute to real policy.

President: Is it possible then for you to do the job we are advertising – to represent philosophers and ethicists in public policy debates?

Dr. Demos: I could be a representative of APE insofar as I could be “someone who speaks or does something officially for another person or group of people”,(CUP, 2011) but I could not adequately represent the range of diverging views of the individual members of APE. My role would be to bring important arguments to the policy debate, demonstrating that, despite the lack of consensus for example on principles of distributive justice, philosophy has an important contribution to make. As much moral reasoning is complex, and built on many sources, communicating philosophical ideas is not easy. Inevitably, I would represent most persuasively the philosophical thinking to which I am sympathetic. However, I would feel an obligation to ensure that I also aired some of the other relevant philosophical arguments and theories from the literature if I felt they could be applied constructively to policymaking.

Prof. Wright: So you would advocate philosophical theories that you did not believe to be true?

Dr. Demos: If they were relevant, I would offer them for consideration. I have read a little of the extensive debates on the existence of philosophical truth, and it leaves me unsure of whether philosophical truth exists, and what it would look like if I saw it. What I know is that there are numerous important normative questions facing us today and the policy debate over the answers will be the poorer if the voices of philosophers and ethicists are not heard.

Prof. Wright: We cannot ignore what we know to be true. “If we cannot convince some people that some answer is true, that is no objection to realism. If there are answers to normative questions, these answers would have to be truths. If there were no truths about what we have reasons to care about, or to do, we could not make better

or worse decisions. We might as well act on impulse, toss coins, or do nothing. But there are, I believe, such truths.”(Parfit, 2011, p. 419)

Dr. Demos: Democracy need not pursue a single plain truth. “It makes perfectly good sense to say, ‘My view is true, but other views, while not true, are reasonable to believe, and what matters for democracy's public reason is reasonableness not truth.’”(Cohen, 2009, p. 31)

Thus, fortunately, democracy does not rely on the existence of singular philosophical truths to make decisions. In their absence, we need not resort to tossing coins or acting on impulse. We can decide which actions are better and which are worse on the basis of experience.(Dewey, 1958, p. 7)

Prof. Wright: So is there room for philosophical theory in this democratic process or do we simply leave it to the people to use their experience to decide?

Dr. Demos: “Radical philosophical arguments are a vital part of the debate, and add to the stock of ideas that enrich discussion. But on their own they will settle nothing.”(Wolff, 2011, p. 35-6) It is “doubtful that any high level philosophical theory can be fruitfully “applied” directly so as to yield univocal answers to complex problems of professional practice and public policy.”(Arras, 2010)

President: So, if it is not theory, what do we bring to the policy debate?

Dr. Demos: Theory can have a role, but additionally we “can help clarify the terms of public debate. Philosophers are not the only people who can do this of course, but it is part of our training to make distinctions, to follow arguments out to their conclusions, and to reconstruct relatively loose arguments in a more rigorous form. But to do this one has first to become immersed in the debate in which one wishes to intervene.”(Wolff, 2011, p. 36) I would argue that we ought to intervene more effectively and more often.

Prof. Wright: Are you suggesting we have a duty to participate in the policy-making process? That would be a strong claim.

Dr. Demos: I would not choose to impose duties on colleagues. However, “the fundamental question of ethics is: ‘what should I, ought I, or must I do?’”.(Parfit, 2011, p. 415) That can be extended: ethics is also about what groups of people do. It’s about what we do as a society, about policy. If that is our business, then we must be prepared to explain our thinking to others in society. How can we claim to have found truths about how we should live together when we speak only to a few like-minded souls? One test of philosophical truths is whether they ring true to people other than philosophers, and with ordinary experience.(Dewey, 1922, p. 1a - 39)

Many philosophers have written of the importance of the legitimacy that democracy can bring, and particularly of an ideal where policy is derived from the deliberation of citizens.(Rehg and Bohman, 2002) We do not live in an ideal world, but in a representative democracy - an imperfect polyarchy.(Dahl, 1971a) In a pluralist democracy like ours, elected governments are responsible and accountable to citizens for policy, but that policy will be shaped by many voices. Compared to non-democratic alternatives, the advantages of these imperfect democracies are compelling. (Dahl, 2000, p. 44-61) Even those ethicists amongst us that see democracy as an inferior form of government must nevertheless live within its structures; we must follow its rules. But we can also contribute to making our society a better and fairer place to live by contributing to the democratic process.

Prof. Wright: So are we failing in this democratic duty to participate in policy making?

Dr. Demos: We could do more. We speak to ourselves more than to the public at large. As a result, when people have an ethical problem or question, they do not necessarily think of asking an ethicist. For example, BBC Radio 4’s Today Programme – one of the most influential broadcast news programmes in the UK – recently ran a story about the Lancet Oncology Commission’s conclusion that countries like the UK and USA might spend too much on interventions of meagre benefit to cancer patients as they near end of life.(BBC, 27 Sep 2011) The interviewer probed about whether it was acceptable to ration medicines according to the age or life expectancy of the patient. One interviewee explained he was ageist, giving no ethical reasoning as to why ageism might be justified. The other clinician avoided answering this question, even though pressed twice by the interviewer. The

interviewer's question is an old one, discussed at length by bioethicists, but the producers chose two doctors to answer this question. They did not choose a bioethicist.

President: Can I take you back to something you said earlier about public opinion. It sounds as though you have a lot of faith in the public. Should policy be made by polling the public?

Dr. Demos: I have faith in the public, which is not the same as faith in public opinion polls on complex policy questions that report responses made by people who have only been partially informed of the issues. Furthermore, "merely aggregating preferences through voting or surveying ends up making majority might determine what is right, with no real constraints on the kinds of reasons that play a role in the decision. In moral disagreements, we want people to bring reasons to bear in an effort to persuade each other. We want a deliberative process that takes seriously the considerations people bring into a dispute. A dispute resolved by democratic procedures after careful deliberation about the various reasons put forward on both sides has in its favor the fact that even the losers will know that their beliefs about what is right were taken seriously by others."(Daniels and Sabin, 2008, p. 39)

Even if we doubt the reasoning powers of members of the public, we ought to recognise that everyone has a say in how our society is organised. That is an implication of "the idea of seeing democracy as 'government by discussion', which is so widely accepted in political philosophy today."(Sen, 2009, p. 326)

Prof. Wright: "While public opinion should sometimes be taken into account when framing policy, there is no necessary connection between what 'society thinks' about any given issue and the moral truth of the matter."(Garrard and Wilkinson, 2005, p. 85) "For policy-makers, the arguments must prevail over the views of the majority when the two come into conflict."(Garrard and Wilkinson, 2005, p. 87)

Dr. Demos: I agree that those accountable to the public for making policy are not obliged always to follow public opinion, especially on complex policy problems where the public may not be well informed. But they do have a responsibility to explain their thinking, and to listen and take account of the views and values of citizens. Establishing the opinions and values of the public is, of course, far from

straightforward, but policymakers and, ethicists have much to learn from citizens who have come together, or been brought together, to deliberate on complex ethical policy questions.(Kim et al., 2009)

At the same time, a policy maker should be prepared to challenge societal values, rather like Adam Smith's impartial spectator.(Smith, 1759, Sen, 2009, p. 45)

Prof. Wright: Consider a problem like allocating organs to transplant patients. "It does not make sense to base policies on the views of people who do not understand the issues involved. Complicated matters such as how and when to use outcomes data to determine allocation may simply exceed what many people in the public can comprehend."(Ubel and Loewenstein, 1996, p. 1053)

Dr. Demos: Perhaps, although lack of understanding may be the result of inadequate information and explanation. And we should be careful not to underestimate the moral reasoning of others. "While the public's ability to make acceptable rationing decisions may be limited, public opinion regarding these matters should not be dismissed. Indeed, much of the value of democracy rests on an assumption that the public is capable of making important and difficult decisions. As long as we function in any type of democratic state, we ought to test how members of the general public view important social issues."(Ubel and Loewenstein, 1996, p. 1054)

Prof. Wright: Public opinion may matter to policy makers, but "it is not clear why ethicists should care about the fact that '90% of people disapprove of x'."(Garrard and Wilkinson, 2005, p. 85) "Although it would be rewarding for ethicists to be able to persuade others of the validity of their arguments, a failure to do so does not in any way imply that normative importance should be accorded to intuitive feelings about what is morally acceptable or desirable."(Kirklin, 2007, p. 386)

Dr. Demos: If ethicists are also democrats, then for all the reasons we have discussed, we ought to care about societal values. Furthermore, because other people are just as capable of moral reasoning, we might do well to think again about the validity of any philosophical claim that was rejected by 90% of people, and be slow to judge and discard their thinking as mere moral intuition. It is debateable whether moral expertise is our dominion.(Archard, 2009, Gordon, 2012)

President: So how can a philosopher or ethicist contribute to the public policy debate?

Dr. Demos: Firstly, by listening to the prevailing policy arguments. "It is frequently the case that matters of apparently grave public concern are matters of almost complete indifference to a great many philosophers. For example, the organ retention "scandal" of a few years ago was not treated as such in academic circles; a good number of philosophers claimed not really to be able to see what all the fuss was about... This, it might seem, indicates an aloofness from the concerns of the demos."(Brassington, 2012b)

Second, by writing and speaking in ways and in places so that more people will listen.

Thirdly, by recognising the limited relevance of philosophical truths to policy. "The attempt to suggest that public policy ought to be shaped a particular way because that follows from a true moral principle is likely to meet with the response 'who says?'. More progress is likely by appealing to values that are widely shared, and in the public policy arena there seems little to be gained by asking whether values are 'objective' or 'subjective'."(Wolff, 2011, p. 196) What is the best policy depends in part on context: on the history, culture, institutions and the values of the society. For example, "in some societies, 90% of the people believe if jobs are scarce, men have more right to a job than women; in others, only 8% so."(Inglehart and Welzel, 2005, p. 15) That might be of little significance in ethics, but it matters in policy making. If ethics is to influence policy, it should recognise, and be constrained by, the context in which policy is to be made and applied.

Fourthly, by recognising that "what matters in public policy debate is not convincing yourself that you have the best position, but carrying others with you. This is not so much a matter of pragmatic compromise, but of working out how people can get much of what they want without taking too much away from others."(Wolff, 2011, p. 203)

Fifthly, and this is of particular relevance to non-consequentialists, recognising that outcomes will always matter to policy makers who are obliged to consider and weigh up the likely effects of alternative policies on different sections of society and on existing laws and policies.(Brock, 1987, p. 787)

Sixthly, to seek to learn from others. For example, when bioethicists like me come to a practical policy problem like end-of-life care, “we would expect practitioners to have particular skills in practical judgment, and to have something to teach us and...be sensitive to the possibility that we are indeed out of touch.”(Dickenson, 2000, p. 259)

Lastly, by assisting others to articulate clearly their arguments. Our training enables us to structure arguments and separate different concerns. We can use those skills to clarify the terms of the debate, to advise and coach non-philosophers, and also to prevent policy discussion from being dominated by the forceful. For example, on a policy committee, we can listen to, and assist those, who are less experienced or skilful in debate to express their values and reasoning. We can help non-philosophers “play their proper part, as good citizens, in democratic self-government”.(Archard, 2009, p. 127)

President: Do you believe that other ethicists would accept and could apply such ways of working?

Dr. Demos: It’s a good question. “The standard model, and to an even greater extent, the rhetoric of ethics, often imply that there is only one right solution to each policy making decision, and that it is possible to find this solution, and to know that it is the right decision. ‘Knowing that you are right’ is in general a bar to a positive engagement with the views of others, but ‘knowing that you are right after proper philosophical reflection’ can be even more problematic... Attempting to reach a legitimate public policy in a morally pluralistic liberal democracy is not a social activity of the same kind as trying to win a philosophical argument.”(Holm, 2005, p. 1)

“When philosophers move into the policy domain, they must shift their primary commitment from knowledge and truth to the policy consequences of what they do. And if they are not prepared to do this, why did they enter the policy domain? What are they doing there?”(Brock, 1987, p. 787)

It may be that the kind of participation in policy that we have been discussing is only possible when philosophy and ethics are practiced according to a less adversarial and more co-operative ‘peacemaking model’, as James Sterba has proposed.(Sterba, 1998, p. 1-13)

Prof. Wright: Philosophy is not about peacemaking! “We have more confidence in our own opinion, and a livelier chance of persuading others, if we can show that those who hold the contrary opinion have made mistakes of fact, or that their arguments are demonstrably fallacious, or that they are incapable of sustained reasoning, or that they have reasons of self-interest for holding their view, or that they have shown themselves on other occasions unaware of or insensitive to the suffering of others, or that they lack some other virtue of character essential to sound moral judgment.”(Dworkin, 1996, p. 106)

President: Thank you, Professor, but we must finish up now. I should add, to be fair, that much philosophical argument is not adversarial. Just one final question: do you believe one can be both an ethicist and a democrat?

Dr. Demos: The things we have discussed: the paramountcy of reason, the pursuit of truth, a rejection of compromise, the tendency for positions to diverge, and so on; none of these things sits easily with being a democrat. And yet it is these traits of ethics and ethicists that can stir up a stagnant pool of ideas, and illuminate what it is to be alive.

Perhaps we need both those who seek to conjure truths out of pure reason, and those who pull those ideas from the ethicist’s hat and into the world of democracy to test whether they are mere illusion. These are two different assignments, needing different skills. So, to answer your question: yes, I do believe that some philosophical ethicists have, or can gain, the skills to contribute effectively to public policymaking.

President: Thank you. We will be in touch soon.

As the door closed, the President turned to his colleague.

President: An ideal candidate - wouldn’t you agree?

Prof. Wright: Yes. Pity, from her CV, I thought she might have a promising future as a philosophical ethicist.

REFERENCES

- ANDERSON, J. E. (2010) Public policymaking: An introduction, Belmont: Wadsworth Pub Co.
- ARCHARD, D. (2009) Why moral philosophers are not and should not be moral experts. *Bioethics*, 25, 119-127.
- ARRAS, J. (2010) Theory and Bioethics [Online]. Available: <http://plato.stanford.edu/archives/sum2010/entries/theory-bioethics/> [Accessed 8 Feb 2012].
- BBC. (27 Sep 2011) Today Programme [Online]. Available: http://news.bbc.co.uk/today/hi/today/newsid_9601000/9601179.stm [Accessed 8 Feb 2012].
- BOHMAN, J. (1997) Deliberative democracy: Essays on reason and politics, Boston: The MIT press.
- BRASSINGTON, I. (2012) What's the Point of Philosophical Bioethics? *Health Care Analysis*, 20, 1-11.
- BROCK, D. W. (1987) Truth or consequences: The role of philosophers in policy-making. *Ethics*, 97, 786-791.
- COHEN, J. (2009) Truth and public reason. *Philosophy & Public Affairs*, 37, 2-42.
- CUP. (2011) Cambridge Dictionaries Online [Online]. Cambridge University Press. Available: http://dictionary.cambridge.org/dictionary/british/representative_1?q=representative [Accessed 1 Nov 2012].
- DAHL, R. A. (1971) Polyarchy: participation and opposition, Newhaven: Yale Univ Pr.
- DAHL, R. A. (2000) On democracy, Newhaven: Yale Univ Pr.
- DANIELS, N. & SABIN, J. E. (2007) Setting Limits Fairly - Can we Learn to share Medical Resources?, New York: Oxford University Press.
- DEWEY, J. (1922) Human Nature and Conduct, New York: Henry Holt & Co.
- DEWEY, J. (1958) Experience and nature, New York: Dover Pubns.
- DICKENSON, D. L. (2000) Are medical ethicists out of touch? Practitioner attitudes in the US and UK towards decisions at the end of life. *Journal of Medical Ethics*, 26, 254.

DWORKIN, R. (1996) Objectivity and truth: You'd better believe it. *Philosophy & Public Affairs*, 25, 87-139.

GARRARD, E. & WILKINSON, S. (2005) Mind the gap: the use of empirical evidence in bioethics. *Bioethics and social reality*. Amsterdam: Rodopi, 73-87.

GORDON, J. S. (2012) Moral philosophers are moral experts! A reply to David Archard. *Bioethics*.

HABERMAS, J. (1996) *Between facts and norms: Contributions to a discourse theory of law and democracy*, Cambridge, MA.: MIT Press.

HOLM, S. (2005) Bioethics down under - medical ethics engages with political philosophy. *Journal of Medical Ethics*, 31, 1.

INGLEHART, R. & WELZEL, C. (2005) *Modernization, cultural change, and democracy: The human development sequence*, Cambridge: Cambridge Univ Pr.

KIM, S. Y. H., WALL, I. F., STANCZYK, A. & DE VRIES, R. (2009) Assessing the public's views in research ethics controversies: deliberative democracy and bioethics as natural allies. *Journal of empirical research on human research ethics: JERHRE*, 4, 3.

KIRKLIN, D. (2007) Minding the gap between logic and intuition: an interpretative approach to ethical analysis. *Journal of Medical Ethics*, 33, 386-389.

PARFIT, D. (2011) *On what matters*, Oxford: Oxford Univ Pr.

REHG, W. & BOHMAN, J. (2002) Discourse and democracy: The formal and informal bases of legitimacy in between facts and norms. *Discourse and Democracy. Essays on Habermas's Between Facts and Norms*. New York, 31-60.

SEN, A. (2009) *The idea of justice*, Cambridge, MA.: Belknap Press.

SMITH, A. (1759) *The Theory of Moral Sentiments* (The Glasgow Edition of the Works and Correspondence of Adam Smith. Oxford: Oxford University Press.

STERBA, J. P. (1998) *Justice for here and now*, Cambridge: Cambridge Univ Pr.

UBEL, P. A. & LOEWENSTEIN, G. (1996) Distributing scarce livers: the moral reasoning of the general public. *Social Science & Medicine*, 42, 1049-1055.

VANHANEN, T. (2003) *Democratization: A comparative analysis of 170 countries*, Hove, England: Psychology Press.

WOLFF, J. (2011) *Ethics and Public Policy: A Philosophical Inquiry*, London: Routledge.

5. Looking elsewhere for an answer

Why look beyond bioethics?

As a student on a PhD. Programme in Bioethics and Medical Jurisprudence, I might have concentrated on either bioethics or medical jurisprudence or both. Bioethics would be the obvious choice for my research question, and philosophical bioethics in particular, with little consideration of other fields like the social sciences.

Traditionally, bioethical research has had little to do with the social sciences, but is now beginning to accommodate empirical analysis.(Borry et al., 2005) It can be argued that a separate strand of inter-disciplinary bioethics exists, accommodating social scientists and others from outside the traditional academic domain of philosophy and ethics.(Bennett and Cribb, 2003) There is much disagreement on the nature of bioethics, but “there does seem to be consensus...it should be in some way relevant to policy and practice”.(Chan and Coggon, 2013, p. 4) My goal in this thesis is to address an ethical policy question – what a healthcare system in a democracy should do - using arguments drawn from philosophy, ethics and other disciplinary perspectives.

Reading literature from these disciplines has illustrated how their separate traditions and methods can lead to fundamental disagreement on many questions of policy and practice. It has also prompted me to question a strict application of the “is/ought distinction”.

Pushing at the “is/ought distinction”

I do not pretend to have anything original to say on the big subject of the “is/ought distinction” (or naturalistic fallacy).(Searle, 1964) (Hunter, 1962) (Geuss, 2008, p. 16-17). I accept that knowing “what is” does not tell us “what ought to be”. However, it seems fanciful to think that “what ought to be” can be discovered with no understanding of “what is”.

The extent to which the “is/ought distinction” is recognised has an effect on this thesis. Strict observance of the “is/ought distinction” would imply that answers to the question of what a healthcare system should do should be grounded in normative argument, drawn from philosophical thinking, without reference to the sciences or social sciences. Respect for the distinction is evident in the writing of many, but not

all, philosophers and bioethicists. Raymond Geuss's mission in "Philosophy and Real Politics" is to undermine the "is/ought distinction" with arguments like the following:

"First, political philosophy must be realist. That means, roughly speaking, that it must start from and be concerned in the first instance not with how people ought ideally (or ought "rationally") to act, what they ought to desire, or value, the kind of people they ought to be, etc., that is, rather, with the way the social, economic, political, etc., institutions actually operate in some society at some given time, and what really does move human beings to act in given circumstances... it does not imply that humans are not sometimes "rational", or that it would not often be of great benefit to them to be "rational." What it does mean, to put it tautologically, is that these ideals and aspirations influence their behaviour and hence are politically relevant..." (Geuss, 2008, p. 9)

Like Geuss, I am doubtful that decision making in a modern representative democracy ought to begin with philosophical principles (as I argue in papers 2 and 4 of this thesis). Like Geuss, I reject the claim that what is done has no relevance to what ought to be done. For example, if something has been done in a particular way for many years in many places and it works, then that should be taken into account when deciding what should be done. What economics and psychology tell us about how people make decisions is relevant when considering how a particular decision ought to be made. Thus some of the normative claims I make in this thesis are backed by both normative arguments and empirical evidence. For example, in the article "What has the state got to do with healthcare?", I back up the normative claim that we ought to care about people who need healthcare but have no resources partly by using empirical evidence that humans are compassionate. If, on the contrary, neuroscience suggested that human beings lacked compassion for their fellow creatures, then it would be very difficult to maintain an ethical justification that relied on the primacy of compassion. The normative argument in favour of compassion would pull against what science tells us about the way humans tend to behave, and thus would have to overcome competing normative arguments supporting, for example, autonomy and liberty. Given that studies of the brain tell us that humans are compassionate, we can

expect people to act freely to care about the plight of their fellows.(Saarela et al., 2007) There is no necessary inconsistency then between compassion and autonomy.

This interpretation of the “is/ought distinction” opens the way for use of empirical evidence to add weight to normative argument, and for a multi-disciplinary approach.

Why I have chosen a multi-disciplinary approach

I have several reasons for adopting a multi-disciplinary approach.

Firstly, healthcare resource allocation, and more specifically what a healthcare system in a democracy should do, cuts across not just bioethics and economics, but other academic disciplines, such as law, political philosophy, systems theory, and history. Any thesis written on this subject requires some consideration of these different disciplinary approaches. If I were to focus on, for example, philosophical bioethics, it would be necessary at the very least to explain why other disciplines did not merit attention. . In trying to understand the research question, I have been drawn to ask more and more fundamental questions, and thus read more broadly across disciplines. If the research question I was addressing was narrower (e.g. “should a person's age matter when allocating resources?”) then I might have read more deeply into, and concentrated primarily on, the bioethical literature.

Secondly, given the vast literature on resource allocation from different disciplines that already exists, I believe that there is a greater chance of contributing something new and of value by drawing on thinking from multiple disciplines. Each academic tradition brings different knowledge and different methods to apply to a problem. Many scholars read, and write for, colleagues from within their own field. A more eclectic approach seems more likely to offer new insights. All methods of inquiry should be open to an inquirer.(Churchman, 1979, p. 13-14) Although I would not claim that this thesis is any more than multi-disciplinary, I am drawn to the logic of philosopher and system theorist Russell Ackoff(Ackoff, 1999, p. 425):

“Effective research is not disciplinary, interdisciplinary, or multidisciplinary; it is transdisciplinary. Systems thinking is holistic; it attempts to derive understanding of parts from the behaviour and properties of wholes rather than derive the behaviour and properties of wholes from those of their parts.

Disciplines are taken by science to represent different parts of the reality we experience. In effect, science assumes reality is structured and organized the way universities are. This is a double error. First, disciplines do not constitute different parts of reality; they are different aspects of reality, different points of view. Any part of reality can be viewed from any of these aspects. The whole can be understood only by viewing it from all the perspectives simultaneously. Second, the separation of our different points of view encourages looking for solutions to problems with the same point of view from which the problem was recognized. Paraphrasing Einstein, we cannot deal with problems as effectively as possible by employing the same point of view as was used in recognizing them.”

Furthermore, the subject area I have chosen is characterised by disagreement, both within and across the disciplines. These are mainly disagreements on principles, often resulting from the different ways of thinking, and different methods, of the disciplines. I am particularly keen to explore whether there are some basic principles on which many people from different disciplines could agree. That is my aim, and so I attempt in this thesis to create a basic framework, rather than a detailed blueprint, of what a healthcare system in a democracy should do.

Lastly, choosing a multidisciplinary approach enables me to draw on educational experience as an undergraduate studying economics; from doing a Masters in Medical Ethics and Law; and on my many years of work experience which has involved interpreting law and policy, consulting people from different backgrounds and disciplines, and synthesising this thinking into detailed policy rules that should govern access to healthcare records and systems.

There are risks in taking a multidisciplinary approach. A Ph.D. thesis is normally narrow and deep. I am choosing a fairly broad research question. Even if I were taking a purely bioethical approach, there would be a large potential literature to read. There is a danger that I tiptoe across vast areas of literature from many disciplines, without delving deeply enough to understand the breadth and rigour of the arguments. A little knowledge can be a dangerous thing. One way to ameliorate this risk is to read review articles, which summarise the state of thinking on a particular topic. Nevertheless, I

recognise that my reading is partial, and that considerable care is required to justify the arguments in this thesis.

Furthermore, drawing from multiple disciplines may obscure or obstruct discovery of truth. Incompatible arguments from different disciplines, or arguments rooted in policy expediency rather than rigorous academic scholarship, may lead to confused conclusions.(Brock, 1987) I am uncertain that there are simple, stable truths to be discovered, but I must be careful to make clear logical arguments that are properly substantiated, especially when drawing from different epistemologies and academic disciplines. As Edward O. Wilson argues:

“A balanced perspective cannot be acquired by studying disciplines in pieces but through pursuit of the consilience among them. Such unification will come hard.”(Wilson, 1999, p. 14)

However, to my mind, the potential benefits of a multidisciplinary approach outweigh the risks. I consider relevant arguments from outside bioethics below.

Relevant arguments from other disciplines

Economics

There are numerous health economists writing about resource allocation. Indeed, in addition to the many health economics journals publishing articles on this subject, there is a journal (“Cost Effectiveness and Resource Allocation”) devoted to the economic analysis of resource allocation in healthcare. Although there were early debates between economists and bioethicists (see section 2), I have found little recent argument in the literature between the two disciplines. It appears that the two camps are publishing primarily to their own kind even though both disciplinary perspectives can illuminate questions of resource allocation in healthcare.

Interestingly, many writers from the two disciplines agree that the prioritisation of healthcare cannot be determined without some recognition, and application of, social values. However, they reach this conclusion through very different logic, and envisage different ways of establishing and applying social values. As discussed earlier, writers such as Daniels and Sabin conclude that decisions about priorities

should involve citizens (and thus reflect social values to some degree) in a fair process, where citizens deliberate together to reach decisions that people can understand and accept (even where they disagree). There are two main rationales for this conclusion: firstly, that fair procedures are needed because philosophers and other writers cannot agree on fair principles, and secondly so that decisions made have legitimacy.(Daniels and Sabin, 2008, p. 1-6)

Few economists are comfortable making such normative arguments; they tend to look to data for answers. Some see the notion of QALYs, and indeed the whole discipline of economics, as value free.(Seedhouse, 1995) That claim can be contested.(Sandel, 2012, p. 43-93)

Many economists are concerned that QALYs may not be the right yardstick to use to determine what a healthcare system should do, and have sought out data to test the QALY formula. Typically, they use data from surveys of public opinion to weight the QALY formula. In two “surveys of surveys”, David Schwappach(Schwappach, 2002) and Paul Dolan et al(Dolan et al., 2005) review the outcomes of numerous “social value” studies (the latter article providing an overview of the results of 64 published studies). Whilst these surveys will interest anyone researching healthcare resource allocation, the majority of the findings reviewed appear to be based on the following implicit assumptions:

- a) public opinion should determine, or at the very least influence, the policy that should be adopted in relation to the difficult healthcare resource allocation policy questions that arise (such as the relevance of age to prioritisation);
- b) surveying people’s preferences is a reliable means of establishing public opinion on such questions.

If public policy-making was merely a matter of satisfying the preferences of the majority of citizens, and if surveys adequately reflected those preferences, then these assumptions would be legitimate. But both of the assumptions above would be difficult to justify, and they are not assumptions that I make, or defend, in this thesis.

Firstly, policymaking in practice is not simply a question of finding out what the public think, and deciding accordingly, or at least not in a modern representative democracy. There are many other considerations, as I explore in paper 6.

Secondly, surveys alone are not an adequate means of determining what a healthcare system should do, or of determining other complex policy decisions. I agree broadly with Daniels and Sabin (Daniels and Sabin, 2008, p. 38):

“We risk having uncovered only tastes, not values, if we carry out a straightforward survey of attitudes toward trade-offs. We may be getting at reasons and values if we instead develop and deploy more complex methods. For example, we might lead subjects in these surveys through a series of questions that import arguments and reasons that might be the basis for making these trades. This complex technique...begins to approximate...philosophical exploration”

Not only is a survey unlikely to encourage ethical reasoning, but participants are unlikely to be given sufficient information as part of the survey process to allow them to weigh competing arguments about complicated policy questions.

The danger of instant surveys was illustrated in a recent deliberative process sponsored by the UK government to assist in deciding whether to protect health spending during a period of government cuts. When surveyed beforehand, 79% of the 24 members of the citizens' jury were in favour, but after three days of deliberation where the citizens had the opportunity to hear and discuss expert evidence, only 9% wanted to rule out cuts in health spending (Stratton, Tuesday 10 August 2010). When people are properly informed and have the opportunity to deliberate with their peers, they can reach very different policy conclusions.

There is another assumption made by those economists who use survey data to adjust the QALY formula. They imply that proper account can be taken of public values, mostly about questions of fairness, through weighting, or otherwise adjusting, the QALY formula. The QALY was not designed, and cannot be weighted, to deal adequately with questions of fairness. I elaborate this thinking, which comes from John Broome, in paper 5 which includes a critique of QALYs.

Economics can inform policy, but it is not a sufficient basis for making normative policy decisions. I agree with Lamont and Favor that:

“Contrary to a popular misconception, economics alone cannot decide what policy changes we should make. Economics, at its best, can tell us the effects of pursuing different policies; it cannot...recommend which policy to pursue.”(Lamont and Favor, 2007)

Similarly, Broome argues that:

“...economics inevitably involves ethics. But most economists don't like to engage in ethical theory. As you know, economists are self-effacing people, who don't like to throw their weight about, and they hate the idea of imposing their ethical views on other people. So they sometimes pretend to themselves and other people that economics is an ethics-free zone.(Broome, 2005, p. 1)

Churchman, one of the founders of systems theory, makes a similar point:

“Many economists have the odd idea that the methods of their discipline raise no serious philosophical problems.”(Churchman, 1979, p. 19)

However, economics has much to offer, and I draw on economic thinking, sometimes in preference to philosophical thinking, in several of my published papers. For example, in paper 5 where I assess the relative fairness of different theories of resource allocation, I argue that the reliance on data is a strength of QALYs, and the lack of reliance of any evidence is a weakness of accountability for reasonableness.

Economics has been developed to deal with large numbers. Broome argues that this is less true of philosophy and ethics, and makes this point in relation to a much-criticised outcome of QALYs in general, and resource allocation in Oregon in particular, where the benefit of relieving headaches for many people was compared with curing a serious illness for one person:

“Because betterness is transitive, I believe there is some number (which is very large) such that curing that number of people of a short, mild headache is better than curing one person of AIDS. However Temkin and Rachels do believe the opposite...Their view is founded on their intuitions. But we are

dealing with very large numbers of people, and we have no reason to trust anyone's intuitions about very large numbers, however excellent their philosophy. Even the best philosophers cannot get an intuitive grasp of, say, tens of billions of people. That is no criticism; these numbers are beyond intuition. But these philosophers ought not to think their intuition can tell them the truth about such large numbers of people. For very large numbers, we have to rely on theory, not intuition...indeed, we are more dependent on theory than engineers are, because moral conclusions cannot be tested in the way engineers' conclusions are tested. If an engineer gets her calculations wrong, her mistake will be revealed when the bridge falls down. But a mistake in moral theory is never revealed like that. If we do something wrong, we do not later see the error made manifest”(Broome, 2004, p. 56-7)

Perhaps Broome is slightly unfair here; Temkin and Rachels may not be relying on intuition, but simply think differently about the notion of good. Economists tend to think in a different way than philosophers about both good and fairness. Many philosophers and bioethicists defend absolute principles, rarely allowing for exceptions, or accommodating competing theories or claims. Furthermore, they tend to write about justice, or good, rather than consider whether one thing is fairer than another, or better than another. John Broome writes:

“There are things that can be learnt from economics. The first is very basic: betterness, like preference, is a *relation*. It relates two things together: one thing is better than another. It is a matter of the comparative value of things. Since economists deal so regularly in preferences, they think naturally in comparative terms and, when they come to think of good, they will naturally ask not what is good, but what is better than what. Philosophers seem not to have this same instinct to think comparatively.”(Broome, 1999, p. 9)

John Broome's writing has encouraged me to think in relative terms (but not become a moral relativist). In addressing the question of what a healthcare system in a democracy should do, I draw heavily on his ideas of relative goodness, and relative fairness. This is not moral relativism. It means thinking about whether one thing is better than another, or whether something is fair to Jack relative to Jill, but does not mean that there is no right and wrong or that all arguments are valid.

Amartya Sen, another scholar of both economics and philosophy, also values a comparative approach, particularly around questions of justice. (Sen, 2009, p. 106) (Sen, 2000, p. 499) Sen recognises the importance of great works in political philosophy, such as Hobbes, Rousseau and Rawls, but argues that there has been too much concentration on what he calls “transcendental institutionalism”:

“First, it concentrates its attention on what it identifies as perfect justice, rather than on relative comparisons of justice and injustice. It tries only to identify social characteristics that cannot be transcended in terms of justice, and its focus is thus not on comparing feasible societies, all of which may fall short of the ideals of perfection. The inquiry is aimed at identifying the nature of ‘the just’, rather than finding some criteria for an alternative being ‘less unjust’ than another.(Sen, 2009, p. 5)

Political institutions exist, and it is arguable whether universal justice makes sense without government(s). Thomas Nagel takes a similar pragmatic position, recognising that universal justice can only emerge through imperfect political institutions.(Nagel, 2005, p. 147)

I am sympathetic to Sen’s and Nagel’s arguments. Policymakers today must try to make things better and fairer within the constraints of existing imperfect political institutions. That is one reason to choose modern representative democracies as the context for this thesis.

Social policy

I argue in this thesis that the question of what a healthcare system in a democracy should do is a public policy question. I have chosen representative democracy as the context for this thesis. Therefore, public and social policy literature is relevant to my thesis.

One of the leading writers on healthcare rationing is Rudolf Klein, a professor of social policy. Interestingly, he reached similar conclusions to those of Daniels and Sabin as far back as 1993. In “Dimensions of rationing: who should do what?”, he concludes(Klein, 1994, p. 311):

“To put it another way, this is an argument that will never be finally settled, but in which we can try at least to ensure that it is conducted with due concern about openness, the appropriate use of evidence, and attention to what counts as good currency in the debate”.

Daniels and Sabin see policy being set by the deliberation of “fair-minded people”, and similarly Klein looks for policy making through debate that “should promote reasoned, informed, and open argument, draw on a variety of perspectives, and involve a plurality of interests”(Klein, 1994, p. 309). Klein explains that rationing is evident throughout the health system (though it may be implicit and hidden).(Wirtz et al., 2003) It occurs not only at national level where budgets are set, but also in countless everyday clinical decisions(Klein, 1997):

“If resources are limited then in certain circumstances it may be reasonable to opt for the second best treatment. In hip surgery, for example, a steel prosthesis is less expensive than a titanium one but less durable. It must be considered acceptable for a physician, as is often the case, to choose a steel prosthesis for a patient aged over 80 while giving a titanium one to a patient who is 70 years old and might perhaps need renewed surgery after a few years...if resources are limited, it may be justifiable to refrain from expanding surgical activities and to stick to medication - which is simple, inexpensive but less effective - instead.”

I pick up two of these themes in papers 5 and 6. In paper 5, I argue that cost and cost effectiveness of treatment does matter. Paper 6 considers who should make resource allocation decisions, and argues that “micro” clinical decisions about what healthcare a patient should receive ought to be shaped by “macro” policy decisions about what a healthcare system should do, and that these “macro” normative policy choices ought to be shaped by the values of the citizens of a democracy.

Political philosophy and political science

In my publications, I draw on a few big themes from political philosophy, and especially theories of justice. Principles of distributive justice are particularly relevant to the question of what a healthcare system should do. There are many such theories, and I explore none in detail. In papers 5 and 6, I consider the relevance of many of the

principles of distributive justice described in the Stanford Encyclopaedia of Philosophy.(Lamont and Favor, 2007)

The institutions and process of public policy-making can vary within and across democracies. However, there are certain characteristics, and certain government responsibilities, that should hold true in every modern representative democracy.

Robert Dahl refers to these as “polyarchies”.(Dahl, 1971a) He identifies and explains six institutions of polyarchal democracy that are necessary to satisfy democratic criteria:(Dahl, 2000, p. 92-99)

1. elected representatives
2. free, fair, and frequent elections
3. freedom of expression
4. alternative information
5. independent political associations
6. inclusive citizenship.

Tatu Vanhanen assessed 102 out of 170 countries in 2001 to be democracies, based on a threshold comprising similar criteria for democracy to those from Dahl above.

(Vanhanen, 2003, p. 188) Clearly whether a state meets a threshold for democracy is not a question of objective measurement, but of subjective assessment. The degree to which a democratic state tolerates, for example, freedom of expression, will vary from place to place. For example, in the United States of America, whilst defamation and “the right to be let alone” are recognised in law, freedom of speech is particularly important, and the subject of the First Amendment of the United States Constitution(Wade, 1961). In the United Kingdom, the law strikes a different balance, and the Human Rights Act 1998 recognises qualified rights to both privacy and freedom of expression (in Articles 8 and 10 respectively).

To Dahl’s list, I would add a requirement from Ronald Dworkin: that democratic governments have a responsibility to show equal concern for all citizens, whatever their gender, colour or shape.(Dworkin, 2006, p. 97) Equal concern does not mean treating everybody the same, but it does mean recognising that every person is of equal worth.

These basic minimum conditions define what I mean by democracy, and thus set the context for this thesis. Whilst I have read a little about some of the ideal theories of democracy proposed by political philosophers, they are not the context for this thesis – they are outside its scope.(Barber, 1984) (Bohman, 1997) (Caspary, 2000) (Christiano, 2011) (Fishkin and Laslett, 2003) (Habermas, 1996) (Kim et al., 2009) (Raz, 1988) (Sen, 1999) My interest is in exploring what a healthcare system in a real democracy should do.

Given the basic minimum conditions for democracy above, it follows that societal values matter in a democracy. Citizens have a voice in public policy decisions in a democracy, even though the influence of most people will be negligible in practice, and a few will have significant influence. (Dworkin, 2006, p. 141) As political philosopher and lawyer Ronald Dworkin explains, our values are rightly shaped by those around us:

“The values and actions of other people may influence us in a more diffuse and reciprocal way: through their impact on the culture in which we all live. Critics sometimes accuse liberals of thinking that human beings can be self-contained atoms who decide questions of value entirely from within their own intellectual resources. It would of course be absurd to think this, and I know of no competent philosopher, liberal or not, who does. Culture is inescapable; few even wish to escape it.”(17)

In paper 6, I consider further the role that values have to play in decisions about what a healthcare system in a democracy should do.

The early political philosopher Thomas Hobbes wrote (Hobbes, 1996, p. 237):

“The safety of the people requireth further, from him or them that have the sovereign power, that justice be equally administered to all degrees of people”

Hobbes’ idea - that it is a fundamental responsibility of a government to protect the safety of all of its people - is now widely accepted. In “what has the state got to do with healthcare?” (paper 3), I argue (and a similar argument has been made by Charles Erin and John Harris (Erin and Harris, 1993, p. page 166)) that in the current era the state should ensure that every citizen has access to healthcare that provides

protection to their safety. Clearly, healthcare cannot ensure that people's safety is always protected – people will die regardless - but a basic level of access is necessary to provide some protection. The idea that public policy should ensure that a basic minimum level of healthcare is accessible to all is taken up by some bioethicists. (Beauchamp and Childress, 2009, p. 258-281) (Ram-Tiktin, 2011) (Buchanan, 1984) Like Beauchamp and Childress, I argue in this thesis that the state has a responsibility to ensure the provision of at least a basic minimum level of healthcare (in paper 3).

Many of the concepts that bioethicists apply when writing about priority setting in healthcare, such as theories of justice and liberty, are drawn from the domain of political philosophy. Similarly, most of the fundamental values held by citizens in a society could be linked to different theories of political philosophy (even though many of the citizens themselves may be unaware of this). Each society places a different emphasis on fundamental concepts like liberty and justice, and these societal values ought to shape policy in a particular democracy.

There has long been doubt in political philosophy about universalist claims; Edmund Burke challenged the French declaration of the “rights of man”, arguing that such abstract rules could never account for varying times and circumstances. (Sen, 2005, p. 159) Whilst universalist claims should be questioned, it does not follow that no universal values, such as the common morality described by Beauchamp and Childress, exist. (Beauchamp and Childress, 2009, p. 3-4)

Law and jurisprudence

The scope of my thesis is a healthcare system in a modern representative democracy. Thus it is applicable to many possible legal jurisdictions. A brief analysis of the relevant law in England provides context for real-life resource allocation, and to how the law of one democracy shapes what is done by one healthcare system (the NHS). It also illustrates some of the difficulties of turning resource allocation theory into practice in a working democracy.

English law recognises the existence of, and court judgements have condoned, healthcare rationing.

Under the National Health Service Act 2006 sections 1 and 3, the Secretary of State was given a duty to *promote* a comprehensive health service, providing services that meet “reasonable requirements” free of charge to patients. As the judgement concluded in *R v North and East Devon Health Authority ex p Coughlan*² “he has the duty to continue to promote a free health service...a comprehensive health service may never, for human, financial and other resource reasons, be achievable”. The NHS Act 2006 has now been amended by the Health and Social Care Act 2012. After much controversy, when early versions of the Bill omitted this duty,(Pollock et al., 2012) the Health and Social Care Act 2012 (in section 1) reworded, but essentially retained, this duty to promote a comprehensive health service provided free of charge. Clinical commissioning groups become responsible under section 13 of the Health and Social Care Act for ensuring that the “reasonable requirements” of individuals are met.

The courts have recognised that the NHS cannot fund all possible treatments requested by patients. Furthermore, they have steered away from telling health authorities how they ought to spend their budgets, only stepping in if an authority acts irrationally or when proper procedure has not been followed (the traditional grounds for judicial review, as explained by Lord Diplock in *Council of Civil Service Unions v Minister for the Civil Service*)³. In *R v Central Birmingham Health Authority ex p Walker* the judge concluded that “it is not for this court, or indeed any court, to substitute its own judgement for the judgement of those who are responsible for the allocation of resources”⁴. Rather like Daniels and Sabin, the law and the courts have become concerned with ensuring that the NHS has fair processes for rationing, rather than assessing the fairness of their rationing principles.

The law required primary care trusts, and now requires their successor bodies the clinical commissioning groups and NHS Commissioning Board (now renamed NHS England), to decide what healthcare services to commission, but backed by policies and procedures. As Christopher Newdick explains in relation to (the now defunct) primary care trusts:(Newdick, 2007, p. 236)

² [2001] QB 213

³ [1985] AC 374 at 410

⁴ [1987] 3 BMLR 32 at 32

“Primary care trusts (PCTs) require reasonable and lawful policies to control their expenditure. Inevitably, this means that some treatments may be regarded as low priority and difficult to obtain within the NHS; for example, cosmetic surgery, or expensive treatment where clinical effectiveness is marginal, or unknown. However, general policies of this nature must also include ‘exceptional case review’ procedures. Individuals should be entitled to argue that, the general policy notwithstanding, their treatment is likely to be of such exceptional benefit that it deserves to be funded by the NHS.”

However, as Newdick goes on to explain (Newdick, 2007, p. 236-238), only legitimate priority setting by commissioners is acceptable, balancing the duty to promote the health of the community with the duty to keep spending within budget. One of the factors that primary care trusts have had to take into account in their decision-making is guidance from the National Institute for Health and Care Excellence; PCTs have been under a legal obligation to make available all NICE-approved treatments normally within three months. (Department of Health, July 2003) With the abolition of PCTs, these responsibilities have now passed to clinical commissioning groups under the Health and Social Care Act 2012 (sections 13, 34).

It is clear from *R v North West Lancashire Health Authority, ex p A, D and G*⁵ that commissioners’ policies and procedures for rationing must be rational. Authorities must allow for exceptional individual cases, and where a decision seriously affects a citizen’s health, it will require substantial consideration. Auld LJ explained:

“To deny treatment except in exceptional circumstances such as overriding clinical need is not in principle irrational, provided that the policy genuinely recognises the possibility of there being an overriding clinical need and requires each request to be considered on its individual merits.”⁶

In *R. (Linda Gordon) v. Bromley NHS Primary Care Trust*⁷, Bromley Primary Care Trust failed to explain precisely enough why it had refused her access to the drug

⁵ [2000] 1 WLR 977

⁶ [2000] 2 FCR 525 at 526

⁷ [2006] EWHC 2462

Tarceva. Their decision-making process did not withstand judicial scrutiny, and the judicial review ordered that the primary care trust must reconsider its decision. However, it is far from easy to make a rational argument as to what makes one patient exceptional and another unexceptional, and the courts have failed to give commissioners clear guidance on how such distinctions should be made.(Ford, 2012)

In addition to these demands of exceptional case review, EU law adds additional complications for commissioners. It is clear from *R(on the application of Watts) v Bedford Primary Care Trust*⁸ that patients may go overseas for treatment in certain circumstances, as Newdick explains:

“The European Court of Justice (ECJ), however, has developed a different approach focusing simply on the need of individual patients. Ignoring the opportunity costs of diverting finite resources from Peter to treat Paula, it has said that if ‘normal’ treatment cannot be obtained at home without ‘undue delay’, it may be purchased in the EU abroad on the basis that the cost will be met by the ‘home’ health authority.” (Newdick, 2007, p. 244)

The UK government plans to clarify this right by implementing Directive 2011/24 EU(Department of Health, 2013) Individual rights are protected under the European Convention on Human Rights, and article 14 prohibits discrimination in the application of those rights on numerous different grounds, including gender, race, and religion. However, article 14 protects individuals against discrimination only of their rights under the convention. There is no human right to distributive justice, as the House of Lords made clear (in *Matthews v Ministry of Defence*):

“I think it is well arguable that human rights include the right to a minimum standard of living, without which many of the other rights would be a mockery. However, they certainly do not include the right to a fair distribution of resources or fair treatment in economic terms – in other words, distributive justice. Of course, distributive justice is a good thing, but it is not a fundamental human right.”⁹

⁸ [2006] 90 BMLR 150

⁹ [2003] UKHL 4 paragraph 26

However, as Charles Foster explains in relation to that judgement:

“It could be argued that the expression “distributive justice” is being used rather inaccurately here, and indeed that by supporting rational refusals to allocate resources for a particular purpose, the courts are really maintaining the overall size of the fund available for NHS patients as a group, so promoting, rather than inhibiting, distributive justice. By saying that distributive justice “is not a fundamental human right”, all that the House of Lords is really saying is that an individual patient does not have an enforceable right to put their own hand into the public purse and take out what they happen to need.” (Foster, 2007)

Systems theory

A section on systems theory may seem an unlikely component of a Ph.D. thesis in Bioethics and Medical Jurisprudence. Systems theory has been developed over the last sixty years. I will try to explain here a little about systems theory and systems thinking, and why it is relevant.

When designing a system – any system – we must know what we are trying to achieve, and any constraints on achieving it. We also want to know other variables: the actors who achieve it, the system boundary, intended beneficiaries and the key decision-makers who “own” the system.

When designing a gas-fired power station, we might aim to maximise the amount of electricity we can produce from gas, subject to constraints like legal limits on carbon emissions. Acme company might own the system, and its workforce are the actors. A local electricity distributor may be the customer. All of these things – the aims, constraints, actors and owners - are very likely to be known from the outset. It is a systems engineering problem for which there will be a “hard system” solution.

In contrast, a healthcare system is an example of what Peter Checkland, the architect of soft systems methodology, calls a “soft systems” problem: a “messy, ill-structured, real-world problem”(Checkland, 1985, p. 763). For a healthcare system, it is likely to be difficult to define the fundamental design variables. For example, what is the purpose of the healthcare system? Is it, for example, “restoring human functioning to

a decent minimum”(Schneiderman) or “maximising health benefit” (as with QALYs)? Are there constraints of fairness on the system, such as equal access to healthcare for all citizens, or no discrimination according to age?

According to Checkland, soft systems methodology is designed to “cope with the complexities of human affairs”(Checkland, 2000, p. S39). When defining soft systems, Checkland argues that we not only must define the purpose, constraints etc. as with a “hard system”, but we must also try to establish “weltanschauungen” – the worldviews incorporating values or beliefs that could underpin the system. By explicitly establishing these differing worldviews, a system may be defined from a number of differing viewpoints, thereby highlighting from the outset potential conflicts that should be addressed.

Consider, for example, a prison system. Depending on your worldview, you could see it primarily as an institution to: incarcerate dangerous people to protect the public, to punish people, and/or to rehabilitate people. Different types of stakeholders (e.g. citizens, politicians, civil servants, judges, police, probation officers etc.) are likely to place different emphases on these potential purposes of a prison, as will different individual stakeholders. By identifying different worldviews, each with different purpose(s) and potential impact on a future prison system design, enables these different purposes to be discussed more meaningfully, and enables some kind of reconciliation of different perspectives in the course of a system’s design. Two very different prison systems could result from two different worldviews.

Citizens of a democracy, as well as the government and clinicians, are stakeholders in their society’s healthcare system(s). Their worldviews and values will inevitably vary. As a result, they are likely to disagree about what the aims of the healthcare system ought to be, and how it should be constrained (for example, if fairness is a defined constraint, what counts as fair). Some method of recognising differing worldviews and establishing a worldview to underpin the system is necessary. This ties in with the thinking of Daniels and Sabin(Daniels and Sabin, 2008, p. 2):

"Unfortunately, no democratic society we are aware of has achieved consensus on such distributed principles for healthcare. Even people who want to cooperate in steering a society's health system will hold diverse moral and

religious views. Their individual value systems would lead them to disagree morally about what constitutes a fair allocation of resources to meet competing healthcare needs."

The concept of a "worldview" is closely linked to the concept of "values" which I discussed in earlier sections. In the Concise Oxford Dictionary (Soanes and Stevenson, 2004), "worldview" is defined as "a particular philosophy of life or conception of the world", and "values" is defined as "principles or standards of behaviour". Thus, "worldview" is a broader concept encompassing more than just "values", but both are part of a person's fundamental beliefs. The German term "weltanschauung" is used in systems theory. It is a richer term than "worldview", conveying underpinning beliefs and values, as well as a philosophy of life.

Most of the discussion above is about soft systems methodology. Another related approach, critical systems thinking, has much in common with the soft systems methodology approach to defining a system. Both soft systems methodology and critical systems thinking have their roots in the work of C. West Churchman and Russell Ackoff – originally philosophers and subsequently founders of the field of operations research (a subject closely linked to systems theory). Ackoff, Churchman and Checkland are all concerned with a process of human inquiry and with purposeful behaviour (Checkland, 1985). Like soft systems methodology, critical systems thinking recognises:

- A goal, transformation of some kind, or purpose, to be achieved by the system (Ison, 2008, p. 154-5);
- A defined boundary setting the scope of the system;
- Constraints within which the system must operate; and
- The importance of worldviews of stakeholders in shaping the system.

In addition, both methodologies take a whole systems, rather than reductionist, approach, and consider a system to be more than just a sum of its parts (Fuenmayor, 1991, p. 421). Analysing a problem situation therefore involves considering it within its wider context.

However, whilst the soft systems approach focuses on capturing multiple perspectives of a situation, critical systems thinking acknowledges power relations that may shape the problem situation such as age, gender, ethnicity, social-economic class etc (Ramage and Shipp, 2009, p. 153).

An overview of the work and thinking of Churchman, Ackoff and Checkland is presented in “System Thinkers” (Ramage and Shipp, 2009). In that book, Magnus Ramage and Karen Shipp provide an introduction to systems theory and theorists, and a description of the main strands of systems thinking: general systems theory, early and late cybernetics, soft and critical systems, system dynamics, complexity theory and learning systems. The strand which is most relevant to this thesis is soft and critical systems thinking, which has been developed to address problematical human situations.

Systems theory provides an understanding of the nature of systems, and of what systems (such as a healthcare system) should do, and so is relevant to this thesis. In paper 6, I draw on systems theory, and soft and critical systems thinking in particular. That thinking contributes to some of the underpinning themes of this thesis, such as:

- The problem of what a healthcare system in a democracy should do can be considered from many perspectives, including a systems perspective;
- It is important to take into account the differing worldviews of different stakeholders (e.g. citizens, patients, clinicians, government etc.) when considering what a healthcare system in a democracy should do;
- Context matters in systems theory, and in this thesis the context of democracy matters, and shapes how worldviews are reconciled and decisions are made; and
- If worldviews and values (e.g. about what is good and fair) vary across democracies (see below), then what a healthcare system should do should also vary from democracy to democracy.

I also draw on publications from some other disciplines, including neuroscience, psychology and history.

6. A good and fair answer

Two articles addressing the question of what a healthcare system in a democracy should do

The majority of the analysis, and conclusions, in response to the question of what a healthcare system in a democracy should do, are contained in two articles: papers 5 and 6 at the end of this section.

Paper 5, which is entitled “Accountability for reasonableness: as unfair as QALYs?”, analyses three competing frameworks for prioritising resources in healthcare: accountability for reasonableness, maximisation of quality adjusted life years, and a “good and fairness framework” that I construct from the writing of John Broome. In it I conclude that the last of these three approaches is the least vulnerable to large-scale injustice. It has been submitted to, and is under review by, the *Journal of Health Politics, Policy and Law*.

Paper 6 addresses head-on the research question of this thesis, being entitled: “In a democracy, what should a healthcare system do?”. It analyses the question from first principles, drawing from philosophy, economics, and systems theory. It concludes that Broome’s thinking on good and fairness, interpreted and applied by policymakers, provides an answer. The paper has been accepted by *Politics, Philosophy and Economics*, and is due for publication later in 2013.

Why good and fairness are separate considerations

It should be noted that papers 5 and 6 discuss “good” and “fairness” as though they are entirely separate notions that must be considered separately. But if two options are equally good, and one is fairer than the other, then we might say that one is better than the other. It could easily be argued that it is good to be fair, so fairness is part of goodness. (Nussbaum, 2004, p. 436) Indeed, this is what Broome believes. (Broome, 2004, p. 37-39) But, Broome explains, fairness is different in that it is a “second-order” good, “concerned with how first-order goods are distributed among people”. (Broome, 2004, p. 37) Thus it is not practical to weigh it alongside other goods. For this reason, I consider good and fairness separately in the two papers.

A partial answer

Paper 6 sets out the theoretical underpinnings of a framework, and the framework is elaborated in more detail in paper 5. Together these two papers provide an answer to the question what a healthcare system in a democracy should do, but stop well short of a blueprint. The good and fairness framework is intended to be a structure on which a variety of more detailed resource allocation rationale could be built. For example, it could be developed further to accommodate different social values, political manifestos or philosophies. Much room for contention remains, and will always remain. (Klein, 1994, p. 311) As Broome says:

“In the meantime, we have no uncontentious way, in practice, of fixing a value on life. This is a difficulty for governments, which have to make decisions about the allocation of resources. But the difficulty is scarcely unique. We also have no uncontentious way of assigning a value to the inequality of income in a society, or to education, or to many other things; yet governments have to act. We need research and discussion to help us move nearer to the truth. But we must not give the impression that the truth has already been discovered.” (Broome, 1999, p. 227)

Papers 5 and 6 follow directly below.

Paper 5: Accountability for reasonableness: as unfair as QALYs?

ABSTRACT

When allocating resources to healthcare, we might expect that an approach which aims specifically to promote justice, such as Daniels and Sabin's accountability for reasonableness, would be unlikely to lead to injustice, whereas quality-adjusted life years (QALYs), much criticized as unfair, would be more likely to lead to injustice. I conclude here that accountability for reasonableness is as vulnerable to large-scale injustice as QALYs.

Using a recently-reported case of large-scale injustice against mentally-ill people in England as an example, I assess how likely it is that such injustice could occur under three competing theories for allocating resources to healthcare. Accountability for reasonableness is vulnerable, primarily because it relies on individual judgments of fair-minded citizens, and does not require decisions to be based on evidence of the costs and benefits of healthcare. QALYs recognize the good of healthcare, and can be used to maximize health gain, but do not take specific account of fairness. A 'good and fairness' framework, based on the writing of John Broome, and drawing on both economic and philosophical thinking, is least vulnerable to injustice because it recognizes both the good of healthcare to be distributed, and how that can be traded off for reasons of fairness.

INTRODUCTION

Aim and Structure

Large-scale injustice is a genuine risk when allocating resources to healthcare. For example, a recent report alleged unfair discrimination by the National Health Service (NHS) against millions of mentally ill people in England. I consider this example, and then assess which of the following frameworks for prioritising healthcare resources are likely to prevent such injustice:

- quality-adjusted life year (QALY) maximization;
- Norman Daniels and James Sabin's accountability for reasonableness (A4R);
- A 'good and fairness' framework I have drawn from the writing of John Broome.

The article finishes with conclusions.

Terms Used

I will use the term *fairness* to mean "to attribute to each his or her due".(de Villanueva, 2010, p. 102, Hobbs, 2010) It rests on the assumption that each person matters in themselves, but does not mean each person is entitled to an exactly equal share of whatever is being distributed (Hobbs, 2010). Raymond Geuss refers to a very similar definition of *justice* that dates back to Roman law: "iusstitia est constans et perpetua voluntas ius suum cuique tribuens" or "justice is the constant and unflagging will to give to each person what is due to him".(Geuss, 2008, p. 73) Thus, for the purposes of this article, I do not make a distinction between 'fairness' and 'justice'; I use the two terms interchangeably.

When allocating resources to healthcare, it is distributive justice that concerns us, and the question that is begged by the definition of fairness above, namely 'what is due to each of us?'. As Julian Lamont and Christi Favor explain in the Stanford Encyclopaedia of Philosophy, "principles of distributive justice are normative principles designed to guide the allocation of the benefits and burdens of economic activity", and there are many competing principles, including strict egalitarianism, the difference principle, and welfare-based principles(Lamont and Favor, 2007). Different

principles provide different answers to the question ‘what is due to each of us?’, and are at the root of many of the debates about what constitutes fair prioritisation of resources in healthcare.

I give the term *good* the meaning used by Broome, so that there is no more to good than *betterness* - it is a comparative term (Broome, 1999, p. 163-4). It does not refer to a specific conception of the good or a good life. *Utility* is a term used by economists to represent preferences, either actual preferences or the preferences of a rational, self-interested person.(Broome, 1999, p. 28) Economists can draw a utility function and use it to illustrate which of two options is *better* for a person. In the context of healthcare resource allocation, doing good involves producing benefits or eliminating harms, and thus it is broadly consistent with the principle of “beneficence” which Beauchamp and Childress describe as “all forms of action intended to benefit other persons”.(Beauchamp and Childress, 2009, p. 197) In this article, the concept of “good” excludes the value that we place on fairness. It is used to capture: the direct health gain to an individual from healthcare, but can also include any non-health gains that an individual realizes as a result of receiving healthcare (e.g. additional income received from returning to work); plus what economists refer to as *externalities* – the knock-on effects on others of healthcare provided to an individual. For example, an effective treatment benefits an employer and society at large when we return to work, and the vaccination of one person is good for other people because it reduces their risk of infection.

Thus the term *health gain* is a narrow conception of good derived from healthcare, being just the health benefit derived by a person receiving health services. A *quality-adjusted life year (QALY)* is one measure of health gain, but not the only possible measure. One QALY represents a healthy year of life(Williams, 1985).

THE RISK OF LARGE-SCALE INJUSTICE

When a decision is made to deny an individual needed healthcare, this could be an injustice. However, when a decision is made to deny treatment to thousands or millions of people, this could be a large-scale injustice. It matters morally if one individual is harmed as a result of unfair treatment by decision-makers, even though some such incidents may be inevitable when distributing resources across millions of people. But if millions of people are treated unfairly, the wrongdoing increases commensurately.

An Example of Alleged Injustice in the NHS in England

Such large-scale injustices can occur. The London School of Economics (LSE) recently published, and gained much national media attention (BBC News, 2012) for, a report entitled “How mental illness loses out in the NHS”. (Mental Health Policy Group, 2012) It follows on from similar work published by Richard Layard, one of the report’s authors (Layard, 2004, Layard, 2006). The report begins by claiming that “there is one massive inequality within the NHS: the way it treats mental illness as compared with physical illness”.

The authors argue that people with mental illness are being treated unfairly because: a) mental illness has a debilitating effect on individuals; b) approximately three quarters of the people suffering mental illness are not given treatment; c) the mental health treatments being denied would significantly increase quality of life; d) these treatments are very low cost, or even zero cost when allowing for the improvements to physical health that also result; and e) treatments for physical health are being funded that do not achieve the same improvement in quality of life for the money spent.

Some would challenge whether priorities in mental health are this straightforward, and whether solutions are easy to find and apply. (Callahan, 1994) It is also possible that the empirical data underpinning these claims may be challenged. However, these figures *could* be accurate: there is no reason to suggest they are impossible, and that such claims could not be true of the NHS. Indeed, such spending disparities could be true not just in the NHS, but in any healthcare system where resources are limited and limits are set, whether it be by a government or other public body allocating tax or state insurance revenues, or a private company deciding on the boundary of its health

insurance policy. As Norman Daniels and James Sabin explain in the opening sentence to their book "Setting Limits Fairly", "all societies set limits to healthcare one way or another, fairly or unfairly"(Daniels and Sabin, 2008, p. 1)

Is the Reported Treatment of Mentally-Ill People by the NHS Unfair?

Assuming then that the empirical evidence is valid, people in England are not being treated equally; people with mental illness are much less likely to receive NHS treatment than people suffering to a similar extent from physical ill-health. This represents an inequality. Distribution is unequal.

However, because there are competing principles of distributive justice, it does not follow that such unequal treatment is necessarily unfair. A libertarian like Robert Nozick rejects patterned principles of distributive justice because it is not for institutions but for individuals "to decide for themselves to whom they will give the thing and on what grounds"(Nozick, 1974, p. 235). For Nozick, the inequality identified in the NHS would not necessarily be an injustice. However, under almost any other principle identified in Lamont and Favor's summary of distributive justice, the alleged treatment of people with mental illness in England appears not only unequal, but also unfair.(Lamont and Favor, 2007) Discriminating against people with mental illness would not satisfy John Rawls' 'difference principle', which " treats everyone equally as a moral person, and which does not weight men's share in the benefits and burdens of social cooperation according to their social fortune or their luck in the natural lottery".(Rawls, 1999, p. 65) Denying treatment to people with a mental illness increases, rather than reduces, disadvantage. It would certainly be incompatible with welfare-based principles and with utilitarian ideals. Those advocating desert-based principles, such as David Miller, (Miller, 1979, p. 83-121) have no reason to argue that people with a mental illness are less deserving of treatment than those with a physical illness. Even under resource-based principles, such as the "prudent insurer" model proposed by Ronald Dworkin, such inequality could only be fair if people had consciously chosen in advance to insure themselves against physical ill-health, but not against mental ill-health. (Dworkin, 2002, p. 319-321)

Thus it is reasonable to conclude that, when considered against almost any principle of distributive justice, the gross inequality in service provision as reported in the LSE report is unfair to people who suffer from mental illness and do not receive treatment.

The LSE report makes a second argument. It suggests that this inequality is all the more unacceptable because treating people with mental illness is relatively cheap and successful, and reduces the amount spent on their physical ill-health so that the net cost of treatment is zero or even negative. Does this make things all the more unfair?

Yes, it does. There is little consensus in the literature on healthcare resource allocation, but almost all writers agree that resources are inevitably limited. No matter how healthcare is funded, be it publicly or privately, whether through insurance schemes or not, limits must be set. The policy dilemma only exists because resources are limited. Therefore, the cost of different healthcare treatments must matter. It cannot be ignored under any of the principles of distributive justice because money is the thing that is in short supply. The actual costs of treating mental illness, and the reported knock-on effects of reducing the future costs of treating physical ill-health, are relevant. Depending on the principle of distributive justice adopted, it may or may not be unfair to deny a person beneficial health treatment if the cost is \$1 million. However, under almost any conception of distributive justice, it will be unfair to deny that treatment if the net cost is zero, or close to zero.

Therefore, if the alleged under-funding of mental health services is true, it is not only unequal but also unfair to millions of people. It is injustice on a huge scale.

The Risk of Large-Scale Injustice when Allocating Resources

Although the government is criticized for setting inappropriate targets, it is primary care trusts that attract much of the criticism in the LSE report. Primary care trusts decide how much of the health budget for a local population should go on mental health services. They tend to use a variety of criteria for determining priorities, with much variation in criteria between primary care trusts.(Klein, 2010) Where there is no strong and consistent rationale or procedure underpinning their decisions, it is perhaps unsurprising that large-scale injustice, such as that alleged in the LSE report, could occur.

However, systematically applying a theory of resource allocation could also result in large-scale injustice. If the theory is flawed, or particularly vulnerable to injustice, then injustice on a large-scale could result. But how likely is this to happen? How vulnerable are different theories of resource allocation in healthcare to injustice affecting millions of people?

In the next two sections of this paper, I address these questions in relation to the two most widely-cited approaches to resource allocation in economics and philosophy: quality-adjusted life year (QALY) maximization, and accountability for reasonableness (A4R). QALY maximization has been much criticized as unfair, and so might be expected to be more vulnerable to large-scale injustice. A4R, a theory of procedural justice, might be expected to fare better. However, unlike A4R, QALY maximization means getting as much health gain as possible from available resources, which is what the LSE report said that the NHS was failing to do.

I will also assess a framework drawn from John Broome's writing, which aims to take account of both health gain and justice.

WOULD QALY MAXIMIZATION PREVENT SUCH INJUSTICE?

Quality-adjusted life years (QALYs) provide a measure of the benefit that is derived from healthcare. A healthy year counts for one QALY, and a less-than-healthy year counts for less than one. A QALY score for a person can be reached by multiplying the health gain per year (a figure between 0 and 1) by the number of years of gain. By aggregating scores across groups and populations, alternative healthcare treatments or other courses of action can be compared.

Since they were first proposed, economists have given considerable attention to assessing the validity of QALYs. It has been recognized that the simple concept of health gain, measured in expected health improvement multiplied by the number of years of improvement, may not capture the full goals of a health service. Theoretical arguments have been put forward in favor of weighting or otherwise adjusting a simple QALY maximization formula in order to take account of various factors including:

- Age and life expectancy(Tsuchiya, 2000);
- The contribution, and potential loss of productivity due to lost health, to society from the individual (e.g. as an employee, a parent, a tax payer)(Brouwer et al., 1997);
- The severity of an individual's health condition prior to treatment(Nord, 1993);
- The size of the health benefit(Culyer, 1997); and
- The duration of health benefit and discounting over time(Nord, 1999, p. 50-57).

The results of QALY maximization, or indeed of applying an adjusted QALY maximization formula listed above, depends on the system adopted for measuring health states and health gain.(Grieve et al., 2009)

QALYs are about Good, not Fairness

Many writers, and particularly philosophers and bioethicists, have criticized QALYs on grounds of fairness.(Harris, 2005, Nord et al., 2009, Clark and Weale, 2012, Beauchamp and Childress, 2009) For example, it is argued that QALYs are unfair to

older people and disabled people who have on average fewer good quality life years to gain. According to some, but not all, principles of distributive justice, QALY maximization is unfair.

John Broome argues that QALYs should not be expected to be fair:

In medical decisions, benefit is obviously an important consideration, but it is often not the only one. Another is fairness: when treatment is to be given some patients and denied others, to treat those whose treatment would do the most good is not necessarily the fairest thing to do. Other things being equal, for instance, treating a younger person is likely to do more good in total than treating an older one, because the younger has longer to enjoy the benefits. But if resources are concentrated on the young for this reason, that may be unfair to the old. So benefit and fairness may conflict. Qalys are only concerned with benefit. Consequently, they cannot entirely determine which decision is the right one. The friends of qalys have not always acknowledged this limitation, and this has exposed qalys unnecessarily to attacks from their enemies. The main objection raised against them is that their use is unfair. Qalys certainly do not take account of fairness; they cannot be expected to. Fairness must be considered separately.(Broome, 1993, p. 149-150)

Perhaps Broome's critique is rather strong because QALYs embed a type of fairness, even if it is one that not everyone accepts. For instance, QALYs are blind to the specific recipient, all that matters is that somebody benefits. But the general point is true – they are built to measure good, not fairness.

Many economists attempt to take account of fairness by weighting the good that QALYs bring, using the results of public surveys of social values (Dolan et al., 2005, Schwappach, 2002). Whether or not public surveys are a useful source of knowledge on fairness (and few philosophers would say they are), surveys should only be used to adjust the notion of "good" that QALYs capture, because QALYs are about good and not fairness. Good and fairness are distinct concepts. Fairness should be taken into account outside of the QALY formula, not within it.

A Systematic Application of QALYs would Provide Protection against the Large-Scale Injustice in the NHS

Therefore, because QALYs do not address fairness, when used in isolation, they could lead to unjust outcomes. However, because the criticisms of the NHS in the LSE report are all about the unequal apportionment of good, and not about the strength of the fairness claims of different people, the systematic application of QALYs should avoid the gross inequality alleged by the report authors. QALYs are designed to take account of the debilitating effect of mental illness relative to physical illness, of the benefit of improving the health of people with a mental illness at relatively low cost, and of the potential benefit to physical health that can result from treatment for mental illness. Assuming the LSE's empirical data is accurate, a systematic evaluation of all treatments in the NHS, both for physical and mental ill-health, would reveal that many mental health treatments are under-funded. As a result, unless the overall NHS budget was increased, some treatments which generated fewer QALYs per pound would be withdrawn so that mental health treatments were funded.

Therefore, assuming that states of health can be assessed accurately, and that levels of health improvement can be predicted, and that the knock-on effects of treatment on physical health can be identified and measured, QALY maximization should prevent the large-scale injustice identified in the LSE report (even though it does not prevent some other unfairness). The systematic application of QALYs would highlight not only this injustice, but also the under-achievement of the NHS: it could, and should, be doing more good with its limited resources.

QALY Measurement is Error-Prone

However, the above conclusion depends on some big assumptions. Significant practical issues arise when applying QALYs, such as:

- Can health states be measured objectively (e.g. using a quality of life scale such as EQ-5D)?
- Can one person's health state be compared with another's?
- Does data exist enabling health gains to be reliably predicted and measured?

These are not reasons to reject QALYs or other forms of measurement. They are reasons to strive for better measures of good. It is much better to approximate good than to ignore good. An imperfect measurement is better than none at all.

QALYs Provide only a Partial Indicator of Good

QALYs provide a narrow conception of good. Importantly, QALYs do not address the extremely difficult question of valuing new life. Should the good of a new life that a technology such as in vitro fertilisation provides be counted or ignored? This is a complex question that has been much debated by both economists and philosophers, including Broome. (Broome, 1993, p. 161-163, Broome, 2004) If it were resolved, QALYs could be applied accordingly. Whilst unresolved, it undermines to some extent any theory, like QALY maximization, that relies on measuring good.

QALYs do not take account of externalities. As much healthcare brings positive externalities, QALYs may systematically undervalue healthcare relative to other goods, and undervalue one intervention in relation to another, leading to poor choices. The externalities are hard to measure, but failing to estimate benefit inevitably leads to systematic, and potentially significant, bias. Consider two examples.

Firstly, consider the effect on a person who cares for a patient suffering from Alzheimer's. Medication can benefit the patient, and as a result, the patient's carers. But how can the effect on the carers be measured when we may know nothing about the carers, and when the beneficial effect of treatment on the carer may vary greatly from person-to-person? Taking these factors into account is not without difficulties. However, unless some attempt is made to take account of these externalities, we can be sure we will under-estimate the benefits of one intervention relative to another intervention, leading us to make sub-optimal choices. These choices are also likely to be unfair, for example on the carers of patients with Alzheimer's (Herring, 2007, p. 54-56).

Secondly, consider the effect of working days lost on employers and to the state in lost taxes. QALYs take no account of these effects. These too are hard to measure. Furthermore, as Alan Williams explains, it will lead us to prioritize healthcare for the working population, especially the well-paid, and discriminate against the low-waged and unwaged (Williams, 1992, p. 8-9). This, says Williams, is a problem because it

“seems to run counter to the principle that the provision of treatment should not be influenced by whether you are rich or poor”. But this thinking highlights the problem with trying to adjust the QALY maximization formula to account for fairness.

QALYs provide a means of measuring health gain. Fairness should be considered separately. The QALY score should indeed reflect externalities, so as to estimate “good” as accurately as possible, even if a judgment is then made on grounds of fairness to adjust for the differential effects on a rich and poor person (for example, to decide to treat each the same). Failing to take any account of the positive externality of reduced working days lost will result in systematic under-valuation of healthcare relative to other goods.

Without Separate Adjustment for Fairness, other Large-Scale Injustices could Occur

As QALYs are not equipped to address fairness, QALY maximization could lead to other types of large-scale injustice. For example, if according to an agreed principle of distributive justice, it is unfair to older people to deny them treatment where a younger person receives it, because they have a lower QALY score (and thus lower level of good), then a large-scale injustice against older people would result.

Similarly, because the maximum QALYs for a year for a disabled person is less than one, they have fewer QALYs to gain from healthcare. When a disabled person and an able-bodied person each need life-saving treatment then, all other things being equal, the able-bodied person would have more QALYs to gain. If resources were allocated purely according to QALYs, this could potentially cause large-scale injustice. This of course depends on what counts as fair.

WOULD A4R PREVENT SUCH INJUSTICE?

Accountability for Reasonableness (A4R)

Philosopher Norman Daniels asks “how can we meet health needs fairly under resource constraints?”(Daniels, 2008, p. 11). He and James Sabin recognize the difficulty in reaching agreement on the normative principles of distributive justice discussed earlier (Daniels and Sabin, 2008, p. 2). The divisions are deep, both within and across academic disciplines, with economists typically advocating theories that maximize, or at least emphasize, utility, whilst most philosophers and bioethicists pursue competing notions of justice.

Daniels and Sabin’s response, both to disagreement on principles and to Daniels’ questions above, is procedural justice, and specifically “accountability for reasonableness” (A4R). This shift towards process, and away from a defined rationale, has been called the “second phase of priority setting in healthcare”.(Holm, 1998) Since its initial publication in the late 1990s, A4R has been applied (often with support from Daniels and Sabin) in many developing and developed nations(Daniels and Sabin, 2008, p. 149-209). The National Institute for Health and Clinical Excellence claims to use A4R in conjunction with QALYs, although this claim has been disputed.(Schlander, 2008)

Daniels and Sabin describe the essence of A4R: (Daniels and Sabin, 2008, p. 44)

Accountability for reasonableness is the idea that the reasons and rationale for important limit-setting decisions should be publicly available. In addition, these reasons must be ones that "fair-minded" people can agree are relevant to pursuing appropriate patient care under necessary resource constraints.

Where resources are limited (as they inevitably are), reasonable people disagree about how healthcare resources should be prioritized. This, says Daniels, is why a “fair deliberative process” is required, where citizens consider and debate how to prioritize resources(Daniels, 2008, p. 282). For such a process, the four conditions of A4R must be met(Daniels and Sabin, 2008, p. 43-66):

- Publicity: prioritisation decisions made, and their rationale, must be publicized;

- **Relevance:** the rationale on which decisions are made must be reasonable, taking account of how the organisation setting priorities provides value for money and meets varied health care needs;
- **Revision and appeals:** there must be a mechanism for individuals to challenge and dispute decisions, and for the organisation to learn and revise its policies; and
- **Regulation:** there must be either external or self-imposed mechanisms for enforcing the first three conditions above.

For Daniels and Sabin, resource allocation will not be fair unless these four conditions are met.

Is meeting these conditions a way to avoid large-scale injustice, or could A4R result in services like mental healthcare being grossly under-funded? The analysis below addresses this question. It assesses A4R specifically, and not Daniels and Sabin's wider writing on justice and health.

A4R is Designed to be Fair

Given A4R is designed to provide procedural justice, we would expect it to be relatively successful in preventing the kind of large-scale injustice reportedly taking place in the NHS. This is because the process through which decisions are made should be fair, being made transparently, and based on relevant reasons. In principle, this focus on procedural fairness should enable resources to be allocated, and to be seen to be allocated, fairly. Daniels and Sabin argue, and the empirical evidence supports their argument (Tyler, 2006), that procedural justice engenders trust and legitimacy, so that people are prepared to accept decisions as fair even when they go against them. However, as Daniels and Sabin explain: "The legitimacy and fairness problems are distinct. A legitimate authority can act unfairly... Conversely, an illegitimate authority can deliver fair decisions".(Daniels and Sabin, 1997, p. 307)

The Relevance Condition Provides Protection against Deliberate Unfair Discrimination

The A4R procedure, with its insistence on relevant reasons, should guard against intentional under-funding of mental health services because unreasonable arguments

in favour of discrimination against the mentally ill should be ruled out. Such unreasonable discrimination would be unfair under A4R.

The Lack of a Step-by-Step Process Allows for Considerable Flexibility, and thus for Fair and Unfair Outcomes

A4R “is essentially a framework for the process of priority setting” (Hasman and Holm, 2005, p. 263). However, A4R does not provide a step-by-step approach to priority setting (Hasman and Holm, 2005, p. 268):

Albeit A4R in recent years has received increasing attention in the international debate, it still seems largely inapplicable as a practical policy framework for priority setting in health care. The reason for this is that although Daniels and Sabin comprehensively account for an organisational structure for priority setting, which they claim will facilitate and promote a process of proper deliberation they fail to describe or discuss the actual form and nature of such a process. “Process” is in fact something of a “black box” in A4R.

The lack of a clear process description makes it difficult to assess how well A4R would prevent the kind of large-scale unfairness alleged in the LSE report. A4R allows institutions to adapt the procedure to their own priority-setting context, but that flexibility also enables variation in priority-setting practice to arise, and thus an opportunity for both fair and unfair decisions to be made.

A4R Relies on Consistent Judgments being made by Different Individuals

QALYs provide the basis for a rationale that enables decisions to be made consistently (and perhaps consistently and unfairly), by different individuals in relation to different treatments or services. QALY maximization provides a formula for allocating resources. A4R is not underpinned by a resource allocation rationale, and different decision-makers could reach mutually-inconsistent conclusions over time and in relation to different interventions. Much depends on individuals and their fair-mindedness, and that the same notions of fairness are applied consistently. This reliance on individuals, rather than a formula, leaves A4R vulnerable to injustice. For example, hip operations might be ruled in by a group that placed a high value on personal mobility, and knee operations might be ruled out by a group that valued

mobility less highly. On the basis of the widely-accepted rule of justice that people in similar positions should be treated similarly,(Beauchamp and Childress, 2009, p. 242) that would be unfair to people needing knee operations.

Daniels and Sabin recognize this problem. Variation is inevitable, especially when decisions are made by different bodies, or different people over time. But less easily justified, and more likely to be considered unfair, are instances where a single organisation makes inconsistent decisions, as Daniels and Sabin point out.(Daniels and Sabin, 2008, p. 79-81) They suggest that decisions based on precedent could provide, amongst other things, more consistent decision-making.(Daniels and Sabin, 2008, p. 47-9, Daniels and Sabin, 1998) Decisions, and reasons for decisions, are made public under A4R and so could provide body of ‘case law’. This suggestion has received support from some academic commentators, and from people involved in setting priorities.(Giacomini, 2005, Martin et al., 2002, p. 286) Whilst it should aid consistency, it is questionable how reliably in practice citizens or policymakers would follow precedent and make internally coherent choices, especially when a large body of evidence was accrued. Even judges, with their obligations to be impartial and their years of training and experience, and a well-documented body of case law, are liable to make intuitive decisions rather than routinely follow precedent.(Guthrie et al., 2007)

If resource allocation reasoning and decision-making is not consistent, it is liable to be unfair (for example, because similar cases would not be treated similarly). A “case law” approach should assist in providing fairness, but in practice may not prevent large-scale injustice.

Unintentional Discrimination is Possible under A4R because Decision-Making does not depend upon Empirical Evidence

The threat to fairness is more likely to be unintentional than intentional. Under A4R, reasoning is a constraint and “rationales for coverage decisions should aim to provide (a) a reasonable construal of (b) how the organization (or public agency) seeks to provide “value for money”...”.(Daniels and Sabin, 2008, p. 51) A4R does not specify how value for money should be demonstrated, or what evidence must be used: “a rationale will be reasonable if it appeals to evidence, reasons and principles that are

accepted as relevant by fair-minded people”.(Daniels and Sabin, 2008, p. 45) Thus Daniels and Sabin appear to expect evidence of value-for-money to have a role, and reports of A4R implementation suggest that evidence is normally used.(Daniels and Sabin, 2008, p. 149-229, Sabik and Lie, 2008) However, A4R does not *stipulate that evidence as being necessary*. The test is whether evidence is accepted as relevant by fair-minded people, and more generally whether the decision-making process meets the four criteria. Therefore, data on the clinical effectiveness and cost of available treatments could be taken into account as relevant, and indeed Daniels and Sabin explain that such factors would meet the relevance condition.(Daniels and Sabin, 2008, p. 52-3) But use of such evidence is not *necessary* under A4R, as it is when applying QALYs. An institution applying A4R could, but need not, take specific account of the demand for one service or treatment, relative to other healthcare services or treatments, or the degree of unmet demand. A4R does not rely on an assessment of the healthcare status or need of individuals. Fair-minded individuals might seek out such evidence, and indeed the wider writing of Daniels and Sabin would encourage such action, but the four conditions that make up A4R do not stipulate that empirical evidence must play a part in the A4R decision-making process.

Thus, fair-minded individuals involved in A4R deliberation may not be aware, for example, that “mental illness is generally more debilitating than most chronic physical conditions” – or that “costs of psychological therapy are low and recovery rates are high”(Mental Health Policy Group, 2012, p. 1). Fair decisions about priorities depend on such information, and yet A4R does not identify as essential the use of this information.

Therefore, although A4R promotes a fair procedure based on reasonable deliberation by fair-minded citizens, it nevertheless could (albeit unintentionally) lead to the kind of large-scale injustice alleged in the LSE report. Fair-minded citizens may voluntarily seek out relevant evidence on which to base their decisions, but it is not a necessary part of A4R, and so A4R is vulnerable to large-scale injustice.

A4R does not Explicitly Recognize the Role of the Good of Healthcare

Furthermore, A4R does not *require* decision-makers to identify any notion of the good that is to be derived from healthcare. Their concern is justice, as is evident from the second page of “Setting Limits Fairly”:

Our task would be much simpler if people could agree on principles of distributive justice that would determine how to set fair limits to healthcare. If societies agreed on such principles, it would be possible to check decisions about health care limits against them. If the proposed limits conformed with these principles, they would stand. If the limits failed to conform, they would be judged unjust and changed. Disagreements about the fairness of actual limit-setting decisions would either be about how to interpret the distributive principles or about the facts of the situation.

So for Daniels and Sabin, if we could only agree on principles of justice, then we would agree how to allocate resources. Justice is the only thing that matters when resources are limited. Much of Daniels’ writing draws explicitly on John Rawls’ “Theory of Justice”, a work which famously begins:

Justice is the first virtue of social institutions, as truth is of systems of thought. A theory however elegant and economical must be rejected or revised if it is untrue; likewise laws and institutions no matter how efficient and well-arranged must be reformed or abolished if they are unjust. Each person possesses an inviolability founded on justice that even the welfare of society as a whole cannot override. (Rawls, 1999)

This claim, about the pre-eminence of justice, has been criticized, stated as it is, baldly and with little justification (Geuss, 2008, p. 71-89). But for Rawls’ subject, which concerns how societies, and their laws and institutions, should be structured, such a claim seems plausible, especially in the context of Rawls’ ‘original position’. A primary, if not the primary, function of our laws, and institutions like the courts, is to deliver justice. But a healthcare system is different. It exists primarily to deliver healthcare, to make ill people better. It does not exist to deliver justice. Doing good matters, sometimes more than justice. For example, as Geuss asks, in a famine where the need for healthcare is urgent, is it not more important “to save the lives of as many

as possible rather than to ensure that the distribution is fair”?(Geuss, 2008, p. 84) We want a system to distribute the good of healthcare, and to do that as fairly as possible.

Daniels and Sabin may have a clear idea of the good of healthcare; Daniels’ wider writing suggests this.(Daniels, 2008, p. 29-78) But, perhaps because there is much disagreement on the good of healthcare, A4R does not prescribe the consideration of health benefit or good as a necessary component of A4R. Disagreement is not a reason to ignore the essential role of doing good within the priority-setting process. The role of good could be recognized, identified as contentious, and questions on the good of healthcare resolved as part of the A4R process. A4R is concerned with fairness, and good is given no explicit role to play. A4R could be included if considered relevant by fair-minded individuals, but it is not necessary.

Without being able to compare the good of one potential use of resources against another, decision-makers cannot judge whether an allocation of resources is fair or unfair. How can one assess whether people have received what is due to them if the thing to be distributed is not given a value? How can those allocating the resources know whether they have acted fairly in choosing to spend resources on one thing rather than another if no value is assigned to these things? In truth, the problem is much more complicated than that: decision-makers must prioritize amongst hundreds, if not thousands, of possible alternative uses of resources. How can decisions be justified as fair unless at least relative value and cost is assigned to each competing use of resources?

A possible explanation of the omission of health benefit or a broader notion of good from Daniels and Sabin’s framework is that it is incorporated within their concept of justice – whether it is or not is not clear. However, it is incorporated in justice in Norman Daniels’ work with Donald Light and Ronald Caplan on “benchmarks of fairness”(Daniels et al., 1996). With healthcare systems around the world subject to continual review and change, Daniels, Light and Caplan propose ten benchmarks of fairness for evaluating healthcare reforms, including:

6. Value for money-clinical efficacy: services should be efficient, and of value, and the value that counts is health status and functioning;

7. Value for money-financial efficiency: a healthcare system should exhibit strong financial discipline, and have efficient management systems.

They explain that:

Fairness is at issue when health care dollars are spent in ways that do not produce health benefits. Those wasted resources will leave some people with unmet medical needs, or they may force us to spend money from elsewhere in our social budgets, leaving others with unmet educational or housing needs.(Daniels et al., 1996, p. 51)

This suggests that where medical needs are not met when they might be, an injustice is done. That conclusion does not follow from the definition of fairness I have used, which is concerned only with being fair to one person relative to others. Their conclusion follows from the kind of rights-based thinking evident in Daniels' wider work (Daniels, 2008, p. 15).

That thinking – of a right to health and healthcare - is contentious, based on particular principles of distributive justice. But with A4R, Daniels and Sabin intentionally seek to avoid the contention of a rights-based stance or a particular theory of distributive justice. They seek to find consensus through the four conditions of procedural justice. Therefore, their concept of what is fair in A4R should not be based on a particular principle of distributive justice. A definition of justice or fairness based only on relative fairness does not rely on rights. Under that definition, it does not follow that an inefficient health care system is unfair. There is no “fair” level of efficiency. High levels of efficiency are always desirable because they are likely to deliver more good. Less efficiency is less good, but not unfair.

Under that conception of fairness, the two value-for-money benchmarks are benchmarks for assessing health care reform, but they are not benchmarks of fairness. Value-for-money relates to the good of healthcare, and not justice.

John Broome makes a similar point about Amartya Sen's book “An Idea of Justice” which, like A4R, does not recognize the important but separate role of good:

I am not convinced Sen is really offering us an idea of justice in his book...Sen is looking for particular ways to make the world better. Not all those ways necessarily make it more just. If we concern ourselves with improving justice only, we shall miss some of the most important improvements we can make.(Broome, 2010, p. 6)

Like Broome, Beauchamp and Childress also distinguish clearly between these two ethical principles, and rather like Broome they insist “throughout this book on the possibility of contingent conflicts between beneficence and justice”. (Beauchamp and Childress, 2009, p. 281). John Rawls recognizes the distinct role of ‘good’ within his Theory of Justice; for Rawls, a thing is ‘good’ if it has the properties that it would be rational for a person to want in that thing.(Rawls, 1999, p. 350-1) But Daniels, much of whose philosophy draws on Rawlsian thinking, does not make this distinction, or at least not within A4R.

Thus good (which can include value-for-money, or efficiency) should not be conflated with fairness, and fairness is not the only criterion to use when evaluating resource allocation in health care.

By not explicitly recognizing and measuring the good of healthcare explicitly within A4R, and not systematically evaluating treatments according to their good and cost, A4R is vulnerable to the kind of large-scale injustice identified in the LSE report. Injustice can result from using an inappropriate or inaccurate notion of good, but the risks are inevitably present if good is not recognized at all.

WOULD A ‘GOOD AND FAIRNESS’ FRAMEWORK BASED ON BROOME’S WRITING PREVENT SUCH INJUSTICE?

In their discussion of distributive justice principles, Lamont and Favor argue that:

Contrary to a popular misconception, economics alone cannot decide what policy changes we should make. Economics, at its best, can tell us the effects of pursuing different policies; it cannot, without the guidance of normative principles, recommend which policy to pursue.(Lamont and Favor, 2007)

John Broome makes the same point(Broome, 2005). But just because economics does not settle normative arguments does not mean that economics cannot make an important contribution to ethics in structuring the arguments. And that is something that economist and philosopher John Broome brings in his collection of essays entitled “Ethics out of Economics”. What I will refer to here as a ‘good and fairness framework’ is mostly but not entirely from Broome, with much drawn from essays in those essays. Broome does not refer to such a framework explicitly; it is my sketch drawn mainly from his much deeper, richer arguments. It is a framework for prioritising resources in healthcare that draws on both economic and philosophical thinking. Compared to QALY maximization and A4R, Broome’s thinking on prioritising resources in healthcare has received relatively little attention over the last twenty years from both economists and philosophers writing in the field, perhaps partly because he does not present it in one place as a theory for resource allocation.

The Good and Fairness Framework

A utilitarian believes in satisfying people’s preferences, and the more they are satisfied the better. In deciding what to do, utilitarians advise that we ought to aggregate preferences in order to do as much good as possible. Broome explains that economic cost/benefit analysis that relies solely on aggregating people’s preferences may be more democratic (because everyone’s preferences count) but may not lead to the best decisions(Broome, 1999, p. 192). For example, it takes no account of future people. Therefore the analyst “needs a theory about what makes a life good, a theory about how wellbeing that comes in a life is aggregated together to determine the overall goodness of a life”.(Broome, 1999, p. 194) Broome describes this as a structured approach to valuing life, and he cites QALY maximization as an example

of such a structured approach (albeit an imperfect one). For Broome, the “badness of death” is the goodness of the life that is taken away from you.(Broome, 2004, p. 249-50) “What is in store for us is an end that is worse than living longer would have been, and better than dying sooner would have been. That is all.”(Broome, 1999, p. 171) The greater the well-being you are denied, and the longer that good life would have been, the more good that would have been gained from living, all other things being equal. Therefore, in healthcare, the greater the wellbeing to be gained, and the longer the period of gain, the more good there is to be done. Thus more good would be done by giving a life-saving treatment to a person who can regain full health and live 20 years, than to a person who will go on to live in poor health for 20 years, or to a person who will go on to live in good health for 2 years.

Unlike utilitarians, Broome believes that we may sometimes choose an option that is less good because it is fairer. Some good may be traded off for fairness. But when should that happen?

For Broome, “fairness is concerned only with how well each person’s claim is satisfied compared with how well other people’s are satisfied. It is concerned only with relative satisfaction, not absolute satisfaction”.(Broome, 1999, p. 117). Claims should be satisfied, and where they cannot all be fully satisfied, fairness requires that claims are satisfied in proportion to their strength. “Proportion” is not a precise mathematical calculation of strength, but:

- two equal claims require equal satisfaction;
- a stronger claim requires greater satisfaction; and
- a weaker claim requires less satisfaction - it should not be completely overridden by stronger claims.

A person who stands to benefit more from a good has a greater claim to that good. But a claim is not a right, or a side-constraint that must be satisfied(Nozick, 1974, p. 29). Therefore, decisions can be made by weighing up different claims, taking account of their relative strength. If Jack stands to benefit more than Jill, then all other things being equal, Jack has a stronger claim, and is given relative priority, although Jill’s claim still deserves some satisfaction. In some cases, such as life-and-death decisions,

fairness demands that the claims of Jack and Jill are treated equally, even though that means that some good is sacrificed.

This is not a resource allocation formula; difficult judgments are still necessary to decide when to trade off some good in order to be fair. One of Broome's examples illustrates how this works:

“Take the case of two candidates for lifesaving treatment, one disabled and the other not. I explained that each candidate has a reason of benefit why she should have the treatment, but the disabled person has a weaker one. The aim of doing the most good tells us to give the disabled person lower priority. If resources were scarce, it might tell us to treat the other person and allow the disabled person to die. However, we know this is unfair. Our intuition is clear on this: although one candidate has a stronger reason of benefit than the other, each candidate has an equal claim...We know that in this case fairness requires the two candidates to be treated equally. They should have equal shares of the resources, and they should have equal priority.”(Broome, 1994, p. 38)

Note that this conclusion (that fairness requires that the two candidates should be treated equally) need not rely on intuition; judgments about fairness could be based on one of several different principles of distributive justice, or result from the sort of deliberation amongst citizens that is proposed under A4R, or could come from the policy of a democratically-elected government. In other words, the framework could accommodate different approaches to deciding when it is fair to sacrifice some good. The framework explains that good and fairness should be considered separately, that good is valued, and that as much good as possible is done, except where it is fair to trade off some good for fairness.

The Framework Relies on Measuring Health Status, and Health Gain

Like QALY maximization, this good and fairness framework relies on measurement, to assess the good of competing healthcare treatments. Unlike A4R, it relies on evidence, and so avoids some of the significant risks of A4R.

However, reliable evidence implies accurate measurement and this poses considerable challenges.(Mauskopf et al., 2003, Mason et al., 1993) That is not a reason to reject the very idea of measurement. Whilst measuring health status and health gain will always pose practical problems, and will never be perfect, improvements are possible, for example through more research. Imperfect information is better than no information at all, and is more likely to prevent large-scale injustice.

It does not Resolve the Difficult Ethical Questions that Arise when Prioritising Resources

Almost all of the normative issues arising in the healthcare resource allocation literature can be understood either as questions about what counts as good, or about what is fair. A useful list, and initial analysis, of such questions of “social value” has been provided by Shepley Orr, Jonathan Wolf, and Stephen Morris.(Orr et al., 2011) The authors analyse 31 different questions, and shortlist 12 as relevant to healthcare technology evaluation. All 12 can be categorized either as a question of what counts as good, or about whether some overall good should be traded for fairness:

1. Should a) years of life gained count, and b) does each count the same? (good)
2. Should a) the amount of health gain count, and b) how can it be quantified? (good)
3. Should side-effects of treatment be taken into account as well as outcomes? (good)
4. Should the effect of treatment on a carer’s health be taken into account? (good)
5. Should the effect of treatment on a carer’s well-being be taken into account? (good)
6. Should the severely ill be given additional priority? (fairness)
7. Should those who have been severely ill or disabled for a long time be given additional priority? (fairness)
8. Should people requiring urgent, life-saving treatment be given additional priority? (fairness)

9. Should people nearing the end of life who seek life-extending treatments be given additional priority? (fairness)
10. Should populations that suffer poorer health because of their socio-economic status be given additional priority? (fairness)
11. Should people whose ill-health has been caused by the healthcare system itself be given additional priority? (fairness)
12. Should people whose treatment is relatively expensive because their condition is rare be given additional priority? (fairness)

Broome's writing, and the framework I have sketched here, provides answers to some of these normative questions. The first five questions are all about what good we seek from healthcare. The framework provides a "yes" to questions 1a, 2a, 3, 4, and 5. The framework shapes, but does not fully determine, how to value the good that comes from healthcare, which should be maximized subject to fairness.

The final seven questions are concerned with fairness. The good and fairness framework I have sketched explains how such issues of fairness, if sufficiently weighty, provide a reason to sacrifice some of the good of healthcare. It does not provide definitive answers to these specific questions; the framework can accommodate different answers because it is not based on a single principle of justice. Answers could be based on principles of distributive justice, or reached through the sort of deliberation amongst citizens envisaged by Daniels and Sabin, and then fitted within the general good and fairness framework.

It Recognizes, and Explains how to Trade Off, Good and Fairness

Unlike QALY maximization and A4R, the framework provides a way forward which guards against injustice because it recognizes the role of good, of fairness, and of how good can be traded off for fairness. Like QALYs, and unlike A4R, it requires that the good of healthcare is taken into account, thus addressing the alleged injustice in the NHS. Furthermore, unlike QALYs, it is able take account of the good beyond health gain, such as the good realized by carers, and of the good generated by a person

returning to work. That need not result in discrimination against the unemployed; fairness may demand that the employed and unemployed are treated alike.

The framework makes specific allowance for fairness, so is better equipped than QALY maximization to protect against other potential injustices. Injustice may still occur because, for example, good is measured inaccurately, or because a mistaken concept of justice is chosen. But by recognizing the role of both good and fairness, the framework provides significant protection against large-scale injustice that QALY maximization and A4R are unable to offer.

It is not Clear how the Framework would Work in Practice

The framework may recognize both good and fairness but that does not explain how it should be applied, or demonstrate that it *will* prevent injustice. It has considerable potential, but unlike QALY maximization and A4R, it is not a mature theory that has been subject to extensive criticism. I have provided a simple sketch based on Broome's thinking and relatively little information on how it could be put in practice; it is no blueprint for resource allocation. Like A4R, this 'good and fairness' framework does not provide a step-by-step approach to follow. That is deliberate; there is scope to build onto this simple framework in a number of different directions. The aim here is to explain the importance and role of good and fairness, and how they can be traded, and why that provides protection against large-scale injustice. However, to illustrate its potential, the framework could be put into practice by:

1. Defining a measure for the good of healthcare e.g. as an adjustment of QALYs (for potential adjustments to QALYs, see the list of "difficult ethical questions" above) plus some recognition of the value of non-health gains to the individual and others;
2. Defining a cardinal scale, and means of measuring, the level of good of states of health;
3. Gathering the best information that is practicable about the cost of, and good derived from, a wide range of healthcare interventions worthy of consideration for funding;

4. Defining the general circumstances where fairness requires that some good should be sacrificed (i.e. where good should not be maximized) – as potential exemplar circumstances, see the list of difficult ethical questions above;
5. Applying the output of steps 1-4 so as to maximize good, subject to fairness;
6. Recording decisions made, and the logic for decisions, thus (as Daniels and Sabin suggest) building up a “case law” illustrating how these steps have been applied, to aid consistency of decision-making;
7. Publicising the process and its results, and providing opportunity for the process to be revised and for individuals to appeal, as advocated by A4R.

Like QALY maximization, this requires considerable amounts of information. Like both QALYs maximization and A4R, it demands a great deal of work. None of the above steps is straightforward, and each throw ups questions that cannot be addressed here. The above steps, and particularly steps 1 and 4, require difficult decisions to be made on questions which, as Daniels and Sabin have explained, there is much division and little consensus, and here the kind of democratic deliberation envisaged under A4R could be deployed. But it would take place within the good and fairness framework, with citizens deliberating on the good of healthcare, and on when fairness means that some good should be sacrificed. It would provide a structure for allocating resources, less open to individual judgment than A4R, but not formulaic like QALY maximization. The framework draws on both philosophical and economic thinking, and applies rational rules as well as deliberation about what is fair within a priority-setting process.

The framework does not answer the crucial question of *when* some good would be traded off for fairness. Broome’s writing provides the theoretical framework for why and how this should be done, but does not explore many real-life examples. This is important work to do, as it could illustrate in more detail than I have here how a good and fairness framework could be made to work. One principle, emanating from Ronald Dworkin rather than Broome, that could be used to steer decisions as to when fairness should prevail over the maximization of good, is that each person is due equal respect and concern when resources are allocated. It does not mean that each person necessarily receives the same allocation.(Dworkin, 2006, p. 144-5) It would rule out,

for example, prioritising life-saving for the able-bodied at the expense of disabled people when each has equivalent life-expectancy. It would not rule out differentiating between those with higher and shorter life expectancy because we all age and suffer from reducing life expectancy, as recognized in Dworkin's "prudent insurer" model.(Dworkin, 2002, p. 317) The idea that each person demands equal concern when resources are allocated is consistent with most, if not all, principles of distributive justice, and theories of justice in general.(Kymlicka, 2002, p. 3-4)

CONCLUSION

This article assessed three frameworks for allocating resources in healthcare, asking how vulnerable each framework was to large-scale injustice, such that alleged to have occurred to mentally-ill people in England.

QALYs provide a means of measuring the good of alternative healthcare interventions. QALY maximization seeks to realize as much health gain as possible from available resources, and so addresses the causes of the alleged injustice in the NHS. Therefore, QALY maximization should prevent the reported injustice. However, like any other approach, inaccurate measurement could mean that one of the above causes might not be addressed, leading to injustice. QALYs are designed to measure good and not fairness, and so are vulnerable to other potential large-scale injustices.

A4R is an unstructured approach which relies on deliberation and judgment, and accommodates but does not require evidence of the cost or value of healthcare. It is concerned only with justice. As a result, an A4R process could be subject to the alleged causes of large-scale injustice in the NHS. It relies heavily on the individual judgment of fair-minded individuals. However, unlike QALY maximization, it is designed to provide justice, and so could prevent some injustices that QALYs alone would not address.

QALYs are not concerned with fairness, and A4R does not value the good of healthcare. Resource allocation theories should be concerned with doing good and being fair. John Broome's writing provides the foundations for such a theory. As it stands, the simple framework described here does not answer all of the difficult questions about precisely what constitutes good and fairness; it could be developed in different directions to explain how these questions are answered. Because it explicitly recognizes both good and fairness, it is most likely to prevent the alleged injustice in the NHS, and other potential large-scale injustices.

As A4R is a theory of procedural justice, we might expect it to provide the best protection against injustice. It does not, and the root cause can be explained simply. A4R allows, but does not require, fair-minded individuals to apply evidence of the value and cost of healthcare. Most likely, fair-minded individuals applying A4R will

use evidence, enabling fair decision-making. However, it is not a necessary part of A4R, and left to individual judgment, A4R is vulnerable to the kind of large-scale injustice alleged to have occurred in the NHS.

Whenever we make decisions that affect what others get, as is inevitable in healthcare, questions of distributive justice arise. Before we are able to decide what is fair, we have to identify what things could be distributed. When money is limited and could be spent on different good things, we must be able to cost these alternatives. But cost is not enough; we must have some means of valuing them. If the things to be distributed had no value, then we could not be unfair. Healthcare treatments and other interventions have value. It may be difficult to value these good things, and we may all value them differently, but that does not mean that we can ignore their value. Until we assign at least a relative value to the good things to be distributed, we cannot begin to assess what is fair. This is not to suggest that recognizing and valuing good as well as fairness in priority setting will necessarily prevent all large-scale injustice. Much depends on what counts as good, on how well good is counted, and on how good is weighed against fairness when trade-offs are to be made.

When the immature concept of QALYs was applied in Oregon in the early 1990s and threw up some unpalatable results (Hadorn, 1991), that was a reason to identify and address what was lacking from the QALY and its implementation. It was not a reason to throw out the baby with the bath water, and abandon cost-effectiveness analysis or any other form of resource allocation rationale. A4R could be improved by specifying that the relevance condition must take account of evidence of costs and benefits, and that fair-minded citizens must aim to do good whilst being fair. As QALY maximization recognizes, we do want healthcare to deliver benefit, and the more the better. But we also want it to be fair, and because people disagree on what is fair, we also need a fair priority-setting process to address difficult ethical questions. John Broome's writing explains how priority setting can be both good and fair. It bridges a gap between economics and philosophy; both disciplines are needed to shape good and fair resource allocation.

References

- BBC News. 2012. 'Shocking Discrimination' in Mental Health Services. Available at <http://www.bbc.co.uk/news/uk-18481943>, accessed 24 July 2012.
- Beauchamp, Tom L. and James F. Childress. 2009. *Principles of Biomedical Ethics*. New York: Oxford University Press.
- Broome, John. 1993. QALYs. *Journal of Public Economics*, 50: 149-167.
- Broome, John. 1994. Fairness Versus Doing the Most Good. *The Hastings Center Report*, 24: 36-39.
- Broome, John. 1999. *Ethics out of Economics*. Cambridge: Cambridge University Press.
- Broome, John. 2004. *Weighing Lives*. Oxford: Oxford University Press.
- Broome, John. 2005. Why Economics Needs Ethical Theory. *Pelican Record*, 42: 80–88.
- Broome, John. 2010. Is this Truly an Idea of Justice? *Journal of Human Development and Capabilities*, 11, 623-625.
- Brouwer, Werner B. F., Marc A. Koopmanschap, and Frans F.H. Rutten. 1997. Productivity Costs in Cost Effectiveness Analysis: Numerator or Denominator: a further discussion. *Health Economics*, 6: 511-514.
- Callahan, Daniel. 1994. Setting Mental Health Priorities: Problems and Possibilities. *The Milbank Quarterly*, 451-470.
- Clark, Sarah and Albert Weale. 2012. Social Values in Health Priority Setting: a Conceptual Framework. *Journal of Health Organization and Management*, 26: 293-316.
- Culyer, Anthony J. 1997. *The Primary Goal of the Health Care System should be to Maximize Health*. In: NEW, B. (ed.) *Rationing: Talk and Action in Health Care*. London: BMJ Publishing Group.

Daniels, Norman. 2008. *Just Health: Meeting Health Needs Fairly*. Cambridge: Cambridge University Press.

Daniels, Norman, Donald Light and Richard L. Caplan. 1996. *Benchmarks of Fairness for Health Care Reform*. New York: Oxford University Press.

Daniels, Norman and James E. Sabin. 1997. Limits to Health Care: Fair Procedures, Democratic Deliberation, and the Legitimacy Problem for Insurers. *Philosophy and Public Affairs*, 26: 303-350.

Daniels, Norman and James E. Sabin. 1998. The Ethics of Accountability in Managed Care Reform. *Health Affairs*, 17: 50-64.

Daniels, Norman and James E. Sabin. 2007. *Setting Limits Fairly - Can we Learn to Share Medical Resources?* New York: Oxford University Press.

De Villanueva, Cecilia F. 2010. The School of Salamanca: Some Thoughts on the Subject of Justice. In *Humanism and Religion in the History of Economic Thought*, ed. Solari Parisi, 96-111. Rome: Franco Angeli.

Dolan, Paul, Rebecca Shaw, Aki Tsuchiya, and Alan Williams. 2005. QALY Maximization and People's Preferences: A Methodological Review of the Literature. *Health Economics*, 14: 197-208.

Dworkin, Ronald. 2002. *Sovereign Virtue: The Theory and Practice of Equality*. Cambridge: Harvard University Press.

Dworkin, Ronald. 2006. *Is Democracy Possible Here?: Principles for a New Political Debate*. Princeton: Princeton University Press.

Geuss, Raymond. 2008. *Philosophy and Real Politics*. Princeton: Princeton University Press.

Giacomini, Mita. 2005. One of these Things is not like the Others: the Idea of Precedence in Health Technology Assessment and Coverage Decisions. *Milbank Quarterly*, 83: 193-223.

- Grieve, Richard, Marina Grishchenko, and John Cairns. 2009. SF-6D versus EQ-5D: Reasons for Differences in Utility Scores and Impact on Reported Cost-Utility. *The European Journal of Health Economics*, 10: 15-23.
- Guthrie, Chris, Jeffrey J. Rachlinski, and Andrew J. Wistrich. 2007. Blinking on the Bench: How Judges Decide Cases. *Cornell Law Review*, 93: 1.
- Hadorn, David C. 1991. The Oregon Priority-Setting exercise: Quality of Life and Public Policy. *The Hastings Center Report*, 21: 11-16.
- Harris, John. 2005. It's not NICE to Discriminate. *Journal of Medical Ethics*, 31: 373.
- Hasman, Andreas and Soren Holm. 2005. Accountability for Reasonableness: Opening the Black Box of Process. *Health Care Analysis*, 13: 261-273.
- Herring, Jonathan. 2007. Where are the Carers in Healthcare Law and Ethics? *Legal Studies*, 27: 51-73.
- Hobbs, Angie. 2010. What is Fairness?. Available at http://news.bbc.co.uk/today/hi/today/newsid_9079000/9079254.stm, accessed 21 June 2012.
- Holm, Soren. 1998. Goodbye to the Simple Solutions: the Second Phase of Priority Setting in Health Care. *British Medical Journal*, 317: 1000.
- Klein, Rudolf. 2010. Rationing in the Fiscal Ice Age. *Health Economics, Policy and Law*, 5: 389.
- Kymlicka, Will. 2002. *Contemporary Political Philosophy*. Oxford: Clarendon Press.
- Lamont, Julian and Christi Favor. 2007. Distributive Justice. Available at <http://www.science.uva.nl/~seop/archives/fall2008/entries/justice-distributive/index.html#Strict>, accessed 28 Nov 2012.
- Layard, Richard. 2004. Mental Health—Britain's Biggest Social Problem. Available at http://www.strategy.gov.uk/downloads/files/mh_layard.pdf, accessed 20 Nov 2012.
- Layard, Richard. 2006. The Case for Psychological Treatment Centres. *BMJ*, 332: 1030-1032.

Martin, Douglas K., Mita Giacomini and Peter A. Singer. 2002. Fairness, Accountability for Reasonableness, and the Views of Priority Setting Decision-Makers. *Health Policy*, 61: 279-290.

Mason, James, Michael Drummond, and George Torrance. 1993. Some Guidelines on the Use of Cost Effectiveness League Tables. *British Medical Journal*, 306: 570-572.

Mauskopf, Josephine, Frans Rutten, and Warren Schonfeld. 2003. Cost-Effectiveness League Tables: Valuable Guidance for Decision Makers? *Pharmacoeconomics*, 21: 991-1000.

Mental Health Policy Group, London School of Economics. 2012. How Mental Illness Loses out in the NHS. Available at http://cep.lse.ac.uk/_new/research/mentalhealth/default.asp, accessed 3 July 2012.

Miller, David. 1979. *Social Justice*. New York: Oxford University Press.

Nord, Erik. 1993. The Trade-Off between Severity of Illness and Treatment Effect in Cost-Value Analysis of Health Care. *Health Policy*, 24: 227-238.

Nord, Erik. 1999. *Cost-Value Analysis in Health Care: Making Sense out of QALYs*. Cambridge: Cambridge University Press.

Nord, Erik, Norman Daniels, and Mark Kamlet. 2009. QALYs: Some Challenges. *Value in Health*, 12: S10-S15.

Nozick, Robert. 1974. *Anarchy, State, and Utopia*. New York: Basic Books.

Orr, Shepley, Jonathan Wolff, and Stephen Morris. *What Values Should Count in HTA for New Medicines under Value Based Pricing in the UK?* Available at <http://www.ucl.ac.uk/cpjh/mcda.pdf>, accessed 24 July 2012.

Rawls, John. 1999. *A Theory of Justice*. Cambridge: Harvard University Press.

Sabik, Lindsay M. and Reidar K. Lie. 2008. Priority Setting in Health Care: Lessons from the Experiences of Eight Countries. *International Journal for Equity in Health*, 7: 4.

Schlender, Michael. 2008. The Use of Cost-Effectiveness by the National Institute for Health and Clinical Excellence (NICE): No (t yet an) Exemplar of a Deliberative Process. *Journal of Medical Ethics*, 34: 534.

Schwappach, David L. B. 2002. Resource Allocation, Social Values and the QALY: a review of the debate and empirical evidence. *Health Expectations*, 5: 210-222.

Tsuchiya, Aki. 2000. QALYs and Ageism: Philosophical Theories and Age Weighting. *Health Economics*, 9: 57-68.

Tyler, Tom R. 2006. Psychological Perspectives on Legitimacy and Legitimation. *Annual Review of Psychology*, 57: 375-400.

Williams, Alan. 1985. The Value of QALYs. *Health and Social Service Journal*, 18: 3-5.

Williams, Alan. 1992. Cost-Effectiveness Analysis: Is It Ethical? *Journal of Medical Ethics*, 18: 7-11.

Paper 6: In a democracy, what should a healthcare system do? A dilemma for policymakers

Abstract

In modern representative democracies, much healthcare is publicly funded or provided, and so the question of what healthcare systems should do is a matter of public policy. Given that public resources are inevitably limited, what should be done and who should benefit from healthcare? It is a dilemma for policymakers, and a subject of debate within several disciplines, but rarely across disciplines. In this paper, I draw on thinking from several disciplines, and especially philosophy, economics, and systems theory. I conclude that economist and philosopher John Broome's writing provides the framework for an answer: a healthcare system in a democracy should do as much good as possible, although sometimes we should sacrifice some overall good for the sake of fairness. This leaves open some detailed questions about what in practice we consider to be good and fair, and about when some good should be traded off in order to be fair. The answers to these questions depend on our values, or as explained by systems theory, our *weltanschauung*. How policy decisions should be made when citizens' values differ is a subject of extensive academic debate. However, it is a separate question. Representative democracies have mechanisms for resolving such debates.

1. Introduction

This article explores the question of what a healthcare system in a modern representative democracy should do. It is a question that must be faced by policymakers. The academic literature offers the policymaker little consensus, and many competing answers from different disciplines. This article seeks an answer by drawing on thinking from economics, philosophy and bioethics, systems theory, law and elsewhere; what a healthcare system should do is relevant to many disciplines. I begin by examining why this question matters, and why it is a public policy concern. I then build up to conclusions by asking:

- What is a system?
- What should a system do?
- What is a healthcare system?
- What should a healthcare system do?

My answer to the final question is that a healthcare system should do as much good as possible, whilst being fair. I conclude that this is what a healthcare system should aim to do in any democracy. This is no blueprint for a healthcare system; in particular, it does not explain precisely when it is right to trade off some good for reasons of fairness. Different people may have different priorities, depending on their weltanschauung (or worldview). I consider how such differences can be resolved in democracies, and finish with conclusions.

Terms used

By “democracies” or “modern democratic states”, I mean functioning representative democracies that exist today, where each citizen has a voice, but where policy is controlled by officials elected at regular intervals through universal suffrage. I could argue that democratic forms of government have many significant advantages over the alternatives (Dahl, 2000, p. 44-61), and that democracy is of universal value because of its intrinsic importance to human life (Sen, 1999, p. 16). But I do not seek to make an ethical case for democracy because democracy in practice is the context for this paper. The paper is concerned with what Robert Dahl calls ‘polyarchy’ (Dahl, 2000, p. 90), and not with ideal theories of a democracy. What counts as a “modern

democratic state” is of course a difficult question. In 2001, Tatu Vanhanen assessed 102 out of 170 countries in 2001 to be democracies, based on a threshold comprising similar criteria for democracy that Dahl advocates for polyarchies.(Vanhanen, 2003, p. 188) As laws, healthcare institutions, medical practices, history, culture and societal values vary from place to place, it is impossible to present a universal blueprint of what a healthcare system in a democracy should do. Nevertheless, I will argue that it is possible to construct a framework for a healthcare system that can then be used in any modern democracy to define in detail what a healthcare system should do.

What I mean by a “healthcare system” is explored in the body of article. The words “should do” are used in the title of this paper, and by this I intend to include goals and purposes of a healthcare system. The word “should” implies it is a normative question - one of value rather than of fact. Science can give us answers when we know in advance what we want a system to do (for example, boil water), but it cannot tell us what the purpose of a system should be.(Churchman, 1971, p. 18) There are no scientific proofs or external standards against which to judge what a healthcare system should do. Nevertheless, science and many other disciplines can contribute towards an answer, even though the question belongs to the field of normative ethics. “The fundamental question of ethics is: ‘what should I, ought I, or must I do?’”(Parfit, 2011, p. 415), and this can be extended: ethics is also about what groups of people should do, and thus about policy. I approach the problem from the perspective of a public policymaker who seeks an ethical answer to the policy question of what a healthcare system should do, and who faces a difficult dilemma with many choices from many different places competing for attention. I argue that it is a policy question that requires an answer.

For simplicity, I refer to philosophy, bioethics, economics, systems theory, and so on as “disciplines”, despite there being much debate over what constitutes a discipline. John Maynard Keynes argued that economics is a branch of logic, and a way of thinking, and Peter Checkland understands systems theory, and management science more generally, in a similar way.(Checkland, 1985, p. 766) It is this sense of disciplines as different ways of thinking, with different perspectives on the problem of what a healthcare system should do, that interests me here.

For now, the term “**fairness**” **can be taken** to mean "to attribute to each his or her due"(Hobbs, 2010) (de Villanueva, 2010, p. 102). The word “**justice**” has a similar definition that dates back to Roman law.(Geuss, 2008, p. 73) Thus, I do not make a distinction between “fairness” and “justice”; I use the two terms interchangeably.

I give the term “**good**” the meaning used by John Broome, so that there is no more to good than **betterness** - it is a comparative term (Broome, 1999, p. 163-4). It does not refer to a specific conception of the good or good life. Doing good involves producing benefits or eliminating harms, and thus is broadly consistent with the principle of “beneficence” which has been described as “all forms of action intended to benefit other persons”(Beauchamp and Childress, 2009, p. 197). In this article, the concept of “good” excludes the value that we place on fairness. These are intentionally broad definitions of “fairness” and “good”. What should count as good and fair is addressed later in the paper.

Why is it a question of public policy?

It is not possible here to develop an argument from first principles, as some have done, about governments’ responsibilities for health (Coggon, 2012) (Powers and Faden, 2006) (Rice, 2001) and more specifically, why the question of what a healthcare system should do is a public policy matter. I will instead consider briefly conclusions from the literature.

Typically economists look first to markets to provide goods and services, as this normally leads to individual preferences being satisfied. However, economists recognise the role of government intervention in healthcare because of “market failure”.(McPake et al., 2012, p. 59-66) For example, some healthcare, especially public health, is a “public good” that cannot be optimally allocated by markets, thus justifying a role for the state:

“Under ideal conditions, the entire economy functions without any central control or direction from the government. However, perfect market conditions...do not occur in the real world. Imperfect market conditions justify government intervention to protect the public’s health...A “public good” is a good or service that does not lend itself to market allocation because it costs nothing for an additional individual to enjoy its benefits, and it is generally difficult or impossible to exclude individuals from consuming it. The

institutional and technical capacity to respond to disease outbreaks and prevention research are examples of public goods. A fundamental problem with public goods is the difficulty of motivating people to pay for them.”(Carande-Kulis et al., 2007, p. 227)

Libertarian philosophers argue state interference in human affairs should be minimised, and against the coercive and unjustified redistribution of property by the state. Richard Epstein concedes a very limited role for the state in healthcare.(Epstein, 2003) Writers advocating consumer-driven healthcare, who look to minimise state intervention and promote informed individual choice in healthcare, nevertheless accept that public authorities have a role in some healthcare (e.g. vaccination).(Goodman, 2006, p. 4) In his utopian vision, Robert Nozick sees no role for the state in healthcare (Nozick, 1974, p. 297-334) However, as Nozick explains, it is a vision of society that bears little resemblance to modern representative democracy (the context for this paper).

At the other end of the spectrum, the World Health Organisation’s vision is one where citizens have a right to “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.(WHO, 1948) It is a strong claim, and few writers today would consider it achievable in practice.(Saracci, 1997) However, many philosophers argue that healthcare has a special moral significance, or of some form of right to healthcare (rather than health)(Green, 1976, Gruskin and Daniels, 2008) and/or that societies should use healthcare and other mechanisms to meet the needs of those lacking basic human capabilities, regardless of the individuals’ resources, (Sen, 2002, Nussbaum, 2001, p. 77-78). All of these philosophical theories explicitly require, or imply, state funding of some or all healthcare, and thus the question of what a healthcare system should do, and who gets what healthcare, becomes the subject of public policy. Where healthcare systems are privately funded, the question merely moves to a different policymaker, although private policymakers are not accountable for their decisions in the same way.

To conclude, there is much written on the state’s involvement in healthcare, with almost all arguing for state intervention in some healthcare. Therefore I conclude that the question of what a healthcare system should do in a democracy is a matter for public policy, although it may also be a matter of private policy (e.g. by insurance

companies). There is empirical backing for this conclusion: public finance is a big (if not the biggest) source of healthcare funding in all OECD countries, and so public policymakers are involved in determining the scope and purpose of their healthcare systems.(OECD, 2011, p. 156-7) Even in the USA, 48% of healthcare was publicly funded in 2009 (rising to approximately 60% when tax subsidies for private insurance are included), and public bodies apply strong legal powers to protect population health. (Gostin, 2001, p. 5-11) (OECD, 2011, p. 157) (Woolhandler and Himmelstein, 2002, p. 88)

What a healthcare system should do is a question of public policy, and in functioning representative democracies, public policymakers have responsibility for finding answers to such questions. The question needs asking, and needs an answer.

Why ask this question?

People providing and using the healthcare system need an answer

A reason to ask the question is that people need to know what their healthcare system should do, and what it should not do. Users should know what they can expect, and healthcare providers need to know what they should do. As way of simple illustration, consider Dr. Foster's dilemma:

Tariq is 44, and lives, works and pays taxes in a democratic state. He has six children aged between 3 and 12, and works hard to earn enough money to feed and clothe his family. His wife died two years earlier, and now Tariq's frail and elderly mother lives with him. She looks after the children when Tariq is out at work, but has another mouth to feed. Tariq is very ill, and in a lot of pain, and visits his doctor. After initial investigations, Dr. Foster discovers that Tariq has developed a rare form of cancer, strongly linked to smoking. Tariq smoked heavily until his wife died.

Dr. Foster explains gently to Tariq that his prognosis is poor. She can prescribe medicine to relieve the pain, but without other treatment, Tariq is almost certain to die within months. The only effective treatment is a new, and extremely expensive, form of chemotherapy. On average, but depending on age and other factors, 30% of patients respond to treatment. In those cases, the response is remarkable, and the patient returns within months to normal health, and normal life expectancy. Tariq

pleads with Dr. Foster to be given the new treatment, so he can live on and provide for his family.

Should Dr. Foster authorise the treatment? This is a clinical question, involving judgement by Dr. Foster to assess, for example, what outcomes could be expected for Tariq, given the state of his health, age and other clinically-relevant factors. However, it is also a normative question about a morally-significant being, namely Tariq. The decision on whether to prescribe relies on broader judgements that go beyond Tariq's case, including, for example, whether age and life expectancy, his family responsibilities, the cost of proposed medication, or his decision to smoke, ought to be taken into account when deciding whether to prescribe. These are not questions that can be answered by Dr. Foster or by Tariq, but questions of policy. Authorising Tariq's treatment would have an impact on others because in a system where resources are limited (as they are whether services are funded out of insurance or from public funds) there is an opportunity cost to allocating the resources to Tariq: it means there will be less available for others.

Therefore, the question facing Dr. Foster is not just one of individual clinical judgement; it is constrained by available resources, and on the policy of the healthcare system. Dr. Foster can only make her judgement if she understands what the healthcare system is there to do, and not do. Prioritisation decisions like this have to be made not only by doctors, but throughout a healthcare system, and these decisions are affected by many different individuals and groups.(Klein, 1994, The Danish Council for Ethics, 1997). Tariq deserves an explanation as to why his treatment is to be given or refused, and that can only be explained in the context of the healthcare system and what it aims to do. So both users and providers within a healthcare system need to understand what the system is there to do. They rely on policymakers to provide a policy that explains what the healthcare system should do, and not do.

The answer is not obvious

An obvious answer to the question is: "to make unhealthy people healthy". But after investigation, it becomes clear that it is more complicated than that, as the Danish Council of Ethics concluded(The Danish Council for Ethics, 1997). For example, there is a potential role for preventing future ill-health, or for not only relieving disease and infirmity, but of aiming towards "complete physical, mental and social

well-being”, as the World Health Organisation advocates. Furthermore, the obvious answer says nothing about enabling the creation of new life, of extending life, or of alleviating suffering when perhaps restoring health is not possible. Nor does the obvious answer help with prioritisation when a healthcare system cannot do everything, as is inevitably the case in healthcare systems around the world, whether they be funded by private insurance, or public monies.(Daniels and Sabin, 2008, p. 1-10)

So what a healthcare system in a democracy should do is far from obvious. This is not unusual to healthcare systems; the purposes of many human systems are not obvious, but contestable.(Sandel, 2010, p. 190-1)

There are many answers from different places

The academic literature provides many answers to the question posed by this paper. Economists are interested in efficient allocation of resources within a healthcare system, for example by looking to improve the welfare of some without reducing the welfare of others, or by optimising overall health gain achieved by a healthcare system.(Culyer, 2001) Many philosophers and bioethicists begin with notions of justice, and argue that the first concern of a healthcare system should be to achieve a fair allocation of resources. Systems theorists are concerned about the design of the system, and in recognising and reconciling the different perspectives that different stakeholders will have about what a healthcare system should do. Political scientists are more likely to begin with an understanding of the political process through which policy decisions are made. Different academics begin from a different position, and use different methods of analysis, leading to different answers, providing policymakers with no obvious way to choose between competing answers to the question of what a healthcare system in a democracy should do. Debate tends to be within disciplines, rather than across disciplines, and few writers synthesise thinking from several fields, as I attempt here.

Why draw on thinking from several disciplines?

With so many answers, each from a different disciplinary perspective, how should an answer be found? There is no answer, or approach to finding an answer, that draws consensus from across the literature. If Dr. Foster posed her dilemma about Tariq to another clinician, an economist, a philosopher, a psychologist, a system theorist, a

management scientist, a lawyer (and so on), each might approach the problem in a different way, and reach different conclusions. But each might shed light on her dilemma. Many disciplines have something valuable to say about what a healthcare system should do. Each provides a different perspective, but not a complete picture. As EO Wilson has argued, “a balanced perspective cannot be acquired by studying disciplines in pieces but through pursuit of the consilience among them”.(Wilson, 1999, p. 14) Disciplines do not constitute different parts of reality; they are different aspects of reality, different points of view.(Ackoff, 1999, p. 425).

By drawing on several disciplines, it should be possible to find a fuller, richer answer to the question of what a healthcare system should do. The discipline(s) most relevant depends on the aspect of the problem being considered. For example, economics is good at comparing options, but we would look to systems theory rather than economics for insights into how to define a system. Additionally, the arguments of one discipline can be validated against thinking in another discipline; if both reach similar conclusions, it adds weight to that conclusion.

Two obvious places to look are systems theory, which provides frameworks for defining and designing systems, and normative ethics, which is the study of what ought to be done. When the system’s purpose is a matter of public policy, we would expect the political sciences and law to be relevant. What a healthcare system can do depends on the resources it is allocated, and so economics should also have something to say, even though it can be, and has been, argued that such normative questions fall outside economics. (Lamont and Favor, 2007) (Broome, 2005)

Thus in this paper I will be drawing primarily on thinking from systems theory, ethics, political science, law and economics. The analysis is of course limited; only some of the possible arguments from some of the relevant disciplines are considered. Furthermore, there is no objective means of picking the right arguments; in this paper, I will be selecting those that I find most persuasive.

I begin by considering what makes something a system, and look to systems theory for guidance. It is a question at the very heart of that field. As in other fields, many competing theories exist.(Reynolds and Holwell, 2010, p. 8-15) However, the discipline could be characterised as having two wings: “hard” systems thinking, and “soft” and “critical” systems thinking. Science and engineering have been major

influences, and particularly evident in “hard” systems thinking. “Hard” systems theory is particularly suitable when the purpose of a system is clear from the outset, as for example, when designing an electricity-generating plant (although system dynamics from the “hard” systems thinking tradition has been adapted and applied to complex human systems like child protection).(Munro, 2011) In this paper, I will be drawing more heavily on soft and critical systems theory, which is specifically designed to deal with “messy” human situations, where goals may be unclear or disputed, such as in a healthcare system.(Checkland, 1985) (Jackson and Keys, 1984) However, in line with “hard” systems thinking, I am interested here in the concept of a system as a real thing comprising real parts in the real world. So for my purposes, systems are the territory, rather than just the maps of territory. However, as soft systems thinkers suggest, how we each understand the same real-world system will vary (depending on our worldview, as discussed later). Much of the thinking underpinning soft and critical systems theory can be traced to philosophers C West Churchman and Russell Ackoff, who were instrumental in developing the field of operational research and systems theory in the post-war era.(Ramage and Shipp, 2009, p. 131-176).

2. What is a system?

The system characteristics that follow are recognised not only in soft and critical systems thinking, but across most other system theories.

More than just the sum of its parts

The roots of systems thinking lie in philosophy, and the fundamental characteristic that a system is more than the sum of its parts, can be traced back to Aristotle (Von Bertalanffy, 1972, p. 407) and through Immanuel Kant (Ulrich, 1994, p. 223). Systems thinking continues to hold that a feature of, say, a gas boiler, or of a healthcare system, is that the system as a whole has an identity and a purpose that makes it more than just a collection of components. However, soft systems thinking suggests that different people will have different ideas about a system's identity and purpose, and so the goals of any system are contestable.

Has inter-related parts

Systems thinking has been described as “a way of looking at the world in which objects are interrelated with one another” (Whitchurch and Constantine, 1993, p. 325) and where systems are “set(s) of elements standing in interrelation among themselves and with the environment”. (Von Bertalanffy, 1975, p. 159)

Has a boundary

If a system is a coherent whole made up of inter-related parts, sitting within a wider environment, then it follows that a system has a boundary. Where that boundary is drawn is important:

“The concept of boundary is an essential one in systems thinking. The very act of identifying several components as a system is equivalent to drawing a boundary between what is included within the system and what is not part of the system. The boundary defines the system and represents the interface, or point of contact between the system and other systems, between the system and its subsystems and suprasystems.” (Whitchurch and Constantine, 1993, p. 333)

Affects, and is affected by, the world around it

Systems thinking is concerned not only with what falls within a system boundary, but also how that interacts with what falls outside. These interactions should not be ignored:

“We “attack” poverty, inefficiency, national belligerence, crime, as though each were a blot on an otherwise pure white carpet, and as though we had no responsibility for showing how the whole system would improve if this part were changed in accordance with our plans.”(Churchman, 1971, p. 41)

This thinking has parallels with economic theory on “externalities”, where actions taken by consumers or producers affect other consumers or producers, and for which producers do not pay or consumers are not compensated.

Has purpose(s)

System thinking begins from the position that man-made systems have purposes, and that system design is a goal-seeking activity.(Churchman, 1971, p. 5-7) Both a “hard” system like a boiler, and a “soft” human system like a healthcare system have a purpose (or purposes). Indeed, it is perhaps the defining feature of a system. A system is designed to achieve something, and that something should be identifiable to some extent in advance; otherwise there would no reason to begin system design. The design process should force the designer to continually challenge, clarify, and specify in more detail, the system’s purpose(s). However, systems theory recognises that the designer’s purpose may not coincide with the purposes of those working within and outside the system, and as a result, the system may not achieve the purpose intended by the designer.(Churchman, 1979)

3. What should a system do?

Transformation subject to constraints

In order to define a “soft” system, it is necessary to identify who benefits (or is harmed), who the actors are in the system, and who owns/controls the system.(Checkland, 1985, p. 763-764) Furthermore, in order to achieve its purpose(s), the system involves a transformation. For example, a gas-fired power station aims to transform gas into electricity, whereas a legal justice system might aim to turn the accused into either guilty or acquitted individuals. However, the transformation achievable is liable to be subject to constraints, including financial, legal, ethical, and environmental constraints.

But what transformation should be performed? This is a normative question. In “hard systems”, there may be little or no debate, but in more complex human systems, different people are very likely to have different ideas about what a system should do.

Depends on Weltanschauung

Soft and critical systems theory addresses this pluralism directly by including “weltanschauung” (or “worldview”) as part of the system definition. This approach originates from Churchman, who was drawing on the work of Immanuel Kant and Georg WF Hegel (Churchman, 1971, p. 169-179). The recognition of worldviews makes this approach particularly appropriate for the study of a “messy, ill-structured, real-world problem”(Checkland, 1985, p. 763) like a criminal justice system or healthcare system where the purpose of the system is disputed or unclear. Part of the process of soft systems design is to tease out the different worldviews of the people with a stake in the system, and articulate alternative ideal system designs for differing worldviews. So, for example, when designing a system like a prison, some people may consider that protecting the public from danger is paramount, and so believe that prisons are required to contain and isolate inmates from the rest of society. Some may see prison as a place of punishment for crimes committed. Others may see a prison as an environment where prisoners should be made ready for rehabilitation into society. Different types of stakeholders (e.g. citizens, politicians, civil servants, judges, police, probation officers etc.) are likely to place different emphases on these potential purposes of a prison, as will different individual stakeholders. So depending on the

worldview adopted, the architecture and procedures of a prison could vary considerably.

Some of the disagreement across academic disciplines about what healthcare systems should do might be explained by their differing worldviews: the aims, methods, interests and traditions of different disciplines shape the way in which economists, philosophers, sociologists etc. think about, and value, the world.

4. What is a healthcare system?

Like other systems, a healthcare system comprises parts. It is more than just the sum of its parts because those parts (e.g. hospital wards, out-patient clinics etc.) connect together for a purpose (or purposes). The system sits within, affects, is affected by, and should be understood in relation to, a wider environment, and for this paper, that environment is fixed as a modern democratic society. A healthcare system should be designed to achieve its purpose(s), subject to constraints, and an important constraint of all healthcare systems in modern democracies is finance. However healthcare is funded, there will be insufficient funds to do all of the possible things that could benefit the citizens of the democracy. This affects what the healthcare system should do, and thus where the boundary around the system should be drawn. For example, given limited resources, some might argue that the boundary should exclude doing any more than alleviating physical ill-health, whereas others might draw a wider boundary that encompasses activities to promote well-being. Thus the boundary is closely linked to what a healthcare system should do – the subject of the next section.

5. What should a healthcare system do?

Thus a healthcare system should have a goal, or goals. Those goals are achieved by carrying out a transformation (e.g. of unhealthy people to healthy people). A boundary to the system must be drawn, and the system goal will influence where that boundary is drawn. Without a goal, and given limited resources, people working within the system (like Dr. Foster) would not know what they could and could not do, and users (like Tariq) would not know what to expect from the system. Systems thinking explicitly recognises that different people who are affected by the system will have different *weltanschauungen* and thus will have different perspectives on the boundary and purposes of a healthcare system. Systems thinkers foresee a negotiation process to resolve these different views and agree and define what a system should do.

What a healthcare system should do is a normative question, and for most philosophers and ethicists such questions are resolved through philosophical reasoning, not through asking those affected. To an economist, the question is about resource allocation for which there will be an answer that achieves an efficient and equitable distribution.(McGuire and Aaron, 1969) For a political scientist, it is a question of social policy, to be resolved in a democracy through a political process. Thus, different disciplines have different perspectives on how to find an answer to the question of what a healthcare system should do.

Consider first philosophers and bioethicists. They tend to be concerned about distributive justice –about who gets what.

Should a theory of justice determine what a healthcare system should do?

Distributive justice

When allocating resources to healthcare, distributive justice tends to be the main concern of philosophers and bioethicists. The definition of fairness in the introduction, namely "to attribute to each his or her due" only begs a further question of "what is due to each of us?". Philosophy provides many possible answers to that question. Julian Lamont and Christi Favor explain in the Stanford Encyclopaedia of Philosophy that "principles of distributive justice are normative principles designed to guide the allocation of the benefits and burdens of economic activity", and the authors summarise many competing principles(Lamont and Favor, 2007). These principles get

to the root of many of the debates about what constitutes fair prioritisation of resources in healthcare, and thus in turn about what a healthcare system should do. I consider briefly below a few of the theories described by Lamont and Favor. Each gives a different account of what is due to each of us, and thus different distributions of healthcare, and of what a healthcare system in a democracy should do.

A libertarian like Robert Nozick rejects patterned principles of distributive justice because it is not for institutions but for individuals “to decide for themselves to whom they will give the thing and on what grounds”(Nozick, 1974, p. 235). Nozick would not accept the basic premise that healthcare is a matter of public policy.

Strict Egalitarianism says that every person should have the same level of material goods and services. “The assumption is that equality needs no reasons, only inequality does so”.(Berlin, 1961, p. 132) However, there are reasons to divide healthcare unequally between people; for example, the need for healthcare varies very considerably from person to person.

Those who adhere to Desert-Based Principles of distributive justice believe that people should get what they deserve, and conversely that they should not get what they do not deserve. In the context of a healthcare system, this thinking leads to the conclusion that some people requiring healthcare are more deserving than others. For example, a person who seeks healthcare because she is ill or injured as a result of doing dangerous sports, being obese, or drinking too much alcohol, has a weak claim (or even no claim) to healthcare if it is funded by others, whereas there are deserving cases of people with especially strong claims to healthcare, such as working parents with dependent children.

The Difference Principle was proposed by John Rawls in his much-cited Theory of Justice, and “treats everyone equally as a moral person, and which does not weight men's share in the benefits and burdens of social cooperation according to their social fortune or their luck in the natural lottery”.(Rawls, 1999, p. 65) This principle applies the “maximin” rule of distributive justice, prioritising resources so as to maximise the minimum level of primary goods that a citizen possesses. Rawls seeks equality of these primary goods. Health and healthcare are not classified as primary goods, although it can be argued that the primary good of fair equality of opportunity implies access to at least basic healthcare for all because healthcare may be needed to keep

people functioning.(Wenar, 2008, p. 311, Daniels and Sabin, 1997) This implies that a healthcare system would prioritise resources towards those who otherwise lack the capability to carry out their life's plans. Some writers, including Norman Daniels, have applied Rawlsian thinking to healthcare.(Daniels, 1985, p. 36-57)

Equality of Opportunity and Luck Egalitarianism promote ex-ante equality of opportunity so as to mitigate the effects of luck (such as features inherited from birth), but not insulate people from the consequences of their chosen actions. Ronald Dworkin, a prominent proponent of luck egalitarianism, argues that justice requires us to consider how individuals would prioritise health spending against other good things. He concludes that the prudent insurer would choose broader healthcare cover in their youth than in their old age, and thus that it is not fair to spend disproportionate sums of money to give someone the chance of a few extra days or weeks of life. He argues his approach is egalitarian but non-paternalistic.(Dworkin, 2002, p. 319) Although an advocate of rights, Dworkin sees health and healthcare as important goods, but not human rights.

Other philosophers and bioethicists consider health to be of special moral significance, and that every person has a right to health or healthcare, or at least to a decent minimum level of healthcare.(Beauchamp and Childress, 2009, p. 258-281) Almost all agree that, given limited resources, healthcare must be prioritised, and that justice is of paramount concern. But as is apparent from the brief discussion above, there is no consensus on what constitutes justice.

Faced with such widespread and fundamental philosophical disagreement, some have concluded that it is not possible to agree on a fair and publicly-acceptable rationale for allocating healthcare resources, or more generally on the goals of a healthcare system (e.g. (The Danish Council for Ethics, 1997, p. 4.3) (Holm, 1998) (Daniels and Sabin, 2008, p. 1-4)). Because of this lack of consensus, they propose that the only reliable guidance that can be given to policymakers is to use fair, transparent and accountable processes to justify their resource allocation decisions, and for deciding on what a healthcare system should and should not do. They advocate procedure in place of principle.

Procedural justice

The most widely-cited approach is “accountability for reasonableness” (A4R) developed by Norman Daniels and James Sabin: (Daniels and Sabin, 2008, p. 44):

“Accountability for reasonableness is the idea that the reasons and rationale for important limit-setting decisions should be publicly available. In addition, these reasons must be ones that "fair-minded" people can agree are relevant to pursuing appropriate patient care under necessary resource constraints.”

The authors set out four criteria which must be met for “accountability for reasonableness” (Daniels and Sabin, 2008):

- **Publicity:** rationing decisions made, and their rationale, must be made public;
- **Relevance:** the rationale on which decisions are made must be reasonable (i.e. based on evidence and relevant reasons), taking account of how the organisation provides value for money and meets varied health care needs;
- **Revision and appeals:** there must be a mechanism for individuals to challenge and dispute decisions, and for the organisation to learn and revise its policies; and
- **Regulation:** there must be either external or self-imposed mechanisms for enforcing the three conditions above.

They propose that citizens with different worldviews can through a deliberative process decide what a healthcare system should and should not do. They argue, with some empirical backing, that procedural justice engenders trust and legitimacy, so that people are prepared to accept decisions as fair even where they go against them.

(Tyler, 2006) (Cohen-Charash and Spector, 2001)

Other bioethicists have supported, and suggested enhancements to, A4R, and the approach (or elements of it) have been tested in several democracies.(Gibson et al., 2005b) (Sabik and Lie, 2008, p. 10-11) (Syrett, 2008) (Daniels and Sabin, 2008, p. 149-229) However, it also has its critics within bioethics.(Rid, 2009) (Ashcroft, 2008)

Few would argue against the value of fair processes in a democracy. But without principles, outcomes are unpredictable and liable to be inconsistent: they may be fair or unfair outcomes. With A4R, the reasonableness of decisions relies on fair-minded individuals. I have argued elsewhere that, because A4R has no underpinning rationale,

and because it does not require healthcare prioritisation to make use of data on the costs and benefits of healthcare, its use could lead to large-scale injustice. [insert reference when available] When resources are limited, fairness requires us to assess what things cost and what benefits those things bring. Some rationale is required; procedural justice alone is unreliable.

Objections to the application of theories of justice

Some philosophers are sceptical about the relevance of theories of justice to real world problems, and challenge whether justice should be of paramount concern. Jonathan Wolff believes that radical philosophical arguments have a role in policy debate, but settle nothing on their own. (Wolff, 2011, p. 35-6) John Arras is “doubtful that any high level philosophical theory can be fruitfully “applied” directly so as to yield univocal answers to complex problems of professional practice and public policy.” (Arras, 2010) Raymond Geuss agrees, but goes further. He is not persuaded by Rawls’s intuitive claim that justice is of paramount concern, and that it trumps all other political and moral values. (Geuss, 2008, p. 80-87) He also doubts that any theory of distributive justice, including those based on equality, should be the starting point for policy: (Geuss, 2008, p. 79-80)

“the distribution of medical services in a modern hospital can be described, depending on the frame of reference chosen, as “equal” (all are to get, notionally, as much as they need”), or “unequal” (those seriously ill get more treatment than those with minor ailments), and our ability to redescribe the situation in each of these two different ways is an indication of the uselessness of the distinction if used in the abstract... There is nothing special about equality; what is objectionable is depriving people of needed medical treatment, if it is in principle available. That in most societies is a definite social ill, and we do not need to appeal to the notion of “equality” to see why it is an ill. It is not, then, that we proceed as follows: first we have an intuition about “equality” as the basis for political philosophy; then we observe that in this particular case equality is violated (because not everyone is getting equal medical care)...”

In summary, there is little agreement within philosophy and bioethics on principles of justice and resource allocation, or on that on their own they provide a sound basis for policymaking. Procedural justice is an alternative, but it does not provide a sufficient

basis for fair resource allocation in healthcare. Justice matters, but it is not the primary goal of a healthcare system. The purpose of a healthcare system is not to carry out acts of justice. Is it to make something or someone better?

Should a healthcare system aim to produce as much benefit as possible?

Economic theories tend to be concerned not with justice, but with getting as much benefit (or good) as possible from available resources. I consider below how good should be assessed, and specifically whether a healthcare system should aim to produce as much good as possible.

Should a healthcare system maximise utility?

‘Utility’ is a term used by economists to represent preferences, either actual preferences or the preferences of a rational, self-interested person.(Bentham, 1996) (Broome, 1999, p. 19-28) Economists can draw a utility function and use it to illustrate which of two options a person would choose based on their preferences. Utilitarianism can be seen as a branch of welfare economics:(Sen, 1980, p. 205)

“Welfarism is the view that the goodness of a state of affairs can be judged entirely by the goodness of the utilities in that state. This is a less demanding view than utilitarianism in that it does not demand - in addition - that the goodness of the utilities must be judged by their sum-total.”

Thus, for a utilitarian, resources are optimally allocated only when the total utility gained from the resources is maximised. This would be achieved by allocating each unit of resource to the person to whom it will give the greatest utility.

If everybody had exactly the same ideas of what was good (for themselves and others), then they would share the same utility function, and utility maximisation would not only maximise overall utility, but it also would be doing the most good. However, people do not all have the same utility function. Different people value different things differently. As Sen explains, person A may get great pleasure from causing pain to person B, and one person may gain great satisfaction from something, whereas another person in an equivalent situation may gain far less satisfaction from that same thing.(Sen, 1980, p. 211)

Furthermore, people do not always act as rational, self-interested individuals who weigh the evidence carefully to make the best choices for themselves.(Ariely, 2009) (Glimcher, 2009) (Broome, 1995, p. 162) (Geuss, 2008, p. 2-6) This is particularly true for healthcare, where large amounts of information may be needed to make an informed judgement, where complicated risk assessments may have to be made, and where clinicians have a significant influence on decision-making.(Berenson and Cassel, 2009) (Tversky and Kahneman, 1981)

For these reasons, maximising overall utility in a healthcare system may not bring about the most benefit, if benefit is based on something objective, and is not just the sum of individuals' preferences.

Furthermore, maximising utility takes no account of the preferences of future people. It could be argued that acting on the basis of the preferences of current people is democratic, and so should be done, even if it does not lead to the most benefit.(Broome, 1999, p. 191) However, decisions in a modern representative democracy are not based entirely on what today's citizens want. That is not how a modern representative democracy works. Complex policy issues are not resolved by satisfying citizens' individual preferences so as to maximise total utility.

Representatives are elected, informed, and either make policy decisions, or decide how policy will be made. Policymakers must think not only about getting the most good out of resources but also about the people to whom that good falls. If all healthcare resources were given to non-smokers, or just to women, or only to a particular ethnic group, because that was the way to achieve the most utility, policymakers would not be treating people with equal respect. Policymakers in a democracy have to consider who receives the resources. They may prioritise certain groups (e.g .those with fewer resources) but they must take into account the relative claims of all citizens, and at least consider whether to take account of the claims of future generations. In short, policymakers are charged with making the decision that they believe to be best, and not with maximising utility.

These are problems for utilitarianism, and welfarism in general. Aggregating the individual preferences of current citizens (if it were practicable in public policy) is not a sufficient basis on which to make decisions about what a healthcare system in a

democracy should do. What people want matters, but it is not the only thing that matters.

Should a healthcare system maximise good?

Therefore, satisfying preferences is not enough. A democracy requires some independent concept of the benefit that can be had from a healthcare system. As John Broome explains, there is a “need for a theory about what makes a life good, a theory about how wellbeing that comes in a life is aggregated together to determine the overall goodness of a life”.(Broome, 1999, p. 194) He provides the structure for that theory. For Broome, the “badness of death” is the goodness of the life that is taken away from you.(Broome, 2004, p. 249-50). “What is in store for us is an end that is worse than living longer would have been, and better than dying sooner would have been. That is all.” (Broome, 1999, p. 171) The good of healthcare is to provide people with a longer life in better health. The greater the wellbeing to be gained, and the longer the period of gain, the more good there is done. So more good would be done by giving a life-saving treatment to a person who can regain full health and live for 10 years, than to a person who will go on to live in poor health for 10 years, or to a person who will go on to live in good health for 1 year.

In the context of a healthcare system, the quality-adjusted life year (QALY) is one possible measure of good.(Williams, 1985) There are variants, including the disability-adjusted life year.(Rushby and Hanson, 2001) The central idea behind a QALY is that the good of healthcare is the amount of good-quality years of life that it can add to a person’s life. The greater the health gain for a person, and the longer that that health gain lasts, the more QALYs are generated, and therefore the more good is done. If the QALY is the right measure of good, and if doing good is the sole purpose of a healthcare system, then QALY maximisation provides the answer to the question of what a healthcare system should do. However, such an approach is open to criticism; two are considered below.

Are some goods incommensurate or incomparable?

Some commentators argue that it is not possible to measure or compare the good that is done, for example, from a hip operation, to the good that is done by delivering a newborn child into the world. If that is true, that is a serious problem for the maximisation of good which relies on comparing goods, and on QALYs which are

based on the idea that the good of healthcare can be measured, and that competing healthcare interventions can be ranked. In other words, QALYs rely on the good of healthcare being both commensurable and comparable.

In her edited book on this subject, Ruth Chang begins by drawing an important distinction between commensurability and comparability:(Chang, 1997, p. 2)

“Comparison does not require any single scale of units of value according to which items can be precisely measured; one alternative can be better than another without being better by 2.34 units. Comparable items can be ordinally ranked – ranked on a list – and need not be cardinally ranked – precisely ranked by some unit of value”. Given that the two ideas are distinct, let us henceforth reserve the term ‘incommensurable’ for items that cannot be precisely measured by some common scale of units of value, and the term ‘incomparable’ for items that cannot be compared.”

As Chang explains, comparability is more significant than commensurability. If two options were incomparable, it would mean we could not say which of the two was better, and the maximisation of good for healthcare systems would fail in such cases. It would not necessarily fail just because goods were shown to be incommensurate (not measurable).

Martha Nussbaum draws the same distinction as Chang between comparability and commensurability, and argues that many goods are comparable but incommensurate enabling goods to be ranked without a “hidden measure of goodness”.(Nussbaum, 2003, p. 110-111) Responding later in the same book, Judith Jarvis Thomson is not convinced by Nussbaum’s analysis, and concludes that without some additional information on what a person values (e.g. if she likes good food), then ranking is not possible, and thus that consequentialist theories cannot succeed without some underlying explanation of what makes life valuable.(Thomson, 2003, p. 154-7)

Like Thomson, John Broome concludes that we can only decide that one option is better than another if we have some notion of value, such as what makes a good life. His detailed analysis of this topic concludes that goods are comparable.(Broome, 1999, p. 123-161) He explains why satisfying individuals’ preferences does not always lead to what is best, and that what is best relies on some independent conception of what makes a life a good life. He calls this approach “structured

valuation” and uses QALYs as an example of a structured approach. In a healthcare system, with so many affected individuals, it would not only be impractical to decide what to do by aggregating preferences, but it is unlikely to lead to the best decision. A structured approach need not rely on a single source of value. In healthcare, life at full health is good, and the more of it the better (as suggested by QALYs). But we might also argue that the final weeks and days of life are of special value, and weight them accordingly.

Different people (be they economists, philosophers or citizens) have very different conceptions of what makes life valuable, and these values can vary across democracies, as John Gray explains:(Gray, 1998, p. 31)

“Depending on their histories and circumstances, different societies will have reason to opt for different mixes even of goods without which no good life can be lived. To impose any single ranking or weighting on the ingredients of the good is unreasonable.”

Gray argues that this makes goods incommensurable. But the value pluralism and the *modus vivendi* about which he writes arise because people’s values differ, and not because goods are necessarily incommensurate or incomparable.

People fail to agree on what a healthcare system should do because they have different values. If we were all rational and shared exactly the same values, we would all agree on whether it is better to give a final six months of good life to a cancer patient or to provide a lifetime of healthcare to a child with diabetes. We would not conclude that if we cannot afford to do both of them then we should do neither on grounds of the two things being incomparable. It would of course be a difficult choice, but such choices are unavoidable in a healthcare system. In a healthcare system, goods must always be compared, however difficult that may be, because choices must be made about what good things should be done and not done. Our differing values mean that we disagree about the good of one thing compared to another, and about what is fair, but that means that we require some means of resolving our differences. It does not mean that goods are incomparable. Goods are comparable.

If goods are measured, then comparison becomes more practical when there are thousands of possible ways to spend money to do good. But it is not an essential step; ranking is what matters.

Is it fair to maximise good?

Another problem with doing as much good as possible, or QALY maximisation more specifically, is that it may not be fair to everyone. QALY maximisation implies that available resources are allocated to a healthcare system in order to realise as many QALYs as possible, regardless of who receives the QALYs. It has been argued that it is a fair system of resource allocation because QALYs are blind to their recipient: what matters is their potential to benefit from the healthcare system, and not their financial status, gender or race. (Williams, 1985, Williams, 1992) However, since it was first proposed in the 1980s, QALY maximisation has been criticised (particularly by philosophers and bioethicists) as being unfair, notably to older people and others with a short life expectancy, and to people who have limited potential to benefit from healthcare interventions (such as some people with a debilitating illness or disability). (Harris, 1987) (Nord et al., 2009) (Clark and Weale, 2012, p. 306) (Beauchamp and Childress, 2009, p. 232-3) For example, even in the best of health, a blind person scores less than one QALY, so has less potential to gain from an intervention than a sighted person, all other things being equal. Some people claim that QALYs are unfair to people who are in need of very costly treatments.

Doing the most good, and more specifically QALY maximisation, may not be the right goal of a healthcare system because it may be unfair. QALYs were not designed to achieve fairness. For example, they take no account of any of the theories of distributive or procedural justice outlined above.

Should a healthcare system aim to maximise autonomy?

In their classic textbook, Beauchamp and Childress identify four principles of bioethics: respect for autonomy, justice, beneficence and non-maleficence. (Beauchamp and Childress, 2009) Justice is discussed above, and beneficence and non-maleficence together relate closely to the concept of “good” described above. What of respect for autonomy - should it have a role in determining what a healthcare system should do?

As argued above, when making public policy (but not necessarily private policy), doing some objective good, rather than simply satisfying individual preferences, is what matters (although the two often coincide). (Broome, 1995, p. 162) A healthcare system should aim to do good rather than always doing what people say they want. That does not imply disrespect for autonomy. When healthcare is provided, individuals should choose whether they want the healthcare that is offered to them. So in the earlier scenario, if the cancer treatment is offered, it is a matter for Tariq to decide whether he wants it. This is what happens in practice in healthcare systems around the democratic world; with a few notable exceptions, (such as where adults lack mental capacity) individuals choose whether to receive the healthcare offered to them. Furthermore, for certain public health programmes, respect for autonomy may influence what is done by the healthcare system, affecting for example how anti-smoking campaigns are delivered. (Nuffield Council on Bioethics, 2007, p. 23-26) Thus, respect for autonomy matters, particularly at the “micro” level, when individuals choose between healthcare treatment options. Autonomy in this sense has a relatively small role to play in determining what a healthcare system should do.

However, autonomy is open to wider interpretation. (Dworkin, 1988, p. 3-20) David Seedhouse sees autonomy as being of fundamental importance, and about much more than enabling choice. For Seedhouse, autonomy is met by cultivating various connected “foundations”, including basic needs like food and shelter, education, and engagement in communal life, so that a person is then capable to go on to fulfil her goals. (Seedhouse, 2004, p. 164-6) It is similar to Sen and Nussbaum’s thinking on capability, in that those lacking basic capabilities should be prioritised when resources are distributed, and not dissimilar to Rawlsian thinking, as Seedhouse recognises primary goods, and looks “first to support the weakest members of society, each person should be brought as near as possible to the foundation level”. (Seedhouse, 1995, p. 218)

These writers are making particular claims about the good of healthcare. Like those advocating QALYs, they are offering structured valuations of good. They place especially high value on healthcare that empowers people in certain ways: such healthcare can be seen as especially good.

This wider notion of autonomy is closely linked to Nussbaum and Sen's concept of capability, which they distinguish from human functioning.(Nussbaum, 2004, p. 499) (Sen, 2005, p. 154-5) (Sen, 1985, p. 217-8) Whilst autonomy can be seen as a legitimate goal in itself, it can also be accommodated within the notion of good. Rather than assessing the good of healthcare according to how it improves a person's functioning and overall health state (as implied by QALYs), good could be assessed in terms of its potential to improve a person's capabilities. Some authors have explored this possibility, considering how health benefit could be measured when capability is valued highly, and whether QALYs could be adapted to take account of capability.(Anand, 2005) (Cookson, 2005) (Coast et al., 2008) In practice this might mean, for example, giving additional weight to the claims for healthcare of a man whose life is impoverished because of a phobia preventing him from leaving the house and participating in a flourishing life. However, this would be in the context of the relative good of healthcare, so his claim to healthcare would not necessarily trump the treatment claim of a very capable woman, currently leading a full, active and rich life, albeit with a malign tumour in her breast that will cut short her considerable capabilities if left untreated. Her claim to carry on living is also strong. Autonomy, and similarly capability, are important attributes of a good life. They can be incorporated within a notion of what is good, but they are not the only good thing that healthcare can provide.

Towards an answer: balancing good and fairness

In this section, I summarise the conclusions from the analysis above, and in so doing attempt to move towards an answer to the question of what a healthcare system in a democracy should do.

Philosophical principles of justice are not a sufficient basis for policymaking. In practice, public policymaking in a democracy does not begin with a theory of justice.(Anderson, 2010) Nor necessarily ought it to begin with philosophical theory.(Arras, 2010) (Geuss, 2008, p. 9-13) That is not to say that philosophy cannot contribute to policy thinking.(Wolff, 2011, p. 1-10)

Good is more relevant than utility to public policymaking in a democracy. When determining what a healthcare system should do, public policymakers should aim to do some objective good based on some notion of the good of healthcare (such as an

improvement in future quality-adjusted life years). Often doing good will coincide with satisfying people's preferences, but sometimes it will not. Although people's preferences for healthcare matter, they do not, and should not, on their own determine what a healthcare system should do.

Outside of the public policy sphere, individual preferences should, and indeed do, in the main determine how resources are allocated. But questions of public policy are not determined by majority voting, and nor should they be, especially on matters of moral concern that affect us all. (Dworkin, 2006, p. 140-1)

All things being equal, the more good that is done, the better. Given limited resources, and a fixed set of people benefiting from the healthcare, it must be better to provide every person with (say) 2X of good than X of good.

Maximising good is important, but not enough. Maximising good across all of the potential beneficiaries is a legitimate objective. However, depending on how the good is distributed, it may be unfair, and so on its own, it does not determine what a healthcare system should do. It may be that less good overall should be done for reasons of fairness.

Doing good and being fair both matter. Ethical decision-making often requires the balancing of important principles such as these, so that one is constrained, or traded off, for another. (Beauchamp and Childress, 2009, p. 198) This is consistent with systems thinking, which recognises that goal-seeking systems are subjected to identifiable constraints.

In order to determine what a healthcare system should do, a theoretical basis is required for balancing good and fairness. John Broome provides just such a theory.

Fairness is a relative, not an absolute, notion.

There are many philosophical theories of justice and of rights that rest on absolute claims about what is good or fair. These absolute principles do not allow for a conclusion that one thing is better than another, or fairer than another. Systems theory suggests that there are usually many important perspectives on complex problems, but many philosophical theories provide a singular perspective, and not a holistic view. The insights such philosophical theories provide compete for our attention, and in general do not lend themselves to synthesis with, or balancing against, other

philosophical or non-philosophical arguments. For example, Robert Nozick argues that fairness is a side-constraint, and that side-constraints must always be satisfied. He leaves no room for relaxing, or trading-off, the hard constraint of fairness. (Nozick, 1974, p. 29)

Broome offers a different idea of fairness:

“The heart of my suggestion is that fairness is concerned only with how well each person's claim is satisfied compared with how well other people's are satisfied. It is concerned only with relative satisfaction, not absolute satisfaction. Take a case where all the candidates for a good have claims of equal strength. Then fairness requires equality in satisfaction. So if all the candidates get the same quantity of the good, then fairness has been perfectly achieved, even if they get very little, or indeed none at all... But then also fairness requires that claims should be satisfied in proportion to their strength. Evidently, claims in my theory do not work as side constraints; they do not necessarily prevail.”

Satisfying claims in proportion to their strength means that stronger claims should get more, but weaker ones should get something. If more good results from the first candidate receiving something (such as a life-enhancing healthcare treatment) rather than the second candidate, then that is a reason for giving more to the first candidate, but not a reason to discount the claims of the second candidate.

However, the demands of fairness might sometimes be so great that everyone's claims should be treated equally. That seems initially difficult to reconcile with satisfying claims in proportion to their strength. Let us return to Tariq and his need for expensive cancer treatment to consider how this works in practice. Because of other clinical factors, Dr. Foster assesses Tariq's chance of benefitting from the treatment and returning to normal health as 20%, whereas to Tarquin, her other, fitter and equally deserving patient of similar age she gives a 40% chance of survival from the same needed treatment. There is a prospect of more good being done for Tarquin so he has a stronger reason to get the good, and so if resources allow only one to receive the expensive treatment, it should be Tarquin. If we believed we should always do the most good, then Tarquin gets treated. However, that would be unfair to Tariq. Fairness is concerned with how well Tariq's claim is satisfied compared to Tarquin's

claim, and Tariq's claim to carry on living is just as strong. The aims of doing the most good and being fair must be weighed. In this case, Tariq's fairness claim is very strong: his very survival for many more years of life. Therefore, in this case, fairness should prevail. If it is not possible for both Tarquin and Tariq to get some treatment, then a lottery would be a fair means of settling which of the two candidates is treated.

However, if a successful outcome for Tariq was 10 weeks' survival compared to 10 years for Tarquin, or if Tariq's prospect of a successful outcome was 4% compared to Tarquin's 40%, then weighing up good versus fairness would suggest that Tarquin should be treated. Had the decision been about, say, a hip replacement, the force of Tariq's fairness claim would be weaker, and doing the greater good for Tarquin might prevail. Much depends on the circumstances of the case.

Thus **a healthcare system should aim to do as much good as possible, whilst being fair**. Clearly, this approach to weighing good and fairness does not provide the basis for a formulaic answer to determining what a healthcare system should do. It provides a structural account of the good of healthcare, for understanding fairness, and that these two distinct concerns should be balanced. However, it does not tell us much about how to determine the strength of a fairness claim, and whether fairness requires that factors like Tariq's smoking or his dependent family make him a less or more deserving case. Many such questions of what is good and fair arise. (Orr et al., 2011) When it comes to deciding what to do, much depends on how we measure good, on how much strength we assign to different fairness claims, and on how much weight is given to good and how much to fairness.

In short, it depends on your *weltanschauung*. That leads to another difficult question.

6. Whose weltanschauung should determine what counts as good and fair?

Systems theory recognises that different people will have different ideas about what is good and fair, and of what a healthcare system should do, because they have different weltanschauungen (worldviews). Economics and philosophy also recognise this plurality of values. The different disciplines in themselves engender different worldviews amongst practitioners, and provide differing perspectives on how social values should be identified and applied to questions of what a healthcare system should do.

A perspective from systems theory

According to systems thinking, questions about what is good and fair for a healthcare system to do can be seen as boundary judgements, and "there is no objective solution but only a critical solution to the problem of boundary judgements".(Ulrich, 1994, p. 230) The thinking of those designing the system, and those affected by the system, both matter.(Ulrich, 1994, p. 265-7) Boundary judgements determine the scope of a system, and an important role for the systems practitioner is to capture and articulate alternative perspectives of an ideal system (for example, using "rich pictures") based on alternative weltanschauungen of stakeholders.(Checkland, 2000, p. S23-4) Having articulated these competing visions, the systems practitioner facilitates debate amongst those affected by the system (for example politicians, managers, doctors, patients) until decisions are made about the purpose and nature of the required system. Soft systems methodology attempts to respect the views of all stakeholders, whereas critical systems theory includes an analysis of power, and seeks to empower and emancipate those whose voice is weak.(Ramage and Shipp, 2009, p. 161-2) However, it is not clear how such conflicts are resolved in practice when the system is healthcare and those affected may be the entire population of a democracy.

A perspective from philosophy and bioethics

Philosophy suggests that value judgements should be made through reasoning, and that deliberation amongst groups of individuals will improve reasoning. This thinking is evident in philosophical writing from Plato to John Stuart Mill to Karl Popper to John Rawls.(Solomon, 2006, p. 28) It is central to Norman Daniels' approach to determining how to make fair decisions about what a healthcare system should do. Some philosophers, including Plato, favour reasoning by experts, whereas many

others, including Daniels, believe that deliberation should be by citizens so that policies that affect everyone in a democracy have legitimacy. (Daniels and Sabin, 2008, p. 64) (Kim et al., 2009)

Perspectives from economics and the social sciences

Some health economists recognise that a concept like a QALY may not be fair, and may not capture the full goals of a healthcare system. A response has been to adjust QALY formulae to account for various factors including age and life expectancy, severity of health condition prior to treatment, health benefit over time, and loss of economic productivity. (Tsuchiya, 2000) (Nord, 1993) (Nord, 1999, p. 50-57) (Brouwer et al., 1997) Numerous public surveys have been carried out to determine the weight that should be given to these factors (Dolan et al., 2005, Schwappach, 2002), and more research is planned. (Littlejohns et al., 2012)

Thus, in contrast to the deliberation advocated by philosophers, economists have sought to answer difficult normative questions of what is good and fair in healthcare by using data accrued from surveys of the public. Few offer any explanation as to why public surveys should provide answers to normative policy questions. An obvious difficulty with such surveys is that participants may be poorly informed. (Kim et al., 2009) Furthermore, whether it is better to provide healthcare to young people in preference to elderly people is more complicated than whether milk chocolate is better than dark chocolate, and so less suited to quick survey. When faced with difficult ethical questions, people may begin with one view and finish with another, as they become more informed and have an opportunity for discussion with peers. This was illustrated by a recent citizens' jury held to inform UK government thinking on whether to protect health spending from budget cuts. When surveyed beforehand, 79% of the 24 members of the citizens' jury were in favour, but after three days of deliberation where the citizens had the opportunity to hear and discuss expert evidence, only 9% wanted to rule out cuts in health spending (Stratton, Tuesday 10 August 2010).

Whose perspective should count?

Such deliberative processes are costly and time-consuming, and in practice can involve only a very small number of people. Citizen deliberation relies on expert evidence, and according to lawyer and psychologist Dan Kahan's research, people

tend to choose to believe the experts, and the evidence, not on a rational basis, but on what fits best with their existing values.(Kahan et al., 2007) Furthermore, bodies like citizens' juries and expert panels may be subject to "group think", suppressing individual expression and valuable dissent, especially where consensus is their goal.(Esser, 1998) Group deliberation may lead to poor decision making because it fails to benefit from the collective information and knowledge of individuals acting independently: the "wisdom of crowds".(Solomon, 2006) So it is far from clear that small groups will collaborate to reach rational decisions.

These are debates about whether it is the weltanschauung of small groups or large groups, of experts or citizens, that count when deciding what a healthcare system should do. But there is also the question of whether only those affected by decisions should have some say. For many philosophers, including John Rawls and Norman Daniels, it is the members of the community who will be affected by the allocation of resources who should come together to agree what should be done. Amartya Sen, drawing from the writing of fellow economist and philosopher Adam Smith, warns against the narrow parochialism of values, which can lead to pertinent arguments being ignored. He promotes the value of an impartial spectator, without vested interest, who can view problems from a distance.(Sen, 2009, p. 44-46) It is an idea that is also at the heart of English law, captured by the notion of the "man on the Clapham omnibus".(Rostow, 1960, p. 177-8) Similarly, in systems theory, the systems practitioner, like the impartial spectator, views problems from a distance, if not independently.

The context of democracy provides an answer

I will not attempt to resolve these debates here about whose weltanschauung should count, and how they should be counted, not simply because of insufficient space, but because the context of democracy shapes the answer. Context matters. The question is not about how a democracy should function, but of what a healthcare system in a functioning democracy should do. It may be that policymaking ought to be done differently, but that is a separate question (with its own large literature). Democracies already have ways of taking account of the worldviews of citizens and others when making policy judgements. They have political institutions created to make such

policy decisions in pluralist societies where people have diverse values and do not agree.

In functioning democracies across the world, policy is made primarily by officials elected at regular intervals through universal suffrage. In all such democracies, citizens have some voice, although their influence varies from substantial to insignificant. (Dworkin, 2006, p. 141) Although they may delegate aspects of policy to others, it is elected politicians who are accountable to citizens for making good use of public resources, and for doing it fairly. Being fair does not mean treating everyone the same, but it does mean showing equal concern for all citizens, whatever their gender, colour or shape. (Dworkin, 2006, p. 97) It means relative fairness.

When judging what is good and fair, there are normative arguments in favour of policymakers in a democracy taking account of many different *weltanschauungen* from many different sources. Because policymakers are elected to serve, and be accountable to, citizens, they should take note of surveys (or indeed referenda), even if those polls reflect opinions from many poorly-informed citizens. However, even in a representative democracy, policymakers are not bound to follow the opinions of poorly-informed voters. It is justifiable for policymakers to take note of the thinking of better-informed groups of citizens, like citizens' juries. Pressure groups whose members may be severely affected by, or may feel strongly about, a policy question, also deserve a hearing. Policymakers should take note of the evidence of experts, and experience from other countries which may bring the wisdom of the impartial spectator. Future generations have no vote, but are due some attention in the policymaking process. Political parties and politicians are elected on their manifestos and their individual values, and so these also legitimately shape policy decisions that are made. Clearly policymakers have many potential worldviews that they should take into account, in addition to their own. They should not merely serve the interests of a particular powerful group, or pursue a policy because it best serves their own individual interests – such action would justify censure, and undermine good and fair policymaking. Policymakers have a duty to weigh up many different perspectives, and make policy that is in the interests of their society. This is what a functioning democracy requires of its policymakers.

How policy decisions should be, and are, made in practice varies from democracy to democracy, depending on political institutions, laws, history, culture, values, and so on. Ultimately, the elected representatives are accountable to citizens for the judgements made about the good of healthcare, and when it is fair to sacrifice some overall good for the sake of fairness. In functioning representative democracies, political institutions and electoral accountability may be far from perfect. How such institutions and accountability should function in an ideal world is a big subject for another paper. This paper asks, given the context of an imperfect but functioning democracy, what a healthcare system should do. The answer is that it should aim to do good whilst being fair. What is good and fair in practice is a dilemma to be resolved by policymakers, having considered the worldviews and legitimate interests of many different groups.

7. Conclusions

In a democracy, there are reasons why healthcare, or at least some healthcare, **should be** a matter of public policy. For the healthcare that **is** publicly funded in democracies around the world, the question of what a healthcare system should do, **is** a matter of public policy.

A healthcare system, like any system, comprises many inter-connected parts, has purpose(s), a boundary, and affects and is affected by the world outside its boundary. People may disagree on the purpose and boundary of a system; it depends on their weltanschauungen.

In order to achieve its purpose(s), a healthcare system uses resources to carry out transformations, typically of unhealthy people into more healthy people. There are constraints on the transformations that can be carried out, and for a healthcare system in a democracy, the most significant constraint is resources. Given limited resources, what should a healthcare system do?

One possible answer from philosophy is that the primary goal of a healthcare system should be justice. I consider several principles of distributive justice, and a leading theory of procedural justice, and though it is important to be fair, a healthcare system is not and should not be designed to produce justice. It should be designed to do some good, and many economists would say, to do as much good as possible, with its limited resources. In a healthcare system, doing good means more than just satisfying individual preferences. It requires some independent notion of the good of healthcare. Few would disagree that the more that a healthcare system can extend life, and the more it can increase health through that life, the better. That is the thinking behind the quality-adjusted life year. There may be other, richer, notions of what is good about healthcare which, for example, take account of non-health benefits, but the QALY is an important candidate. In order to assess and maximise good using QALYs or any other measure, large amounts of information are required about the cost and relative benefit of different healthcare activities.

The QALY was designed as a measure of good, not fairness. Fairness is a separate consideration. It also matters, and I argue here in favour of John Broome's notion of relative fairness. When resources are limited, not all claims for healthcare can be met,

and so fairness means satisfying claims in proportion to their strength. Sometimes being fair may mean doing less good overall.

Having considered many theories, especially from philosophy and economics, **I conclude that the purpose of a healthcare system in ANY democracy should be to do as much good as possible, whilst being fair, based on the notions of good and fairness proposed by John Broome.** This provides policymakers in any democracy with the framework for determining what a healthcare system should do. At the same time, it leaves some room for different democracies to decide what precisely it is to be good and fair in healthcare, and when good should be traded off for fairness. The answers to those questions depend on your weltanschauungen, and in a pluralist modern democracy, people's values differ. Many perspectives deserve proper consideration. Functioning democracies have people and mechanisms to enable differing perspectives to be considered, and differences settled. In democracies, ultimate responsibility lies with policymakers. Policymakers can and should take account of different weltanschauungen in pursuing a healthcare system that aims to do as much good as possible, whilst being fair.

References

- Ackoff RL. (1999) On passing through 80. *Systemic Practice and Action Research* 12: 425-430.
- Anand P. (2005) Capabilities and health. *Journal of medical ethics* 31: 299.
- Anderson JE. (2010) *Public policymaking: An introduction*, Belmont: Wadsworth Pub Co.
- Ariely D. (2009) *Predictably irrational: The hidden forces that shape our decisions*, New York: HarperCollins.
- Arras J. (2010) Theory and Bioethics. In: Zalta EN (ed) *The Stanford Encyclopedia of Philosophy*. Summer 2010 ed.
- Ashcroft R. (2008) Fair process and the redundancy of bioethics: a polemic. *Public Health Ethics* 1: 3.
- Beauchamp TL and Childress JF. (2009) *Principles of biomedical ethics*, New York: Oxford University Press.
- Bentham J. (1996) *An Introduction to the Principles of Morals and Legislation (Collected Works of Jeremy Bentham)*, Oxford: Clarendon Press.
- Berenson RA and Cassel CK. (2009) Consumer-driven health care may not be what patients need—caveat emptor. *JAMA: The Journal of the American Medical Association* 301: 321-323.
- Berlin I. (1961) Equality as an Ideal. In: Olafson F (ed) *Justice and Social Policy*. Englewood Cliffs, N.J.: Prentice Hall.
- Broome J. (1995) *Weighing goods: equality, uncertainty and time*, Oxford: Wiley-Blackwell.
- Broome J. (1999) *Ethics out of Economics*, Cambridge: Cambridge University Press.
- Broome J. (2004) *Weighing lives*, Oxford: Oxford University Press.
- Broome J. (2005) Why economics needs ethical theory. *Pelican Record* 42: 80–88.
- Brouwer WBF, Koopmanschap MA and Rutten FFH. (1997) Productivity costs in cost effectiveness analysis: numerator or denominator: a further discussion. *Health economics* 6: 511-514.
- Carande-Kulis VG, Getzen TE and Thacker SB. (2007) Public goods and externalities: a research agenda for public health economics. *Journal of Public Health Management and Practice* 13: 227.
- Chang R. (1997) *Incommensurability, incomparability, and practical reason*, Cambridge, Mass.: Harvard University Press.

- Checkland P. (1985) From optimizing to learning: a development of systems thinking for the 1990s. *Journal of the Operational Research Society*: 757-767.
- Checkland P. (2000) Soft systems methodology: a thirty year retrospective. *Systems Research* 17: S11-S58.
- Churchman CW. (1971) *The design of inquiring systems: Basic concepts of systems and organization*: Basic books New York.
- Churchman CW. (1979) *The Systems Approach and Its Enemies*, New York: Basic Books.
- Clark S and Weale A. (2012) Social values in health priority setting: a conceptual framework. *Journal of Health Organization and Management* 26: 293-316.
- Coast J, Smith R and Lorgelly P. (2008) Should the capability approach be used in health economics? *Health economics* 6: 667-670.
- Coggon J. (2012) *What makes health public?: a critical evaluation of moral, legal, and political claims in public health*, Cambridge: Cambridge University Press.
- Cohen-Charash Y and Spector PE. (2001) The role of justice in organizations: A meta-analysis. *Organizational behavior and human decision processes* 86: 278-321.
- Cookson R. (2005) QALYs and the capability approach. *Health economics* 14: 817-829.
- Culyer AJ. (2001) Economics and ethics in health care. *Journal of medical ethics* 27: 217-222.
- Dahl RA. (2000) *On democracy*, Newhaven: Yale Univ Pr.
- Daniels N. (1985) *Just health care*, New York: Cambridge University Press.
- Daniels N and Sabin J. (1997) Limits to health care: fair procedures, democratic deliberation, and the legitimacy problem for insurers. *Philosophy & public affairs* 26: 303-350.
- Daniels N and Sabin JE. (2007) *Setting Limits Fairly - Can we Learn to share Medical Resources?*, New York: Oxford University Press.
- de Villanueva CF. (2010) The School of Salamanca: some thoughts on the subject of justice. In: Parisi S (ed) *Humanism and Religion in the History of Economic Thought*. Rome: Franco Angeli, 96.
- Dolan P, Shaw R, Tsuchiya A, et al. (2005) QALY maximisation and people's preferences: a methodological review of the literature. *Health economics* 14: 197-208.
- Dworkin G. (1988) *The theory and practice of autonomy*, New York: Cambridge University Press.

- Dworkin R. (2002) *Sovereign virtue: the theory and practice of equality*. Harvard Univ Pr.
- Dworkin R. (2006) *Is democracy possible here?: principles for a new political debate*, Princeton: Princeton University Press.
- Epstein RA. (2003) In Defense of the Old Public Health-The Legal Framework for the Regulation of Public Health. *Brook. L. Rev.* 69: 1421.
- Esser JK. (1998) Alive and well after 25 years: A review of groupthink research. *Organizational behavior and human decision processes* 73: 116-141.
- Geuss R. (2008) *Philosophy and real politics*, Princeton: Princeton Univ Pr.
- Gibson JL, Martin DK and Singer PA. (2005) Priority setting in hospitals: fairness, inclusiveness, and the problem of institutional power differences. *Social Science & Medicine* 61: 2355-2362.
- Glimcher PW. (2009) *Neuroscience, Psychology, and Economic Behavior: The Emerging Field of Neuroeconomics*. Cognitive Biology: Evolutionary and Developmental Perspectives on Mind, Brain, and Behavior. Cambridge: MIT Press.
- Goodman J. (2006) *Consumer-directed health care*. Available at: http://papers.ssrn.com/sol3/papers.cfm?abstract_id=985572#PaperDownload.
- Gostin LO. (2001) *Public health law: power, duty, restraint*, Berkeley: University of California Press.
- Gray J. (1998) Where pluralists and liberals part company. *International Journal of Philosophical Studies* 6: 17-36.
- Green RM. (1976) Health care and justice in contract theory perspective. *Ethics and Health Police*. Cambridge, Mass.: Ballinger Publ. Co.
- Gruskin S and Daniels N. (2008) Process is the point: justice and human rights: priority setting and fair deliberative process. *American Journal of Public Health* 98: 1573.
- Harris J. (1987) QALYfying the value of life. *Journal of medical ethics* 13: 117.
- Hobbs A. (2010) *What is fairness?* Available at: http://news.bbc.co.uk/today/hi/today/newsid_9079000/9079254.stm.
- Holm S. (1998) Goodbye to the simple solutions: the second phase of priority setting in health care. *British Medical Journal* 317: 1000-1001.
- Jackson MC and Keys P. (1984) Towards a system of systems methodologies. *Journal of the Operational Research Society*: 473-486.

- Kahan D, Braman D, Slovic P, et al. (2007) The second national risk and culture study: Making sense of-and making progress in-the american culture war of fact. *GWU Legal Studies Research Paper*: 08-26.
- Kim SYH, Wall IF, Stanczyk A, et al. (2009) Assessing the public's views in research ethics controversies: deliberative democracy and bioethics as natural allies. *Journal of empirical research on human research ethics: JERHRE* 4: 3.
- Klein R. (1994) Dimensions of rationing: who should do what? *British Medical Journal*: 309.
- Lamont J and Favor C. (2007) *Distributive justice*. Available at: <http://www.science.uva.nl/~seop/archives/fall2008/entries/justice-distributive/index.html#Strict>.
- Littlejohns P, Weale A, Chalkidou K, et al. (2012) Social values and health policy: a new international research programme. *Journal of Health Organization and Management* 26: 285-292.
- McGuire MC and Aaron H. (1969) Efficiency and equity in the optimal supply of a public good. *The Review of Economics and Statistics* 51: 31-39.
- McPake B, Normand C and Smith S. (2012) *Health economics: an international perspective*, London and New York: Routledge.
- Munro E. (2011) *The Munro review of child protection: Final report, a child-centred system*, London: Stationery Office.
- Nord E. (1993) The trade-off between severity of illness and treatment effect in cost-value analysis of health care. *Health Policy* 24: 227-238.
- Nord E. (1999) *Cost-value analysis in health care: making sense out of QALYs*. Cambridge Univ Pr.
- Nord E, Daniels N and Kamlet M. (2009) QALYs: some challenges. *Value in Health* 12: S10-S15.
- Nozick R. (1974) *Anarchy, state, and utopia*, New York: Basic Books.
- Nuffield Council on Bioethics. (2007) *Public Health: ethical issues*. Available at: <http://www.nuffieldbioethics.org/public-health>.
- Nussbaum MC. (2001) *Women and human development: The capabilities approach*, Cambridge, Mass.: Cambridge Univ Press.
- Nussbaum MC. (2003) Comment. In: Thomson JJ (ed) *Goodness and advice*. Princeton and Oxford: Princeton University Press, 97-125.

- Nussbaum MC. (2004) Beyond the social contract: toward global justice. *Tanner lectures on human values* 24: 413-508.
- OECD. (2011) *Financing of health care*
Available at: http://dx.doi.org/10.1787/health_glance-2011-64-en.
- Orr S, Wolff J and Morris S. (2011) *What Values Should Count in HTA for New Medicines under Value Based Pricing in the UK?* Available at:
<http://www.ucl.ac.uk/cpjh/mcda.pdf>.
- Parfit D. (2011) *On what matters*, Oxford: Oxford Univ Pr.
- Powers M and Faden R. (2006) *Social justice: the moral foundations of public health and health policy*, New York: Oxford University Press.
- Ramage M and Shipp K. (2009) *Systems thinkers*, London: Springer Verlag.
- Rawls J. (1999) *A Theory of Justice*, Cambridge, Mass.: Belknap Press.
- Reynolds M and Holwell S. (2010) *Systems approaches to managing change: a practical guide*, London: Springer.
- Rice T. (2001) Individual autonomy and state involvement in health care. *Journal of medical ethics* 27: 240-244.
- Rid A. (2009) Justice and procedure: how does “accountability for reasonableness” result in fair limit-setting decisions? *Journal of medical ethics* 35: 12.
- Rostow EV. (1960) *The enforcement of morals*, Cambridge: Cambridge University Press.
- Rushby JA and Hanson K. (2001) Calculating and presenting disability adjusted life years (DALYs) in cost-effectiveness analysis. *Health Policy and Planning* 16: 326.
- Sabik LM and Lie RK. (2008) Priority setting in health care: Lessons from the experiences of eight countries. *International Journal for equity in health* 7: 4.
- Sandel MJ. (2010) *Justice: What's the right thing to do?*, New York: Farrar, Straus and Giroux.
- Saracci R. (1997) The World Health Organisation needs to reconsider its definition of health. *British Medical Journal* 314: 1409.
- Schwappach DLB. (2002) Resource allocation, social values and the QALY: a review of the debate and empirical evidence. *Health Expectations* 5: 210-222.
- Seedhouse D. (1995) The way around health economics' dead end. *Health Care Analysis* 3: 205-220.
- Seedhouse D. (2004) *Health promotion: philosophy, prejudice and practice*, Chichester: Wiley.

- Sen A. (1980) Equality of what? *Tanner lectures on human values* 1: 195-220.
- Sen A. (1985) Well-being, agency and freedom: the Dewey lectures 1984. *The Journal of Philosophy*: 169-221.
- Sen A. (1999) Democracy as a universal value. *Journal of Democracy* 10: 3-17.
- Sen A. (2002) Why health equity? *Health economics* 11: 659-666.
- Sen A. (2005) Human rights and capabilities. *Journal of Human Development* 6: 151-166.
- Sen A. (2009) *The idea of justice*, Cambridge, MA.: Belknap Press.
- Solomon M. (2006) Groupthink versus the wisdom of crowds: The social epistemology of deliberation and dissent. *The Southern journal of philosophy* 44: 28-42.
- Stratton A. (Tuesday 10 August 2010) NHS funding should not be ringfenced, says citizens' jury. *The Guardian*.
- Syrett K. (2008) NICE and judicial review: enforcing 'Accountability for Reasonableness' through the courts? *Medical law review* 16: 127.
- The Danish Council for Ethics. (1997) *Priority-setting in the Health Service*. Available at: <http://etiskraad.dk/upload/publications-en/misc/priority-setting-in-health.htm>.
- Thomson JJ. (2003) Reply to commentators. In: Thomson JJ (ed) *Goodness and advice*. Princeton and Oxford: Princeton University Press.
- Tsuchiya A. (2000) QALYs and ageism: philosophical theories and age weighting. *Health economics* 9: 57-68.
- Tversky A and Kahneman D. (1981) The framing of decisions and the psychology of choice. *Science* 211: 453-458.
- Tyler TR. (2006) Psychological perspectives on legitimacy and legitimation. *Annual Review of Psychology* 57: 375-400.
- Ulrich W. (1994) Critical heuristics of social planning. *Journal of the Operational Research Society* 36: 878-881.
- Vanhanen T. (2003) *Democratization: A comparative analysis of 170 countries*, Hove, England: Psychology Press.
- Von Bertalanffy L. (1972) The History and Status of General Systems Theory. *Academy of Management Journal* 15: 407-426.
- Von Bertalanffy L. (1975) *Perspectives on general system theory: scientific-philosophical studies*, New York: George Braziller.

- Wenar L. (2008) *John Rawls*. Available at: <http://plato.stanford.edu/entries/rawls/>.
- Whitchurch GG and Constantine LL. (1993) Systems theory. *Sourcebook of family theories and methods*: 325-355.
- WHO. (1948) *Basic documents of the World Health Organization*, Geneva: World Health Organization.
- Williams A. (1985) The value of QALYs. *Health and social service journal* 18: 3-5.
- Williams A. (1992) Cost-effectiveness analysis: is it ethical? *Journal of medical ethics* 18: 7-11.
- Wilson EO. (1999) *Consilience*, New York: Vintage Books.
- Wolff J. (2011) *Ethics and Public Policy: A Philosophical Inquiry*, London: Routledge.
- Woolhandler S and Himmelstein DU. (2002) Paying for national health insurance—and not getting it. *Health Affairs* 21: 88-98.

7. Conclusion

Saying something original

In this thesis, I have drawn on thinking from several disciplines, and especially economics and from philosophy. At the current time, there is some agreement within each of those two disciplines, and almost no agreement across the two disciplines, on how resources should be allocated to healthcare. Although there is already a vast literature on the subject, there is relatively little constructive collaboration, and little debate, between economists and philosophers. In general, they plough separate furrows. Most academic writers draw mainly on arguments and publications from their own discipline. Few attempt to synthesise arguments from across several disciplines. By drawing on thinking from economics, philosophy and elsewhere, I believe I have been able to contribute something original to the literature.

Saying something useful to policymakers

I also believe that this approach provides a better chance of saying something that could be useful to policymakers. Policymakers tend to have large agendas and little time. If a policymaker gives time to look into the vast academic literature on resource allocation in healthcare, she will discover widespread disagreement within and between disciplines. Should she adopt QALYs and ignore philosophical principles of justice (or vice versa)? If so, on what basis? This dilemma was brought home very clearly to me when I was asked to write a policy document on ethical commissioning for the Royal College of General Practitioners. (Oswald and Cox, 2011) It was very difficult to know what to write. General practitioners sought straightforward practical advice, not a long story of irreconcilable differences between economists and philosophers.

To their credit, Daniels and Sabin have recognised and responded to this interdisciplinary disagreement with a solution: accountability for reasonableness (A4R). It provides a way forward that could (and has) been applied by policymakers. But as I argue in paper 5, A4R's reliance on procedure alone makes it vulnerable to large-scale injustice. The good and fairness framework I outline (based on John Broome's writing) draws on thinking from both disciplines, and provides a better and fairer way forward.

I would also argue that by considering the question of what a healthcare system should do within the context of a modern representative democracy, I am more likely to provide an answer that could be useful to a policymaker. Few academic writers appear to set an explicit context for their proposals. Their advice on a policy question too often takes no account of the policymaker's situation. The policymaker must work within existing democratic institutions and processes. When addressing a specific policy question, she does not seek advice that involves changing the way that policy is made. How policy is made is of course a proper subject for academic debate, but it is a large subject in its own right, and better considered separately.

Conclusions

Most of the published papers in this thesis end with a set of conclusions. The main conclusions in response to my primary research question, of what a healthcare system in a democracy should do, are:

- a. there is much for the state to do, including:
 - funding at least basic healthcare, and many public health activities;
 - subsidising (or making the market cross-subsidise) insurance cover for more-than-basic-healthcare for certain people who would otherwise, through no fault of their own, have high-cost insurance premiums;
 - making law and policy on how decisions about who is entitled to healthcare are made, providing procedural justice, and creating a regulatory framework for governing providers of healthcare products and services;
- b. given a. above, the question of what a healthcare system in a democracy should do is a question of public policy;
- c. given that resources are inevitably limited, policymakers require some rationale for prioritising how those resources are allocated;
- d. the disagreements on what rationale should be used are fundamental, especially amongst philosophers, and between philosophy and economics;
- e. philosophers tend to promote theories of justice, and economists tend to seek to maximise health benefit (measured, for example, by quality-adjusted life years)

- f. a framework for prioritising resources can be drawn from John Broome's writing which addresses the concerns of both disciplines, recognising the importance of both doing good and being fair;
- g. in this framework, good is a relative notion, so that there is no more to good than betterness;
- h. quality-adjusted life years (QALYs) provide one possible measure of the good of healthcare;
- i. fairness is relative, and not a side constraint, and involves weighing the strength of the claims of different individuals, and giving more to those with stronger claims (but something to those with weaker claims);
- j. a healthcare system in a democracy should do as much good as possible, although sometimes some good should be traded off for reasons of fairness;
- k. this good and fairness framework is less vulnerable to large-scale injustice than QALYs and accountability for reasonableness;
- l. in practice, what counts as good and fair depends on your values, or weltanschauungen;
- m. in a democracy, there will be many different weltanschauungen,
- n. democracies have processes for resolving debates, and making policy, when different people have different weltanschauungen.

I did not set out to examine, or publish on, questions regarding the nature of philosophical ethics, but that is what I have done. This has been prompted by my reading of the philosophical literature, and with trying to understand the relevance of that literature to public policy in general, and specifically to the question of what a healthcare system in a democracy should do. I have concluded that:

- i. the way in which philosophical arguments are made and won tends to be very different to the way in which public policy is made;
- ii. philosophical ethics has an important contribution to make to public policy, but if ethicists are to influence policy, they should consider the problem from the policymakers' perspective, and communicate in ways and in places that encourage policymakers to listen;
- iii. in particular, writers seeking to influence policy should:
 - o be explicit about the policy context, and their target audience,

- listen to, and address, arguments from other disciplines, and from outside academia, which policymakers could be expected to take into account;
- consider the consequences of their recommendations, as policymakers inevitably must do; and where possible
- make proposals that others might accept, recognising the claims of those who have something to lose.

As Michael Sandel puts it, “moral reflection is not a solitary pursuit but a public endeavour”.(Sandel, 2010, p. 28)

Opportunities for further research

When I began this thesis, I had expected to explore many detailed questions of resource allocation, and of what a healthcare system should do. I soon realised that the divisions were deep, often arising from the very nature of different academic disciplines. For example, you might say that economists and philosophers have different weltanschauungen. Therefore my interest has been in trying to address these fundamental differences, and consider the question from the perspective of the policymaker trying to reconcile, and draw on, arguments across several disciplines.

I have not attempted in this thesis to specify in detail what a healthcare system in a democracy should do. That would be a potential research project for the future. However, it is not a project that I would pursue. I do not believe that there are universal answers to the many difficult questions that arise in healthcare resource allocation. I believe that the general structure of good and fairness is applicable across democracies, but beyond that it depends on your weltanschauung. For example, when/whether it is fair to treat a young person in preference to an old person depends on social values, which vary within societies and across societies. So I would be sceptical about any attempt to produce a universal blueprint of a healthcare system.

I do believe there is useful research that could be done to build on the good and fairness framework, drawing on the social values of a particular democracy at a particular point in time. There is real potential for such research, given the current

international programmes carrying social values surveys.(Littlejohns et al., 2012)

That is research I would be keen to do.

Another theme of this thesis is about making philosophical ethics relevant to policy making and policymakers. Coming late to academia, having spent 30 years working in and around the NHS, sometimes on an aspect of policy, I am struck by how much is written by academics ethicists about policy, but how little of that appears to influence policy. Ethics addresses normative questions, and virtually all policy is about normative questions. I believe that academic ethicists have an important potential contribution to make to the policy process. Relatively few academic staff engage directly in policy work, and many publish important articles that will never be read by anyone who influences or makes policy. Many could do more to make their voices audible in policy circles, and policymakers could do more to listen. For example, a research council, group of universities and/or the government might fund ethicists who are available “on call” to civil servants to inform them of some of the important ethical considerations that are relevant to an emerging policy question. I would be keen to be involved in further work to encourage such communication.

I am also interested in connecting bioethics to other disciplines, and engaging people from outside academia with ethical issues that affect their daily lives. In part, this is about communicating ethical ideas in ways that people can understand. Plain English is important, but so too is the medium and method of communication. I am an admirer of the Philosophy Bites podcasts.(Warburton and Edmonds, 2013) People also respond to narrative; two of my papers take the form of a story. I would be keen to do more work communicating and connecting bioethics to lay people, or in helping to bridge the gap between bioethics and other subjects.

I am working on two further articles aimed at peer-reviewed journals. The first is a collaboration with Martin Reynolds, a systems theorist from the Open University who kindly reviewed paper 6 for me. This led to constructive debate between us, and we are now developing an article aimed at a systems journal. It will be in the form of a debate around some the claims I make in paper 6, and about what I consider to be some limitations of systems theory. I have also begun work on a critical analysis of NHS England’s recent publication “Commissioning policy: ethical framework for priority setting and resource allocation”.(NHS Commissioning Board, 2013)

Appendix A: Bibliography

I refer in my thesis to the publications below. The list, which is in alphabetical order, reproduces the references in my six papers, and also incorporates the references from the main body of the thesis.

- ACKOFF, R. L. (1999) On passing through 80. *Systemic Practice and Action Research*, 12, 425-430.
- ANAND, P. (2005) Capabilities and health. *Journal of Medical Ethics*, 31, 299.
- ANDERSON, J. E. (2010) *Public policymaking: An introduction*, Belmont: Wadsworth Pub Co.
- ARCHARD, D. (2009) Why moral philosophers are not and should not be moral experts. *Bioethics*, 25, 119-127.
- ARIELY, D. (2009) *Predictably irrational: The hidden forces that shape our decisions*, New York: HarperCollins.
- ARNESEN, T. & NORD, E. (1999) The value of DALY life: problems with ethics and validity of disability adjusted life years. *BMJ*, 319, 1423.
- ARRAS, J. (2010) *Theory and Bioethics* [Online]. Available: <http://plato.stanford.edu/archives/sum2010/entries/theory-bioethics/> [Accessed 8 Feb 2012].
- ARROW, K. J. (1963) Uncertainty and the welfare economics of medical care. *The American economic review*, 53, 941-973.
- ASHCROFT, R. (2008) Fair process and the redundancy of bioethics: a polemic. *Public Health Ethics*, 1, 3.
- BARBER, B. R. (1984) *Strong democracy: participatory politics for a new age*: University of California Press.
- BARR, A. (2009) Palin doubles down on 'death panels' [Online]. Available: http://news.yahoo.com/s/politico/20090813/pl_politico/26078 [Accessed 16 Feb 2012].
- BBC. (27 Sep 2011) *Today Programme* [Online]. Available: http://news.bbc.co.uk/today/hi/today/newsid_9601000/9601179.stm [Accessed 8 Feb 2012].
- BBC NEWS. (2011) *The Alder Hey report* [Online]. Available: <http://news.bbc.co.uk/1/hi/health/1144774.stm> [Accessed 30 Aug 2012].

- BBC NEWS. (2012) 'Shocking discrimination' in mental health services [Online]. Available: <http://www.bbc.co.uk/news/uk-18481943> [Accessed 24 July 2012].
- BEAUCHAMP, T. L. & CHILDRESS, J. F. (2009) Principles of biomedical ethics, New York: Oxford University Press.
- BENNETT, R. & CRIBB, A. (2003) The relevance of empirical research to bioethics: Reviewing the debate. Häyry & Takala.
- BENTHAM, J. (1996) An Introduction to the Principles of Morals and Legislation (Collected Works of Jeremy Bentham), Oxford: Clarendon Press.
- BERENSON, R. A. & CASSEL, C. K. (2009) Consumer-driven health care may not be what patients need—caveat emptor. JAMA: The Journal of the American Medical Association, 301, 321-323.
- BERLIN, I. 1961. Equality as an Ideal. In: OLAFSON, F. (ed.) Justice and Social Policy. Englewood Cliffs, N.J.: Prentice Hall.
- BEVAN, G. & VAN DE VEN, W. Choice of providers and mutual healthcare purchasers: can the English National Health Service learn from the Dutch reforms. Health Economics, Policy and Law, 5, 343-363.
- BIEGLER, P. (2012) Symposium on 'after-birth abortion': Public distress as a moral consideration in after-birth abortion. Monash Bioethics Review, 30, 48-51.
- BLOOR, K. (2008) Should patients be able to pay top-up fees to receive the treatment they want? No. BMJ, 336, 1105.
- BOHMAN, J. (1997) Deliberative democracy: Essays on reason and politics, Boston: The MIT press.
- BORRY, P., SCHOTSMANS, P. & DIERICKX, K. (2005) The birth of the empirical turn in bioethics. Bioethics, 19, 49-71.
- BRASSINGTON, I. (2012a) John Harris Clarifies his Position on Infanticide [Online]. Available: <http://blogs.bmj.com/medical-ethics/2012/02/29/john-harris-clarifies-his-position-on-infanticide/> [Accessed 9 Aug 2012].
- BRASSINGTON, I. (2012b) What's the Point of Philosophical Bioethics? Health Care Analysis, 20, 1-11.
- BRITISH MEDICAL ASSOCIATION. (2001) BMA response to Alder Hey Inquiry Report [Online]. Available: <http://web.bma.org.uk/pressrel.nsf/wlu/SGOY-4TGMER?OpenDocument&vw=wfmms> [Accessed 31 Aug 2012].
- BROCK, D. (1993) Quality of life measures in health care and medical ethics. The quality of life, 1, 95-133.

- BROCK, D. W. (1987) Truth or consequences: The role of philosophers in policy-making. *Ethics*, 97, 786-791.
- BROOME, J. 1988. Good, fairness and QALYs. In: BELL, J. M. & MENDUS, S. (eds.) *Philosophy and Medical Welfare*. Cambridge: Cambridge Univ Press.
- BROOME, J. (1993) QALYs. *Journal of Public Economics*, 50, 149-167.
- BROOME, J. (1994) Fairness versus doing the most good. *The Hastings Center Report*, 24, 36-39.
- BROOME, J. (1995) *Weighing goods: equality, uncertainty and time*, Oxford: Wiley-Blackwell.
- BROOME, J. (1999) *Ethics out of Economics*, Cambridge: Cambridge University Press.
- BROOME, J. (2004) *Weighing lives*, Oxford: Oxford University Press.
- BROOME, J. (2005) Why economics needs ethical theory. *Pelican Record*, 42, 80–88.
- BROOME, J. (2010) Is this Truly an Idea of Justice? *Journal of Human Development and Capabilities*, 11, 623-625.
- BROUWER, W. B. F., KOOPMANSCHAP, M. A. & RUTTEN, F. F. H. (1997) Productivity costs in cost effectiveness analysis: numerator or denominator: a further discussion. *Health Economics*, 6, 511-514.
- BRUDNEY, D. (2007) Are alcoholics less deserving of liver transplants? *Hastings Center Report*, 41-47.
- BUCHANAN, A. E. (1984) The right to a decent minimum of health care. *Philosophy & public affairs*, 13, 55-78.
- CALLAHAN, D. (1994) Setting mental health priorities: problems and possibilities. *The Milbank Quarterly*, 451-470.
- CAPPELEN, A. W. & NORHEIM, O. F. (2005) Responsibility in health care: a liberal egalitarian approach. *Journal of Medical Ethics*, 31, 476.
- CARANDE-KULIS, V. G., GETZEN, T. E. & THACKER, S. B. (2007) Public goods and externalities: a research agenda for public health economics. *Journal of Public Health Management and Practice*, 13, 227.
- CASPARY, W. R. (2000) *Dewey on Democracy*, Ithaca: Cornell University Press.
- CHAN, S. & COGGON, J. (2013) Beyond the Is/Ought Divide: Studying the Nature of the Bioethical Enterprise. *Health care analysis: HCA: journal of health philosophy and policy*.

- CHANG, R. (1997) *Incommensurability, incomparability, and practical reason*, Cambridge, Mass.: Harvard University Press.
- CHECKLAND, P. (1985) From optimizing to learning: a development of systems thinking for the 1990s. *Journal of the Operational Research Society*, 757-767.
- CHECKLAND, P. (2000) Soft systems methodology: a thirty year retrospective. *Systems Research*, 17, S11-S58.
- CHEN, L. C., EVANS, T. G. & CASH, R. A. (1999) Health as a global public good. *Global public goods*, 1, 284-306.
- CHRISTIANO, T. (2011) An instrumental argument for a human right to democracy. *Philosophy & Public Affairs*, 39, 142-176.
- CHURCHMAN, C. W. (1971) *The design of inquiring systems: Basic concepts of systems and organization*: Basic books New York.
- CHURCHMAN, C. W. (1979) *The Systems Approach and Its Enemies*, New York: Basic Books.
- CLARK, S. & WEALE, A. (2012) Social values in health priority setting: a conceptual framework. *Journal of Health Organization and Management*, 26, 293-316.
- COAST, J., SMITH, R. & LORGELLY, P. (2008) Should the capability approach be used in health economics? *Health economics*, 6, 667-70.
- COGGON, J. (2012) *What makes health public?: a critical evaluation of moral, legal, and political claims in public health*, Cambridge: Cambridge University Press.
- COHEN-CHARASH, Y. & SPECTOR, P. E. (2001) The role of justice in organizations: A meta-analysis. *Organizational behavior and human decision processes*, 86, 278-321.
- COHEN, J. (2009) Truth and public reason. *Philosophy & Public Affairs*, 37, 2-42.
- COOKSON, R. (2005) QALYs and the capability approach. *Health economics*, 14, 817-829.
- COOKSON, R. & DOLAN, P. (2000) Principles of justice in health care rationing. *Journal of Medical Ethics*, 26, 323.
- COOKSON, R., MCCABE, C. & TSUCHIYA, A. (2008) Public healthcare resource allocation and the Rule of Rescue. *Journal of Medical Ethics*, 34, 540.
- CUBBON, J. (1992) Unprincipled QALYs: a response to Harris. *Journal of Medical Ethics*, 18, 100.

- CULYER, A. J. (1989) Commodities, characteristics of commodities, characteristics of people, utilities, and the quality of life. *Quality of life. Perspectives and policies*. London: Routledge, 9-27.
- CULYER, A. J. (1997) The primary goal of the health care system should be to maximise health. In: NEW, B. (ed.) *Rationing: talk and action in health care*. BMJ Pub. Group, London.
- CULYER, A. J. (2001) Economics and ethics in health care. *Journal of medical ethics*, 27, 217-222.
- CUP. (2011) *Cambridge Dictionaries Online* [Online]. Cambridge University Press. Available:
http://dictionary.cambridge.org/dictionary/british/representative_1?q=representative [Accessed 1 Nov 2012].
- CURTIS, M. C. (2012) 'After-birth abortion': Can they be serious? [Online]. Washington Post. Available: http://www.washingtonpost.com/blogs/she-the-people/post/after-birth-abortion-can-they-be-serious/2012/03/03/gIQADgiOsR_blog.html [Accessed 20 August 2012].
- DAHL, R. A. (1971a) *Polyarchy: participation and opposition*, Newhaven: Yale Univ Pr.
- DAHL, R. A. (1971b) *A preface to democratic theory*, Newhaven: University of Chicago Press.
- DAHL, R. A. (2000) *On democracy*, Newhaven: Yale Univ Pr.
- DANIELS, N. (1985) *Just health care*, New York: Cambridge University Press.
- DANIELS, N. (2008) *Just health: Meeting Health Needs Fairly*, Cambridge: Cambridge University Press.
- DANIELS, N., LIGHT, D. & CAPLAN, R. L. (1996) *Benchmarks of fairness for health care reform*: Oxford University Press, USA.
- DANIELS, N. & SABIN, J. (1997) Limits to health care: fair procedures, democratic deliberation, and the legitimacy problem for insurers. *Philosophy & public affairs*, 26, 303-350.
- DANIELS, N. & SABIN, J. (1998) The ethics of accountability in managed care reform. *Health Affairs*, 17, 50-64.
- DANIELS, N. & SABIN, J. E. (2008) *Setting Limits Fairly - Learning to share resources for health*, New York: Oxford University Press.

- DAVIS, K., SCHOEN, C., STREMIKIS, K. & FUND, C. (2010) Mirror, mirror on the wall: How the performance of the US health care system compares internationally: 2010 update [Online]. Commonwealth Fund. Available: <http://www.commonwealthfund.org/Publications/Fund-Reports/2010/Jun/Mirror-Mirror-Update.aspx?page=all> [Accessed 28 March 2012].
- DE VILLANUEVA, C. F. 2010. The School of Salamanca: some thoughts on the subject of justice. In: PARISI, S. (ed.) Humanism and Religion in the History of Economic Thought. Rome: Franco Angeli.
- DEPARTMENT OF HEALTH. 2013. Cross Border Healthcare and Patient Mobility. Available: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/181168/Cross_Border_Healthcare_and_Patient_Mobility.pdf [Accessed 07 May 2013].
- DEPARTMENT OF HEALTH. (July 2003) Directions to Primary Care Trusts and NHS Trusts in England Concerning Arrangements for the Funding of Technology Appraisal Guidance from the National Institute for Clinical Excellence [Online]. Available: http://webarchive.nationalarchives.gov.uk/+www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsLegislation/DH_4083088 [Accessed 25 Jun 2013].
- DEWEY, J. (1921) Logical Method and Law. *Philosophical Review*, Vol. 33, pp. 560-572.
- DEWEY, J. (1922) *Human Nature and Conduct*, New York: Henry Holt & Co.
- DEWEY, J. (1958) *Experience and nature*, New York: Dover Pubns.
- DICKENSON, D. L. (2000) Are medical ethicists out of touch? Practitioner attitudes in the US and UK towards decisions at the end of life. *Journal of Medical Ethics*, 26, 254.
- DOLAN, P., SHAW, R., TSUCHIYA, A. & WILLIAMS, A. (2005) QALY maximisation and people's preferences: a methodological review of the literature. *Health Economics*, 14, 197-208.
- DWORKIN, G. (1988) *The theory and practice of autonomy*, New York: Cambridge University Press.

- DWORKIN, R. (1996) Objectivity and truth: You'd better believe it. *Philosophy & Public Affairs*, 25, 87-139.
- DWORKIN, R. (2002) *Sovereign virtue: the theory and practice of equality*, Cambridge, Mass.: Harvard University Press.
- DWORKIN, R. (2006) *Is democracy possible here?: principles for a new political debate*, Princeton: Princeton University Press.
- ENGELHARDT, H. T. (1994) Health care reform: A study in moral malfeasance. *Journal of Medicine and Philosophy*, 19, 501-516.
- EPSTEIN, R. A. (2003) In Defense of the Old Public Health-The Legal Framework for the Regulation of Public Health. *Brook. L. Rev.*, 69, 1421.
- ERIN, C. A. & HARRIS, J. (1993) AIDS: ethics, justice, and social policy. *Journal of applied philosophy*, 10, 165-173.
- ESSER, J. K. (1998) Alive and well after 25 years: A review of groupthink research. *Organizational behavior and human decision processes*, 73, 116-141.
- FABRE, C. & MILLER, D. (2003) Justice and Culture: Rawls, Sen, Nussbaum and O'Neill. *Political Studies Review*, 1, 4-17.
- FISCHER, F. (2009) *Democracy and expertise: Reorienting policy inquiry*: Oxford University Press, USA.
- FISHKIN, J. S. & LASLETT, P. (2003) *Debating deliberative democracy*: Wiley-Blackwell.
- FORD, A. (2012) The concept of exceptionality: a legal farce? *Medical law review*, 20, 304-336.
- FOSTER, C. (2007) Simple rationality? The law of healthcare resource allocation in England. *Journal of Medical Ethics*, 33, 404.
- FUENMAYOR, R. (1991) The roots of reductionism: A counter-ontoepistemology for a systems approach. *Systemic Practice and Action Research*, 4, 419-448.
- GAROUPA, N. (2004) *Regulation of professions in the US and Europe: A comparative analysis*. bepress.
- GARRARD, E. & WILKINSON, S. (2005) Mind the gap: the use of empirical evidence in bioethics. *Bioethics and social reality*. Amsterdam: Rodopi, 73-87.
- GEUSS, R. (2008) *Philosophy and real politics*, Princeton: Princeton Univ Pr.
- GIACOMINI, M. (2005) One of these things is not like the others: the idea of precedence in health technology assessment and coverage decisions. *Milbank Quarterly*, 83, 193-223.

- GIBSON, J. L., MARTIN, D. K. & SINGER, P. A. (2004) Setting priorities in health care organizations: criteria, processes, and parameters of success. *BMC Health Services Research*, 4, 25.
- GIBSON, J. L., MARTIN, D. K. & SINGER, P. A. (2005a) Evidence, economics and ethics: resource allocation in health services organizations. *Healthcare Quarterly*, 8, 50-9.
- GIBSON, J. L., MARTIN, D. K. & SINGER, P. A. (2005b) Priority setting in hospitals: fairness, inclusiveness, and the problem of institutional power differences. *Social Science & Medicine*, 61, 2355-2362.
- GIORDANO, S. (2005) Respect for equality and the treatment of the elderly: declarations of human rights and age-based rationing. *Cambridge Quarterly of Healthcare Ethics*, 14, 83-92.
- GIUBILINI, A. & MINERVA, F. (2012a) After-birth abortion: why should the baby live? *Journal of medical ethics*.
- GIUBILINI, A. & MINERVA, F. (2012b) An Open Letter from Giubilini and Minerva [Online]. Available: <http://blogs.bmj.com/medical-ethics/2012/03/02/an-open-letter-from-giubilini-and-minerva/> [Accessed 20 August 2012].
- GLIMCHER, P. W. (2009) *Neuroscience, Psychology, and Economic Behavior: The Emerging Field of Neuroeconomics. Cognitive Biology: Evolutionary and Developmental Perspectives on Mind, Brain, and Behavior*. Cambridge: MIT Press.
- GOLD, M. R., STEVENSON, D. & FRYBACK, D. G. (2002) HALYS and QALYS and DALYS, oh my: similarities and differences in summary measures of population health. *Annual Review of Public Health*, 23, 115-134.
- GOODMAN, J. (2006) Consumer-directed health care [Online]. SSRN. Available: http://papers.ssrn.com/sol3/papers.cfm?abstract_id=985572#PaperDownload [Accessed 18/03/2012].
- GORDON, J. S. (2012) Moral philosophers are moral experts! A reply to David Archard. *Bioethics*.
- GOSTIN, L. O. (2001) *Public health law: power, duty, restraint*, Berkeley: University of California Press.
- GRAY, J. (1998) Where pluralists and liberals part company. *International Journal of Philosophical Studies*, 6, 17-36.

- GREEN, R. M. (1976) Health care and justice in contract theory perspective. *Ethics and Health Policy*. Cambridge, Mass.: Ballinger Publ. Co.
- GRIEVE, R., GRISHCHENKO, M. & CAIRNS, J. (2009) SF-6D versus EQ-5D: reasons for differences in utility scores and impact on reported cost-utility. *The European Journal of Health Economics*, 10, 15-23.
- GROSSE, S. D., LOLLAR, D. J., CAMPBELL, V. A. & CHAMIE, M. (2009) Disability and disability-adjusted life years: not the same. *Public Health Reports*, 124, 197.
- GRUSKIN, S. & DANIELS, N. (2008) Process is the point: justice and human rights: priority setting and fair deliberative process. *American Journal of Public Health*, 98, 1573.
- GUTHRIE, C., RACHLINSKI, J. J. & WISTRICH, A. J. (2007) Blinking on the bench: How judges decide cases. *Cornell L. Rev.*, 93, 1.
- HABERMAS, J. (1996) *Between facts and norms: Contributions to a discourse theory of law and democracy*, Cambridge, MA.: MIT Press.
- HADORN, D. C. (1991) The Oregon priority-setting exercise: quality of life and public policy. *The Hastings Center Report*, 21, 11-16.
- HALL, M. A. (1994) *Reforming private health insurance*: American Enterprise Institute.
- HALL, M. A. (2006) Paying for What You Get and Getting What You Pay for: Legal Responses to Consumer-Driven Health Care. *Law & Contemp. Probs.*, 68, 159.
- HARRIS, J. (1987) QALYfying the value of life. *Journal of Medical Ethics*, 13, 117.
- HARRIS, J. (1991) Unprincipled QALYs: a response to Cubbon. *Journal of medical ethics*, 17, 185.
- HARRIS, J. (2001) One principle and three fallacies of disability studies. *Journal of medical ethics*, 27, 383-387.
- HARRIS, J. (2003) Organ procurement: dead interests, living needs. *Journal of medical ethics*, 29, 130-134.
- HARRIS, J. (2005) It's not NICE to discriminate. *Journal of Medical Ethics*, 31, 373.
- HARRIS, J. (2012) What It's Like to Be Good. *Cambridge Quarterly of Healthcare Ethics*, 1, 1-13.
- HARRIS, J. & ERIN, C. (2002) An ethically defensible market in organs. *BMJ*, 325, 114-115.

- HASMAN, A. & HOLM, S. (2005) Accountability for reasonableness: opening the black box of process. *Health Care Analysis*, 13, 261-273.
- HERRING, J. (2007) Where are the carers in healthcare law and ethics?*. *Legal Studies*, 27, 51-73.
- HERZLINGER, R. E. (2004) *Consumer-driven health care: Implications for providers, payers, and policy-makers*: Jossey-Bass.
- HOBBS, T. (1987) 1651. *Leviathan* London.
- HOBBS, T. (1996) *Leviathan*, Cambridge: Cambridge University Press.
- HOBBS, A. (2010) What is fairness? [Online]. BBC. Available: http://news.bbc.co.uk/today/hi/today/newsid_9079000/9079254.stm [Accessed 21 June 2012].
- HOBSON-WEST, P. (2010) The role of 'public opinion' in the UK animal research debate. *Journal of Medical Ethics*, 36, 46-49.
- HOLM, S. (1998) Goodbye to the simple solutions: the second phase of priority setting in health care. *British Medical Journal*, 317, 1000-1001.
- HOLM, S. (2005) Bioethics down under - medical ethics engages with political philosophy. *Journal of Medical Ethics*, 31, 1.
- HORTON, R. (2012) The Global Burden of Disease Study 2010. *The Lancet*, 380, 2053 - 2260.
- HSIAO, W. C. (1995) Abnormal economics in the health sector. *Health Policy*, 32, 125-139.
- HUNTER, G. (1962) Hume on is and ought. *Philosophy*, 37, 148-152.
- INGLEHART, R. & WELZEL, C. (2005) *Modernization, cultural change, and democracy: The human development sequence*, Cambridge: Cambridge Univ Pr.
- ISON, R. L. (2008) *Systems thinking and practice for action research*. The Sage Handbook of Action Research Participative Inquiry and Practice, 139-158.
- JACKSON, M. C. & KEYS, P. (1984) Towards a system of systems methodologies. *Journal of the Operational Research Society*, 473-486.
- JOST, T. S. & HALL, M. A. (2005) Role of State Regulation in Consumer-Driven Health Care, *The Am. JL & Med.*, 31, 395.
- KAHAN, D., BRAMAN, D., SLOVIC, P., GASTIL, J. & COHEN, G. (2007) The second national risk and culture study: Making sense of-and making progress

- in-the american culture war of fact. GWU Legal Studies Research Paper, 08-26.
- KIM, S. Y. H., WALL, I. F., STANCZYK, A. & DE VRIES, R. (2009) Assessing the public's views in research ethics controversies: deliberative democracy and bioethics as natural allies. *Journal of empirical research on human research ethics: JERHRE*, 4, 3.
- KIRKLIN, D. (2007) Minding the gap between logic and intuition: an interpretative approach to ethical analysis. *Journal of Medical Ethics*, 33, 386-389.
- KLEIN, R. (1994) Dimensions of rationing: who should do what? *British Medical Journal*, 309.
- KLEIN, R. (1997) The case against. *BMJ*, 314, 503.
- KLEIN, R. (2010) Rationing in the fiscal ice age. *Health Economics, Policy and Law*, 5, 389.
- KOTHARI, V. & GULATI, I. (1997) Disability-adjusted life year as a guide for health policy. *Economic and Political Weekly*, 2612-2617.
- KYMLICKA, W. (2002) *Contemporary political philosophy*: Clarendon Press.
- LAMONT, J. & FAVOR, C. (2007) *Distributive justice* [Online]. Stanford University. Available: <http://www.science.uva.nl/~seop/archives/fall2008/entries/justice-distributive/index.html#Strict> [Accessed 28 Nov 2012].
- LAU, D. C. (2003) *Mencius*: Chinese Univ Pr.
- LAWTON, K. & SILIM, A. (2012) *Pressures and Priorities: the long-term outlook for Britain's public finances* [Online]. Institute for Public Policy Research. Available: http://www.ippr.org/images/media/files/publication/2012/09/pressures-and-priorities_Sep2012_9633.pdf [Accessed 15 Dec 2012].
- LAYARD, R. (2004) *Mental Health—Britain's Biggest Social Problem*. Citeseer.
- LAYARD, R. (2006) The case for psychological treatment centres. *BMJ*, 332, 1030-1032.
- LITTLEJOHNS, P., WEALE, A., CHALKIDOU, K., FADEN, R. & TEERAWATTANANON, Y. (2012) Social values and health policy: a new international research programme. *Journal of Health Organization and Management*, 26, 285-292.
- LOCKE, J. (2002) *The second treatise of government: and, A letter concerning toleration*: Dover Pubns.

- MACAULEY, D. (2012) The value of conducting periodic health checks. *BMJ: British Medical Journal*, 345.
- MARTIN, D. K., GIACOMINI, M. & SINGER, P. A. (2002) Fairness, accountability for reasonableness, and the views of priority setting decision-makers. *Health Policy*, 61, 279-290.
- MASON, J., DRUMMOND, M. & TORRANCE, G. (1993) Some guidelines on the use of cost effectiveness league tables. *British Medical Journal*, 306, 570-572.
- MAUSKOPF, J., RUTTEN, F. & SCHONFELD, W. (2003) Cost-effectiveness league tables: valuable guidance for decision makers? *Pharmacoeconomics*, 21, 991-1000.
- MCGUIRE, M. C. & AARON, H. (1969) Efficiency and equity in the optimal supply of a public good. *The Review of Economics and Statistics*, 51, 31-39.
- MCKIE, J. & RICHARDSON, J. (2003) The rule of rescue. *Social Science & Medicine*, 56, 2407-2419.
- MCPAKE, B., NORMAND, C. & SMITH, S. (2012) *Health economics: an international perspective*, London and New York: Routledge.
- MENTAL HEALTH POLICY GROUP. (2012) How mental illness loses out in the NHS [Online]. London School of Economics. Available: <http://cep.lse.ac.uk/new/research/mentalhealth/default.asp> [Accessed 3 July 2012].
- MILL, J. S. 1989. On Liberty. In: COLLINI, S. (ed.) *On Liberty and Other Essays*. Cambridge: Cambridge University Press.
- MILLER, D. (1979) *Social justice*: Oxford University Press, USA.
- MOONEY, G. (1989) QALYs: are they enough? A health economist's perspective. *Journal of medical ethics*, 15, 148.
- MUNRO, E. (2011) *The Munro review of child protection: Final report, a child-centred system*, London: Stationery Office.
- NAGEL, T. (2005) The problem of global justice. *Philosophy & public affairs*, 33, 113-147.
- NATIONAL AUDIT OFFICE. (2012) Progress in making NHS efficiency savings [Online]. Available: www.nao.org.uk/publications/1213/nhs_efficiency_savings.aspx [Accessed 14 Dec 2012].

- NEWDICK, C. (2007) Judicial Review: Low-Priority Treatment and Exceptional Case Review. *Medical law review*, 15, 236.
- NHS COMMISSIONING BOARD. (2013) Commissioning Policy: Ethical framework for priority setting and resource allocation [Online]. Available: <http://www.england.nhs.uk/wp-content/uploads/2013/04/cp-01.pdf> [Accessed 04/07/2012].
- NORD, E. (1993) The trade-off between severity of illness and treatment effect in cost-value analysis of health care. *Health Policy*, 24, 227-238.
- NORD, E. (1999) *Cost-value analysis in health care: making sense out of QALYs*, Cambridge: Cambridge Univ Press.
- NORD, E., DANIELS, N. & KAMLET, M. (2009) QALYs: some challenges. *Value in Health*, 12, S10-S15.
- NORD, E., RICHARDSON, J., STREET, A., KUHSE, H. & SINGER, P. (1995) Who cares about cost? Does economic analysis impose or reflect social values? *Health Policy*, 34, 79-94.
- NOZICK, R. (1974) *Anarchy, state, and utopia*, New York: Basic Books.
- NUFFIELD COUNCIL ON BIOETHICS. (2007) *Public Health: ethical issues* [Online]. Available: <http://www.nuffieldbioethics.org/public-health> [Accessed 21 Jun 2013].
- NUSSBAUM, M. C. (2001) *Women and human development: The capabilities approach*, Cambridge, Mass.: Cambridge Univ Press.
- NUSSBAUM, M. C. 2003. Comment. In: THOMSON, J. J. (ed.) *Goodness and advice*. Princeton and Oxford: Princeton University Press.
- NUSSBAUM, M. C. (2004) *Beyond the social contract: toward global justice*. *Tanner lectures on human values*, 24, 413-508.
- OECD. (2011) *Financing of health care* [Online]. OECD Publishing. Available: http://dx.doi.org/10.1787/health_glance-2011-64-en [Accessed 17 Dec 2012].
- ORR, S., WOLFF, J. & MORRIS, S. (2011) What Values Should Count in HTA for New Medicines under Value Based Pricing in the UK? [Online]. Available: <http://www.ucl.ac.uk/cpjh/mcda.pdf> [Accessed 24 July 2012].

- OSWALD, M. 2012. Should we strive for total scientific freedom? In: GIORDANO, S., COGGON, J. & CAPPATO, M. (eds.) *Scientific Freedom*. London: Bloomsbury.
- OSWALD, M. & COX, D. (2011) *Making Difficult Choices* [Online]. Royal College of General Practitioners. Available: http://www.gpcare.org.uk/cms/document/Making_Difficult_Choices_PBC.pdf [Accessed 12 Jan 2013].
- PARFIT, D. (2011) *On what matters*, Oxford: Oxford Univ Pr.
- PARIS, J. J. (2011) Rationing: A “Decent Minimum” or a “Consumer Driven” Health Care System? *The American Journal of Bioethics*, 11, 16-18.
- PATON, C. (2010) We should eschew UK style rationing here too. *BMJ*, 340.
- POLLOCK, A. M., PRICE, D. & RODERICK, P. (2012) Health and Social Care Bill 2011: a legal basis for charging and providing fewer health services to people in England. *BMJ*, 344, e1729.
- POWERS, M. & FADEN, R. (2006) *Social justice: the moral foundations of public health and health policy*, New York: Oxford University Press.
- RAM-TIKTIN, E. (2011) A decent minimum for everyone as a sufficiency of basic human functional capabilities. *The American Journal of Bioethics*, 11, 24-25.
- RAMAGE, M. & SHIPP, K. (2009) *Systems thinkers*, London: Springer Verlag.
- RAWLS, J. (1999) *A Theory of Justice*, Cambridge, Mass.: Belknap Press.
- RAZ, J. (1988) Liberalism, Skepticism, and Democracy. *Iowa L. Rev.*, 74, 761.
- REHG, W. & BOHMAN, J. (2002) Discourse and democracy: The formal and informal bases of legitimacy in between facts and norms. *Discourse and Democracy. Essays on Habermas’s Between Facts and Norms*. New York, 31-60.
- REYNOLDS, M. & HOLWELL, S. (2010) *Systems approaches to managing change: a practical guide*, London: Springer.
- RICE, T. (2001) Individual autonomy and state involvement in health care. *Journal of medical ethics*, 27, 240-244.
- RID, A. (2009) Justice and procedure: how does “accountability for reasonableness” result in fair limit-setting decisions? *Journal of Medical Ethics*, 35, 12.
- ROBERTS, A., MARSHALL, L. & CHARLESWORTH, A. (2012) *A decade of austerity?* [Online]. Nuffield Trust. Available:

<http://www.nuffieldtrust.org.uk/publications/decade-austerity-funding-pressures-facing-nhs> [Accessed 16 Dec 2012].

- ROSA DIAS, P. & JONES, A. M. (2007) Giving equality of opportunity a fair innings. *Health Economics*, 16, 109-112.
- ROSTOW, E. V. (1960) *The enforcement of morals*, Cambridge: Cambridge University Press.
- RUSHBY, J. A. & HANSON, K. (2001) Calculating and presenting disability adjusted life years (DALYs) in cost-effectiveness analysis. *Health Policy and Planning*, 16, 326.
- SAARELA, M. V., HLUSHCHUK, Y., WILLIAMS, A. C. C., SCHÜRMAN, M., KALSO, E. & HARI, R. (2007) The compassionate brain: humans detect intensity of pain from another's face. *Cerebral Cortex*, 17, 230.
- SABIK, L. M. & LIE, R. K. (2008) Priority setting in health care: Lessons from the experiences of eight countries. *International Journal for equity in health*, 7, 4.
- SANDEL, M. J. (2010) *Justice: What's the right thing to do?*, New York: Farrar, Straus and Giroux.
- SANDEL, M. J. (2012) *What money can't buy: the moral limits of markets*: Allen Lane.
- SARACCI, R. (1997) The World Health Organisation needs to reconsider its definition of health. *British Medical Journal*, 314, 1409.
- SAVULESCU, J. (2012) "Liberals Are Disgusting": In Defence of the Publication of "After-Birth Abortion" [Online]. Available: <http://blogs.bmj.com/medical-ethics/2012/02/28/liberals-are-disgusting-in-defence-of-the-publication-of-after-birth-abortion/> [Accessed 20 August 2012].
- SCHLANDER, M. (2006) NICE accountability for reasonableness: a qualitative study of its appraisal of treatments for attention-deficit/hyperactivity disorder (ADHD). *Current Medical Research and Opinion*®, 23, 207-222.
- SCHLANDER, M. (2008) The use of cost-effectiveness by the National Institute for Health and Clinical Excellence (NICE): no (t yet an) exemplar of a deliberative process. *Journal of Medical Ethics*, 34, 534.
- SCHNEIDERMAN, L. J. Rationing just medical care. *The American Journal of Bioethics*, 11, 7-14.
- SCHNEIDERMAN, L. J. (2011) Rationing just medical care. *The American Journal of Bioethics*, 11, 7-14.

- SCHWAPPACH, D. L. B. (2002) Resource allocation, social values and the QALY: a review of the debate and empirical evidence. *Health Expectations*, 5, 210-222.
- SEARLE, J. R. (1964) How to derive "ought" from "is". *The Philosophical Review*, 73, 43-58.
- SEEDHOUSE, D. (1995) The way around health economics' dead end. *Health Care Analysis*, 3, 205-220.
- SEEDHOUSE, D. (2004) *Health promotion: philosophy, prejudice and practice*, Chichester: Wiley.
- SEN, A. (1980) Equality of what? Tanner lectures on human values, 1, 195-220.
- SEN, A. (1985) Well-being, agency and freedom: the Dewey lectures 1984. *The Journal of Philosophy*, 169-221.
- SEN, A. (1999) Democracy as a universal value. *Journal of Democracy*, 10, 3-17.
- SEN, A. (2000) Consequential evaluation and practical reason. *The Journal of Philosophy*, 477-502.
- SEN, A. (2002) Why health equity? *Health Economics*, 11, 659-666.
- SEN, A. (2005) Human rights and capabilities. *Journal of Human Development*, 6, 151-166.
- SEN, A. (2009) *The idea of justice*, Cambridge, MA.: Belknap Press.
- SHIELDS, P. M. (1996) Pragmatism. *Administration & Society*, 28, 390.
- SINGER, P. (1995) *Animal liberation*: London: Random House.
- SINNOTT-ARMSTRONG, W. (2009) Moral skepticism. In: ZALTA, E. N. (ed.) *Stanford encyclopedia of philosophy*. Stanford.
- SMITH, A. (1759) *The Theory of Moral Sentiments* (The Glasgow Edition of the Works and Correspondence of Adam Smith. Oxford: Oxford University Press.
- SMITH, R. (2000) The failings of NICE. *BMJ*, 321, 1363.
- SOANES, C. & STEVENSON, A. (2004) *Concise Oxford English Dictionary*. 11th ed. Oxford: Oxford University Press.
- SOLOMON, M. (2006) Groupthink versus the wisdom of crowds: The social epistemology of deliberation and dissent. *The Southern journal of philosophy*, 44, 28-42.
- STERBA, J. P. (1998) *Justice for here and now*, Cambridge: Cambridge Univ Pr.
- STRATTON, A. Tuesday 10 August 2010. NHS funding should not be ringfenced, says citizens' jury. *The Guardian*.

- SUNSTEIN, C. R. & THALER, R. H. (2003a) Libertarian paternalism. *American Economic Review*, 93, 175-179.
- SUNSTEIN, C. R. & THALER, R. H. (2003b) Libertarian Paternalism Is Not an Oxymoron. *University of Chicago Law Review*, 70, 1159-1202.
- SYRETT, K. (2008) NICE and judicial review: enforcing 'Accountability for Reasonableness' through the courts? *Medical law review*, 16, 127.
- THE DANISH COUNCIL FOR ETHICS. (1997) Priority-setting in the Health Service [Online]. Available: <http://etiskraad.dk/upload/publications-en/misc/priority-setting-in-health.htm> [Accessed 1 Nov 2012].
- THOMSON, J. J. 2003. Reply to commentators. In: THOMSON, J. J. (ed.) *Goodness and advice*. Princeton and Oxford: Princeton University Press.
- TSUCHIYA, A. (2000) QALYs and ageism: philosophical theories and age weighting. *Health Economics*, 9, 57-68.
- TVERSKY, A. & KAHNEMAN, D. (1981) The framing of decisions and the psychology of choice. *Science*, 211, 453-458.
- TYLER, T. R. (2006) Psychological perspectives on legitimacy and legitimation. *Annual Review of Psychology*, 57, 375-400.
- UBEL, P. A. & LOEWENSTEIN, G. (1996) Distributing scarce livers: the moral reasoning of the general public. *Social Science & Medicine*, 42, 1049-1055.
- ULRICH, W. (1994) Critical heuristics of social planning. *Journal of the Operational Research Society*, 36, 878-881.
- VANHANEN, T. (2003) *Democratization: A comparative analysis of 170 countries*, Hove, England: Psychology Press.
- VON BERTALANFFY, L. (1972) The History and Status of General Systems Theory. *Academy of Management Journal*, 15, 407-426.
- VON BERTALANFFY, L. (1975) *Perspectives on general system theory: scientific-philosophical studies*, New York: George Braziller.
- WADE, J. W. (1961) Defamation and the Right of Privacy. *Vand. L. Rev.*, 15, 1093.
- WARBURTON, N. & EDMONDS, D. (2013) *Philosophy Bites* [Online]. Available: <http://www.philosophybites.com/> [Accessed 24 Jun 2013].
- WENAR, L. (2008) John Rawls [Online]. Available: <http://plato.stanford.edu/entries/rawls/> [Accessed 25 Nov 2012].
- WESTERMAN, P. (2005) A conversation with John Harris about bioethics [Online]. Available:

http://www.paulinewesterman.nl/documenten/THE_MORALIST_HARRIS.pdf [Accessed 9 Aug 2012].

- WHITCHURCH, G. G. & CONSTANTINE, L. L. (1993) Systems theory. Sourcebook of family theories and methods, 325-355.
- WHO (1948) Basic documents of the World Health Organization, Geneva: World Health Organization.
- WILLIAMS, A. (1985) The value of QALYs. Health and social service journal, 18, 3-5.
- WILLIAMS, A. (1992) Cost-effectiveness analysis: is it ethical? Journal of medical ethics, 18, 7-11.
- WILLIAMS, A. & KIND, P. (1992) The present state of play about QALYs. Measures of the quality of life and the uses to which such measures may be put, 21.
- WILSON, E. O. (1999) Consilience, New York: Vintage Books.
- WIRTZ, V., CRIBB, A. & BARBER, N. (2003) Understanding the role of “the hidden curriculum” in resource allocation—the case of the UK NHS. Health Care Analysis, 11, 295-300.
- WOLFF, J. (2011) Ethics and Public Policy: A Philosophical Inquiry, London: Routledge.
- WOOLHANDLER, S. & HIMMELSTEIN, D. U. (2002) Paying for national health insurance—and not getting it. Health Affairs, 21, 88-98.
- WORLD HEALTH ORGANISATION. (2011) Disability weights, discounting and age weighting of DALYs [Online]. Available: http://www.who.int/healthinfo/global_burden_disease/daly_disability_weight/en/index.html [Accessed 24 Jun 2012].

Appendix B: Other publications and presentations linked to my PhD thesis

During the first year of my PhD., I was invited to develop two publications: ethical commissioning guidance for the Royal College of General Practitioners (RCGP) entitled “Making Difficult Choices”(Oswald and Cox, 2011), and a chapter entitled “Should we strive for total scientific freedom?” for an edited book on scientific freedom.(Oswald, 2012)

The former is very closely related to my thesis. I developed it with Dennis Cox, a general practitioner and member of the RCGP Council, and in conjunction with the Ethics Committee of the RCGP. Dr. Cox drafted the section on conflicts of interest. The document was commended, and approved as RCGP policy, by the RCGP Council. It is published on the organisation’s website. It forms part of the RCGP’s guidance to general practitioners involved in commissioning within the newly-formed clinical commissioning groups in England. As it is jointly authored, it is not formally part of this thesis. Nevertheless, developing the guidance for the RCGP contributed significantly to the development of my thinking for this thesis. For example, it contains a sketch of John Broome’s thinking on good and fairness. But perhaps more importantly, it brought home to me how difficult it is to make policy using the existing literature: for example, how is a policymaker with limited time meant to choose between the arguments of economists and bioethicists when there is so much disagreement? It made me realise that what was needed was more attempts to synthesise work of authors from different disciplines. I presented a paper on this theme to the European Association of Centres of Medical Ethics (EACME) conference in Bristol in August 2012 entitled: “In the doorway, looking in: connecting bioethics to policy”.

The chapter in the book on scientific freedom also helped me to develop my thinking for this thesis, particularly around the competing sources from which public policy can be drawn, and how public resources should be allocated. It prompted me to plan and run a session in 2012 on “where should the law come from?” with a group of about 30 fifteen-year-old high school students who were visiting the law school. I split them into four groups (politicians, experts, the people, and citizens’ juries) and

asked each group to deliberate and find reasons why their group should be the source of law. They came up with some interesting arguments. I ran another session in 2013 with sixth form school students visiting the Law School, this time engaging them in the problem of healthcare rationing. Three actors playing needy patients told their story of why they needed and deserved expensive treatment, and the students had to find reasons why their patient should get the treatment. At the request of one of the teachers from Winstanley College, I visited the college and re-ran the session twice with some of their students, and have been asked to do the same again in October 2013. It is my belief that ethics is a subject that is everybody's business, young and old.

I have presented several papers related to this thesis to my post-graduate peers, and members of academic staff in the Law School, at seminars over the three years.

Appendix C: Acknowledgements

I would like to acknowledge the support I have been given by my supervisors, Soren Holm and Catherine Stanton, who have patiently and constructively reviewed many different drafts from me, and given me very useful feedback.

I would also like to thank other staff from the Centre for Social Ethics and Policy and the Institute for Science, Ethics and Innovation, and in particular Becki Bennett, who runs the Bioethics and Medical Jurisprudence programme, and John Coggon and Sarah Chan who have organised and help run weekly seminars where staff and postgraduate students mix and share their thinking on bioethics and law papers presented. These seminars, and the sessions organised as part of the Bioethics and Medical Jurisprudence Programme, nurture a research community. I have gained from presenting draft papers to these sessions, but perhaps more importantly, from listening to others presenting their papers and discussing the papers of others.

I have written a few papers as stories, and then asked others to act them out as a way of presenting the paper in seminars. So I thank all of those actors, and particularly Becki Bennett, Iain Brassington, Sam Walker, and Nicola Williams, all of whom appeared in more than one of these little performances.

I have tested all of my papers on various colleagues, friends and relatives, who have given me their valuable time and feedback, without expecting anything in return. I am very grateful to all of these people, who include: Andrew Balfour, John Broome, John Coggon, Angus Dawson, Amy Ford, David Gibson, Barry Harper, Shepley Orr, Rachel O'Dowd, Andrew Oswald, James Oswald, Martin Reynolds, Ralph Sullivan, Teck Chuan Voo, and Amanda Wogan.

Thanks too go to my wife Diana for putting up with me waking up early in the morning, getting out my laptop, and noting down in bed the latest exciting idea (to me at least) to be worked into this thesis.