DELIBERATIVE DEMOCRACY, PUBLIC REASON AND THE ALLOCATION OF CLINICAL CARE RESOURCES

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Declaration

I, Gabriele Badano, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

ABSTRACT

This thesis discusses how societies should allocate clinical care resources. The first aim of the thesis is to defend the idea that clinical care resource allocation is a matter for deliberative democratic procedures. I argue that deliberative democracy is justified because of its ability to implement equal respect and autonomy. Furthermore, I address several in-principle objections to the project of applying deliberative democracy to clinical care resource allocation. Most notably, I respond to the narrow view of the scope of deliberative democracy and the critiques of explicit rationing.

The second aim of the thesis is to determine what is required by deliberative democracy in clinical care resource allocation. I identify the general requirements that resource allocation agencies should meet, namely public reason, public involvement, transparency, accuracy and revisability. I then examine what is required by deliberative democracy with regard to two particularly salient specific topics, namely the substantive values that should govern resource allocation and the involvement of scientific experts in decision-making.

I demonstrate that public reason imposes severe constraints on the substantive values that should be employed. Most of these constraints are rooted in the idea that, under a regime of scarcity, public reason requires that resources be allocated so as to minimise the strongest complaint anyone may have. Out of the variety of values that are commonly proposed as relevant, only priority to the worst-off, ability to benefit, specialness of

clinical care and cost are consistent with public reason. Turning to expert involvement, I argue that deliberative democracy can overcome several formidable threats, such as the opacity of expert opinions to laypersons and the tendency to hide uncertainty and disagreement from the public. I also discuss how my proposals on substantive values and expert involvement could be implemented, in order to add to the plausibility of my theory.

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1. DELIBERATIVE DEMOCRACY IN CLINICAL CARE RESOURCE ALLOCATION: AN INTRODUCTION

Healthcare is generally thought to play a special role in a well-ordered society: access to effective healthcare can save patients from death, prevent serious disabilities from occurring, relieve suffering and accomplish other tasks that are of the greatest value.[1] In addition to the specialness of healthcare, it is the tragic aspect of its allocation that sparks interest in this topic. Indeed, even affluent societies have no choice but to ration healthcare resources, i.e. to allocate them through a process involving the withholding of care that would be beneficial to patients.[2] Rationing is not limited to the outright exclusion of beneficial treatments. Services may be provided to a sub-group of patients, perhaps on the grounds of a greater ability to benefit. To cite a few more examples, long waiting lists may be put in place, or the quality of services may be diluted, e.g. by reducing follow-up appointments after surgery.[3]

Not everyone accepts that societies have no choice but to resort to rationing strategies. Some maintain that the scarcity of resources we suffer from comes down to inefficient healthcare. Thus, an evidence-based assessment of healthcare procedures and a solid system of clinical guidelines could ensure that no patient is denied beneficial treatment.[4]

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[1] For a list of authors drawing on the idea that healthcare is special, see Segall (2007, 342 and relative footnotes).

[2] Maynard (1999).

[3] For a thorough analysis of the forms of rationing, see Klein and Maybin (2012, 15–25).

[4] Brook and Loor (1986).

Alternatively, one may argue that we should spend more money on healthcare, or that increased competition would drive costs down.

These objections help to highlight the deepest reasons behind the inevitability of rationing. To start with, there is solid evidence that increased competition does not help to reduce healthcare costs.[5] The most glaring example is provided by the U.S., which is the only industrialised country that does not offer universal access to healthcare. In 2012, driven by competition between health insurance companies, the U.S. spent almost 17 percent of its GDP on healthcare. Germany, the Netherlands and other big spenders from Europe did not go beyond 12 percent.[6] In contrast, it is legitimate to suggest that societies should discuss whether more money should be spent on healthcare. For example, British citizens may well have reasons to believe that they should devote more than 9.3 percent of their GDP to healthcare.[7] Analogously, societies should certainly try to identify and eliminate ineffective interventions. To cite one example among many, clinical guidelines have been shown to reduce the use of costly and over-prescribed antibiotics.[8]

Regardless of the value of the last two suggestions, rationing remains inevitable. First, healthcare provision needs to be balanced against a plurality of other social goods that require money from societies.[9] Second, healthcare is a very labour-intensive industry, which involves a large amount of interaction between providers and patients. Indeed, the wage bill generally accounts for the largest part of healthcare expenditures. Therefore, if compared to industries that less heavily rely on personal interaction,

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[5] Callahan (2009, 92–119).

[6] http://www.oecd.org/els/health-systems/oecd-health-statistics-2014-frequently-requested-data.htm (last accessed 14/10/2014).

[7] The figure refers to 2012. See http://www.oecd.org/els/health-systems/oecd-health-statistics-2014-frequently-requested-data.htm (last accessed 14/10/2014).

[8] See the example of Vancomycin discussed by Ruger (2010, 182–183).

[9] Sreenivasan (2012).

healthcare is bound to consume an increasingly large portion of GDP over time.[10] Third, and perhaps most importantly, the medical needs of a population are virtually endless, while the array of available treatments grow at an impressive rate. Consequently, no amount of efficiency savings or extra money spent on healthcare will ever be enough to cover all unmet medical needs that could be treated through available treatments.

In the U.K., cancer drugs like Avastin (Bevacizumab) and Herceptin (Trastuzumab) sparked a wide debate on whether a few extra weeks or, at most, months of life expectancy justify costs that, in some cases, reach above £100000 per patient per year.[11] However, these ultra-expensive and marginally effective drugs are only the tip of the iceberg of rationing. The literature on resource allocation is full of examples explaining why any extra amount of money spent on healthcare would be consumed by our technical ability to tackle unmet medical needs. For instance, Peter Ubel mentions ambulances, whose quick arrival can make the difference between life and death. If we really aimed to provide all the healthcare that patients could benefit from, we should be continually commissioning new ambulances, so that our ambulance network would become thicker and thicker. Still, as in innumerable other cases, it is clear here that societies have to stop somewhere and resort to rationing.[12]

Given that societies cannot provide all the healthcare that citizens could benefit from, how should we choose between competing claims? What are the principles that should be employed to allocate available resources? These questions are at the core of my thesis. In this introductory chapter, I present the aim, structure and main contributions of my work. In section 1.1, I explore the general features of the debate on how healthcare resources

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[10] Baumol (2012).

[11] Sullivan et al. (2011) provides a wide-ranging analysis of the costs of cancer care.

[12] Ubel (2001, 39).

should be allocated. Besides making reference to the emergence of a population-level perspective and what can be described as a procedural turn, I introduce the influential work of Norman Daniels. Section 1.2 presents the main aims of my work. In short, my thesis aims a) to defend a deliberative democratic approach to healthcare resource allocation; and b) to determine what deliberative democracy requires in this context. In this section, I also discuss the structure and limitations of my argument. Section 1.3 describes three themes that run throughout my thesis, helping to distinguish my contribution from existing works on healthcare resource allocation and beyond. Two themes challenge important elements associated with the population-level perspective and the procedural turn. The third theme explores the tensions surrounding the role of administrative agencies and scientific experts in healthcare resource allocation.

1.1. Population-level perspective, procedural turn and accountability for reasonableness

In both academia and policy-making, the debate on healthcare resource allocation is marked by two tendencies, i.e. the adoption of a population-level perspective and a shift in focus towards procedural issues. While exploring such tendencies, this section also introduces the most important theorist of healthcare resource allocation, i.e. Norman Daniels. To start with, consider the population-level perspective, which distinguishes healthcare resource allocation from more traditional debates on ethics in healthcare settings. The population-level perspective is an object of discussion in its own right and consists of at least four elements.

Traditionally, ethicists and regulators who focused on healthcare settings were mainly concerned with dyadic relationships involving a doctor and a patient, or a clinical researcher and research subjects. For example, they explored whether euthanasia is against the duty of a doctor, or whether the use of placebos in clinical trials is unethical. Moral philosophy offers most of the intellectual resources that are needed to tackle these kinds of questions.

In contrast, the distribution of healthcare resources is the result of a chain of decision-making that involves many actors operating at different levels. Focusing on the U.K., ministers and central agencies at the Department of Health work alongside local commissioning authorities, providers and, finally, individual doctors in hospitals and primary or community care.[13] The relationship among decision-makers and between decision-makers and recipients of healthcare is often mediated by institutions. Also, it is often the case that agencies are responsible for allocating resources between a large number of potential recipients. The issues raised in this context are very similar to classic questions of distributive justice, leading to the first element of a population-level perspective on healthcare resource allocation – namely, the pervasive use of the *toolbox of political philosophy*.[14]

Second, the shift to large-scale distributive problems has brought the responsible stewardship of common resources into sharp focus. Policy-makers and scholars are united in claiming that economic tools must be used to control the potentially unlimited costs of healthcare.[15] More specifically, many advocate the use of *cost-effectiveness analysis* as crucial to the sustainability of healthcare resource allocation and provision. In a nutshell, cost-effectiveness analysis explains how available funds should be allocated so as to create the greatest sum total of health benefits throughout the relevant population.[16] Referring back to the example of the ultra-expensive

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[13] Jackson (2013, 64–79) and Klein and Maybin (2012, 4–5).
[14] Wikler and Brock (2008).
[15] Eddy (1991) and Emanuel (2002a).
[16] Brock (2004) discusses the ethics of cost-effectiveness analysis.

cancer drugs constantly hitting the market, decision-makers should establish whether the money to fund the new pharmaceuticals can be redirected from interventions that, for the same cost, create a smaller aggregate health benefit. If the money to fund the new pharmaceuticals cannot be redirected from any such intervention, cost-effectiveness analysis recommends against coverage. Cost-effectiveness analysis is so popular that, most of the time, the question is not whether cost effectiveness should be used to allocate healthcare resources. The real question is whether cost effectiveness should be balanced against other values and, if so, which other values should be taken into account.

Third, leaving dyadic relationships aside to focus on populations has led many authors to question the particular attention traditionally paid to *clinical care as opposed to public health and the social determinants of health*.[17] Public health interventions on sanitation, diet and many other factors have an impressive track record in improving population health. More recently, epidemiological studies have demonstrated that population health and health inequalities among groups are to a large extent determined by the social determinants of health, i.e. social and economic factors like income, education and social inclusion. For example, there are almost 30 years of difference in life expectancy between the residents of the most affluent and the most depressed suburbs in Glasgow, Scotland.[18] Based on this kind of evidence, it is claimed that policy-makers, academics and the common culture of our societies still display a disproportionate interest in the health interventions provided in clinical settings. Comparatively, more attention (and more resources) should be devoted to public health and social determinants of health.

A fourth element associated with a population-level perspective is the

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[17] See Daniels (2006) and (2008, 1–6), as well as Goldberg (2012).

[18] World Health Organization (2008).

stress placed by both scholars and policy-makers on the need to make healthcare resource allocation decisions *in the open*.[19] Explicit rationing is not without opponents – some believe that healthcare resources should be allocated behind closed doors.[20] However, there is a clear tendency towards greater transparency, which is related to the fact that healthcare resource allocation is essentially a political problem. The idea seems to be that secrecy belongs to the doctor-patient relationships, not healthcare resource allocation.

Within a debate characterised by a population-level perspective, a number of theories are proposed as suitable to guide healthcare resource allocation. Many of them are linked to some of the most influential paradigms in political philosophy, including the capabilities approach;[21] communitarianism;[22] libertarianism;[23] luck egalitarianism;[24] and utilitarianism.[25]

In my thesis, I put forward arguments that attack, more or less directly, all the theories that I have listed. However, the *main critical reference* of my work is Norman Daniels's conception of fair process in the allocation of resources, which is called "accountability for reasonableness" (AFR). Two considerations explain why I decided to pay special attention to AFR. First, Daniels's work represents the most influential contribution to the debate on healthcare resource allocation. Second, AFR shares important features with my proposal. I need to show that, underneath the surface, there are key points of disagreement between my model and Daniels's work. Both

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[19] The link between transparency and a population-level perspective is discussed by Emanuel (2002a).

[20] I provide an answer to the critics of transparency in sections 4.1 and 4.2.

[21] Powers and Faden (2006), Ruger (2010) and Venkatapuram (2011).

[22] Mooney (2009).

[23] Engelhardt (1996, 375–410).

[24] Segall (2009).

[25] Eddy (1991), Stein (2012) and Alan Williams (1985).

considerations are discussed at great length between this section and the next two. Before doing that, however, I need to outline Daniels's proposal.

Daniels's work on justice in healthcare resource allocation spans over four decades. Initially, Daniels's main contribution consisted in an appealing conception of the value of health that could fit within the general theory of justice proposed by John Rawls. According to Daniels, the value of health lies in its ability to protect a person’s range of opportunities to pursue life plans. Given that healthcare protects health, Daniels claims that healthcare should be regarded as having special importance: healthcare resources must be distributed in an egalitarian fashion, in isolation from ability to pay, position in society and other social goods.[26]

Over the years, Daniels added two important components to his theory. One of them has to do with the tendency to place great stress on the social determinants of health, which I discussed in the context of the population-level perspective on resource allocation. Daniels now acknowledges that healthcare (defined as including clinical care and public health) is only one of many contributors to population health and the reduction of health inequalities among groups. Therefore, the value of health provides an extra reason to pursue an egalitarian distribution of goods such as the social bases of self-respect, political liberties and income.[27]

Furthermore, Daniels came to the realisation that neither a principle of opportunity nor any other theory of healthcare resource allocation is fine-grained enough to answer the vast majority of *substantive questions* faced by resource allocation decision-makers. Hence, theorists have no choice but to be agnostic about a wide array of key issues concerning the substance of healthcare resource allocation, i.e. which final distribution of resources is preferable. In this context, *procedural fairness* becomes the key to justice in

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[26] Daniels (1985) and (2008, 29–78).

[27] Daniels (2008, 79–102).

resource allocation.

It is worth focusing on this procedural turn at some length, because an emphasis on procedural fairness characterises the whole debate on healthcare resource allocation. Many theorists agree on the idea that numerous substantive issues are too complex for available theories to solve them. Hence, special attention should be paid to the fairness of healthcare resource allocation procedures.[28] Also, Daniels's shift from substantive issues to procedural fairness is paralleled by an analogous move made by several countries going through health reform during the 90s or afterwards.[29] Let us examine in greater detail the arguments supporting Daniels's stance.

According to Daniels, the main problem is that a plurality of substantive values are relevant to healthcare resource allocation, while the theories now available are too abstract to point out how those values should be traded off against one another in the everyday practice of resource allocation. How much priority for the sickest is justified vis-à-vis the production of greater aggregate health benefits regardless of which patients are treated? When should significant health benefits to a smaller number of persons be outweighed by an aggregation of more modest benefits to a larger number of persons? How should the value of a fair chance to be treated be balanced against more cost-effective interventions? Neither Daniels's principle of opportunity nor any other appealing theory of healthcare resource allocation can provide determinate answers to these and other conflicts among substantive values. Therefore, Daniels maintains that his principle of opportunity needs to be complemented with an appeal to procedural fairness. Drawing on the Rawlsian notion of pure procedural justice, Daniels

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[28] Among others, see Dolan et al. (2007), Fleck (2009), Klein (1993), Ruger (2010) and Wailoo and Anand (2005).

[29] For countries like Denmark, the Netherlands, New Zealand, Norway and Sweden, see Ham (1997) and Holm (1998). For references to the health reform in Mexico and the National Health Service in the U.K., see footnotes 34, 35 and 36.

claims that resource allocation decisions should be regarded as fair when they result from a fair decision-making process.[30]

Interestingly, Daniels's argument has much in common with the points made by several authors when commenting on the evolution of health policy in a number of different countries. For example, Søren Holm examines why Denmark and Norway decided to go beyond “simple solutions”, centred on the search for the correct order of priority among the substantive values that should govern healthcare resource allocation. Holm claims that decision-makers realised that numerous values are relevant to healthcare resource allocation. Furthermore, it was unclear how those values should be balanced against each other. Hence, Danish and Norwegian institutions had to shift their focus to the fairness of the process through which substantive issues were dealt with.[31]

How should procedural fairness be defined? Daniels lays down four conditions - if the four conditions are respected, final decisions are to be regarded as fair.

- Publicity condition: both decisions and their supporting rationales must be transparent and publicly accessible.
- Relevance condition: decision-makers must provide a reasonable construal of the way in which resource allocation decisions ensure value for money in meeting the health needs of the relevant population. In this context, a construal is reasonable if it is grounded in considerations that can be accepted as relevant by persons who are willing to provide justifications for the allocation of resources they support.
- Revision and Appeals condition: there must be mechanisms to

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[30] Daniels (2008, 103-110).

[31] Holm (1998).

challenge resource allocation decisions.

- Regulative condition: there must be uniform enforcement of the other three conditions.[32]

The importance of AFR can hardly be overestimated. In particular, Daniels's model is close to being dominant where academic research meets the evaluation of health policy.[33] Furthermore, AFR has been employed as a guide to policy-making on multiple occasions. As far as developing countries are concerned, AFR has been used by the Mexican government and the World Health Organization in its effort to tackle HIV/AIDS in low-income countries.[34]

Turning to more affluent countries, Daniels's model has had a great influence on the British National Health Service (NHS). To start with, consider the National Institute for Health and Care Excellence (NICE). Operating at arm's length from the Department of Health, NICE provides guidance in a number of areas. NICE gives advice with regard to best clinical practice and public health. Starting from 2013, NICE also provides guidance regarding social care. However, NICE has been in the public eye mainly because of its health technology appraisals. Importantly, if NICE recommends in favour of the pharmaceuticals or other health technologies under appraisal, local commissioning authorities are legally bound to fund them. The controversies surrounding the ultra-expensive cancer drugs mentioned earlier have often been created by NICE's refusal to recommend interventions that did not seem to meet NICE's standards of cost effectiveness. NICE explicitly endorses AFR and its decision-making

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[32] Daniels (2008, 117-139). The four conditions draw on the work that Daniels has done with James Sabin - see Daniels and Sabin (2008).

[33] Among others, see de Bont et al. (2007), the articles collected in Ham and Robert (2003), Kapiriri et al. (2009), Maluka et al. (2010), Manning and Paterson (2005), Martin et al. (2002), Norheim (2005), S. Robinson et al. (2011) and I. Williams et al. (2012).

[34] Daniels (2008, 274-296).

procedures are devised so as to satisfy the four conditions proposed by Daniels.[35]

In addition to NICE, local commissioning authorities are key actors in the allocation of NHS resources. In 2013, local commissioning authorities were restructured and Clinical Commissioning Groups replaced Primary Care Trusts. Even though they are bound to provide the health technologies recommended by NICE, Clinical Commissioning Groups bear the ultimate responsibility for allocating the largest part of the NHS budget. AFR is reflected in the work done by several local commissioning authorities in their search for an appropriate process through which to allocate their share of the budget.[36]

Mentions of NICE and local NHS authorities recur in my work. As said earlier in this section, AFR is both the main critical reference of my thesis and a model with important points of contact with my own proposal. Given their close link with AFR, I sometimes make reference to NICE and local NHS authorities to substantiate my criticisms against Daniels. Other times, I make reference to the same NHS agencies to show how things should work.

1.2. A deliberative democratic approach to resource allocation: aims, structure and limitations

Having outlined the general features of the existing debate, I can turn to my own proposal. My thesis aims to a) *defend* the idea that healthcare resource allocation should be a matter for deliberative democratic procedures and b) *determine* what deliberative democracy requires in the context of healthcare resource allocation, both in general and with regard to two particularly salient topics. Regarding the first particularly salient topic, I argue that

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[35] NICE (2008).

[36] Klein and Maybin (2012, 8-9) and S. Robinson et al. (2011).

deliberative democracy provides determinate answers to numerous issues concerning the *substantive values* that should govern healthcare resource allocation. As for the second salient topic, I discuss how the latitude accorded to *scientific experts* in healthcare resource allocation can be reconciled with deliberative democracy.

What is deliberative democracy? Chapter 2 is devoted to the exploration of deliberative democracy or, more specifically, the different justifications offered in its support. Thus, for the time being, a skeletal definition suffices. Generally speaking, the proponents of deliberative democracy distinguish themselves from those conceptualising democracy as an arena where individuals and groups are supposed to pursue their own interests. Rational decision-making is not enough to ensure legitimacy: in a deliberative democracy, participants should be concerned with the common good and willing to endorse the best argument. Subsequently, it is often argued that a well-conducted democratic deliberation should transform the views of participants on the issues at hand.[37]

Another concept that is worth stressing from the outset is that of public reason. I argue for a specific conception of deliberative democracy. Based on a principle of equal respect for the autonomy of individuals, my conception of deliberative democracy places great importance on public reason, i.e. the idea that political decisions should be grounded in reasons everyone might be expected to accept. Like numerous other theories stressing the notion of public reason, my model has important points of contact with Rawls's conception of deliberative democracy.[38]

My argument can be thought of as consisting of two parts. The main aim of part I is to justify the claim that deliberative democracy should govern

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[37] Besson and Martí (2006), Bohman and Rehg (1997), J. Cohen (1989) and Elster (1998a).

[38] Rawls (1996, 212–254) and Rawls (1997).

healthcare resource allocation. During this justificatory process, I also spell out the general requirements that should be satisfied by a deliberative democratic system for healthcare resource allocation. Chapter 2 lays out the reasons why healthcare resource allocation should be governed by deliberative democracy. Two modes of justification fight for supremacy in the field of deliberative democracy. While the supporters of the "epistemic" view maintain that democratic deliberation tracks the right decisions, the proponents of "procedural" modes of justification claim that deliberative democratic procedures are meant to implement intrinsic values such as equality and autonomy. In a context in which multiple bodies of scientific knowledge are relevant to the issues at hand, the epistemic view loses much of its appeal. In contrast, I demonstrate that there is room for a compelling procedural justification for deliberative democracy in healthcare resource allocation.

This argument enables me to raise a first criticism against Daniels or, more specifically, his case for fair procedures. Moreover, choosing between competing justifications helps to give determinate shape to the general requirements of deliberative democracy. While defending a procedural view, I point out that public reason and public involvement are key requirements of a deliberative democratic approach to healthcare resource allocation.

Chapter 3 serves two purposes. First, it resumes the analysis of the general requirements of deliberative democracy in healthcare resource allocation. Public reason and public involvement are further analysed. In addition, I tailor a role for transparency, accuracy and revisability. Discussing the general requirements of deliberative democracy helps me to explain why we should be interested in the topics of the following chapters. For example, I point out that a commitment to the search for the most accurate factual information appears to require that scientific experts should be involved in resource allocation. However, expert involvement is in tension with the idea that resource allocation is a matter for deliberative democratic procedures. Chapters 9 and 10 return to this topic, demonstrating that the tension between deliberative democracy and expert involvement can be solved.

Second, chapter 3 answers a criticism that might be raised from the ranks of deliberative democracy. Some believe that concrete issues such as healthcare resource allocation should fall outside the scope of any conception of deliberative democracy that involves a commitment to public reason.[39] My aim is to identify the reasons backing this position and show that they are flawed.

Chapter 4 focuses on the challenges posed by two positions internal to the debate on healthcare resource allocation. First, I answer the critics of transparency. They draw on a long history of implicit healthcare resource allocation and raise appealing arguments. However, deliberative democracy involves a requirement of transparency, which I aim to defend. Second, I respond to a criticism that targets the stress placed by deliberative democracy on procedural issues. In brief, the charge is that deliberative democracy is bound to create a context in which substantive values are not discussed in any depth. Moreover, some critics maintain that deliberative democracy is unable to provide any guidance as to which substantive values should be used to allocate resources. This is a stimulating criticism, which prompts me to highlight the full potential of deliberative democracy to settle substantive issues.

I outline several routes that can be followed to identify the substantive values that are consistent with deliberative democracy and those that are not.

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[39] The locus classicus for this claim is Rawls (1996, 212-254) and (1997). Given that my model heavily draws on Rawls's conception of deliberative democracy, this criticism poses a particularly difficult challenge to my argument.

I argue that, under a regime of scarcity, public reason requires that decision-makers should allocate resources so as to minimise the strongest complaint anyone may have. Moreover, I show that public reason involves both a commitment to well-constructed rationales and a strong presumption for the compartmentalisation of different areas of governmental activity. These routes to substantive recommendations serve as the basis for the analysis carried out in chapters 5, 6 and 7.

Part II aims to explore what is required by deliberative democracy with regard to two particularly salient topics. Four chapters are devoted to the first salient topic, i.e. the ability of deliberative democracy to provide determinate answers to questions concerning the substantive values that should govern healthcare resource allocation. Chapters 5 and 6 critically analyse the substantive values that are most commonly proposed as suitable to govern healthcare resource allocation, in order to determine which values are consistent with deliberative democracy and which ones are not. I argue that deliberative democracy only upholds priority to the worst-off and ability to benefit, framed by the idea that healthcare has special importance and constrained by cost considerations. I demonstrate that all aggregative values are inconsistent with deliberative democracy, which means that cost-effectiveness analysis should not be used to allocate resources. Furthermore, I argue that deliberative democracy rejects fair chances to be treated, dread, government and stakeholder priorities, personal responsibility for health, innovation, lack of alternative treatments and rarity.

Chapter 7 pulls together the different parts of the analysis carried out in chapters 5 and 6. I argue that it is possible to convert the substantive values upheld by deliberative democracy into a decision-support tool, which is capable of providing guidance to resource allocation decision-makers. Moreover, I demonstrate that in virtue of the constraints imposed on the use of substantive values, my model of deliberative democracy constitutes an alternative to both utilitarian and intuitionistic approaches to resource allocation decision-making. Drawing on a Rawlsian argument, I point out that this fact constitutes a great strength, distinguishing my model from numerous other approaches to healthcare resource allocation. In particular, the ability to find an alternative to both utilitarianism and intuitionism distinguishes my model from AFR, marking the culmination of my critique of Daniels.

Chapter 8 discusses how to implement the conclusions of my analysis of substantive values. I argue that interventions on the design of healthcare resource allocation agencies should be coupled with arrangements aimed at spreading throughout society a positive attitude towards deliberation. With regard to the design of resource allocation agencies, chapter 8 stresses the importance of insulated administrative bodies.

Chapter 9 turns to the second particularly salient topic, namely whether the latitude accorded to scientific experts in healthcare resource allocation can be reconciled with deliberative democracy. I identify two main threats to deliberative democracy, coming down to the opacity of expert knowledge to laypersons and the tendency to hide uncertainty and disagreement from the public. To demonstrate that the tension between expert involvement and deliberative democracy can be solved, I prove that expert opinions and expert communities can be assessed on the basis of public reasons. Moreover, I argue that the public has the necessary abilities to discuss which resource allocation decisions should be made in the face of uncertainty and disagreement about scientific matters.

Chapter 10 discusses how to implement the analysis of expert involvement carried out in chapter 9. I argue that interventions are needed at two levels to reconcile in practice deliberative democracy and expert involvement. Focusing on the design of healthcare resource allocation agencies is not enough – societies should encourage a more general level of deliberation about scientific communities, involving upstream engagement exercises, representative institutions and the media.

The argument of the thesis is limited in at least three ways. First, my thesis focuses on healthcare resource allocation in the domestic realm. Bringing global health into the picture would raise a whole range of new questions, starting from the applicability of my case for deliberative democracy beyond borders.[40] Thus, although I acknowledge the great importance of the ethical issues surrounding global health, addressing them is outside the realm of this work, which sets to explore healthcare resource allocation within states. Whether any of the concepts developed in this thesis should be applied at the global level could be an interesting subject for future research.

Second, my focus is limited to the allocation of the healthcare budget. I take the size of that budget as a given or, in other words, I am not interested in the way in which resources should be allocated between healthcare and other expenditure areas. As stressed by Jonathan Wolff and Avner de-Shalit, intra-departmental and inter-departmental budget allocation may answer to very different logics, which call for distinct analyses.[41]

The third limitation is rooted in the fact that this is a work in political philosophy. This means that my main task is to focus on issues of justification and questions concerning the abstract principles that should govern healthcare resource allocation. Even though chapters 8 and 10 discuss implementation, their aim is to show that my theoretical proposals are not utterly implausible, adding to the justification of my theory.

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[40] For some of the issues of justice arising at the global level, see Benatar and Brock (2011).

[41] Wolff and De-Shalit (2007, 89–107).

Accordingly, chapters 8 and 10 are much shorter than the chapters preceding them, which contain abstract analyses. In sum, an in-depth analysis of institutional design or the most fitting way in which my recommendations could be put into practice falls beyond the scope of my thesis.

1.3. Three themes of my work

In this section, I aim to outline three themes that cut through my thesis. The themes that I intend to discuss are worth our attention because they help to identify the original contributions of my thesis and place my work within existing debates. Two themes are critical explorations of the tendencies that I have described as characterising the debate on healthcare resource allocation, i.e. the population-level perspective and the procedural turn. The third theme concerns the tensions surrounding the involvement of administrative agencies and scientific experts in decision-making.

The first theme concerns the *population-level perspective* dominating the debate on healthcare resource allocation. My idea is that, although some elements of the population-level perspective are fully justified, other elements misunderstand what is required in the passage from dyadic relationships to large-scale distributive issues. More specifically, I welcome the idea that the toolbox of political philosophy is most suitable to explore resource allocation. In fact, my thesis looks at healthcare resource allocation from the perspective of democratic theory. Furthermore, I aim to defend transparency against the supporters of implicit rationing. However, other components of the population-level perspective leave too much behind in the passage from more traditional ethical issues in healthcare settings to resource allocation.

First, *I reject the common-sense view of the function of cost effectiveness*, namely that cost effectiveness must play a role in healthcare resource allocation, although other criteria may be proposed together with it. I believe that cost considerations are important and should be factored in when healthcare resources are allocated. Nonetheless, my thesis demonstrates that looking at healthcare resource allocation from the standpoint of public reason allows us to see that the aggregative logic of cost effectiveness is unacceptable. Therefore, I put forward another method for taking costs into account – namely, a prioritised-list approach to cost considerations. I argue that interventions should be ranked according to the strength of the complaint they respond to. Funding should be allocated starting from the top of the list and until money runs out.

Second, the concern for individuals dictated by public reason sounds *a strong note of caution about the tendency to lament that, comparatively, scholars and policy-makers pay too much attention to clinical care.* Here I do not mean to deny that public health and the social determinants of health are valuable areas of government activity. However, I affirm a sort of primacy of clinical care, which is meant to block all the arguments starting from the premise that clinical care, public health and social determinants of health play the same social function. These are the sorts of arguments claiming that, as a matter of consistency, the very same concern we have for clinical care should be extended to public health and social determinants of health. They generally support the conclusion that members of certain groups could legitimately have their entitlements to clinical care reduced in exchange for targeted public health or social determinants of health interventions.[42] In contrast, I argue that clinical care honours the concern for individuals that is required by public reason at a level that is beyond the reach of public health and interventions on the social determinants of health.

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[42] For example, see Segall (2007) and Wilson (2009).

Indeed, this thesis is set to focus on the allocation of resources for clinical care only.[43] Thus far, I have taken advantage of the somewhat ambiguous term "healthcare". In the literature, healthcare is generally taken to include both clinical care and public health. In the real world, however, most persons consider "healthcare" as a synonym for "clinical care". To avoid misunderstandings, from this point on I employ the more specific term "clinical care" to refer to the object of my analysis. For the time being, I am content to ground my choice of focus on the skeletal argument that I outlined in the previous paragraph. A full justification of the primacy of clinical care would be so extensive that it could not fit within an introductory chapter. However, the authors who denounce the narrowness of the focus on clinical care turn out to pose a serious challenge to further steps in my argument, to be explored in sections 5.2 and 5.3. Specifically, those critics reject the idea of specialness of clinical care, which sections 5.2 and 5.3 aim to uphold. At that point, I engage in an in-depth analysis of the primacy of clinical care, and my choice of focus emerges as retrospectively justified.

I now pause to outline a definition of clinical care, public health and social determinants of health. Roughly speaking, clinical care is delivered by medical personnel and places a great deal of emphasis on diagnosis and treatment. By public health I mean interventions that are concerned with populations, not individuals, and place great importance on prevention.[44] Finally, interventions on the social determinants of health differ from public health because, rather than aiming directly to improve health, they address the systemic causes of bad health.[45] Any plausible definitions of these terms

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[43] My choice of focus is not to be understood as implying that public health and social determinants fall beyond the scope of deliberative democracy – on this point, see section 5.4.

[44] Faden and Shebaya (2010).

[45] Segall (2007, 353-357).

is bound to have fuzzy borders, and the ones within my proposal are no exception. For example, given that preventative interventions aimed at high-risk individuals and delivered in medical settings strike us as part of clinical care, it is difficult to draw a line between clinical care and public health.[46] Still, I do not think that fuzzy borders prevent my definition from helping to clarify what is the focus of my thesis.

Continuing on the topic of definitions, I wish to forestall another misunderstanding. To focus on clinical care resource allocation does not mean restricting one's attention to the choices made by medical practitioners at the point of delivery of care. My thesis is meant to explore both the micro-allocation and macro-allocation of clinical care resources. In addition to decisions regarding particular patients, my argument discusses allocations between broader categories of expenditure, although stopping short of the allocation of resources between clinical care and other areas of social expenditure. Thus, my arguments apply to the whole decision-making chain starting from health ministers and finishing with bedside rationers.

The second theme of my thesis is related to the widespread idea that theorists have no choice but to be agnostic about numerous key issues concerning the substance of clinical care resource allocation. As seen in section 1.1, this retreat from the substance of resource allocation has led to increased attention to procedural fairness. This development is not something I object to: as theories of the most appropriate method for collective decision-making, all conceptions of democracy place great importance on procedural issues.

However, I argue that deliberative democracy can keep together *an adequate concern for procedural fairness and a commitment to suggesting determinate answers to the issues concerning the substance of clinical care*

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[46] For an influential distinction between clinical and public-health approaches to prevention, see Rose (1985).

resource allocation. As I said when discussing the structure of my argument, my thesis aims to critically analyse the substantive values that are most commonly proposed as suitable to govern clinical care resource allocation. In contrast to Daniels's list of unsolved value conflicts, my model of deliberative democracy has much to say about the place of cost effectiveness, priority to the worst-off, ability to benefit, fair chances and many more substantive values that are often used to allocate resources. Among the plurality of substantive values populating the debate on clinical care resource allocation, I argue that deliberative democracy only upholds priority to the worst-off and ability to benefit, framed by the idea of specialness of clinical care and constrained by cost considerations. Moreover, I suggest that there is scope for making the values upheld by deliberative democracy into a decision-support tool capable of providing clear guidance to clinical care resource allocation decision-makers.

Importantly, pointing out the substantive implications of deliberative democracy answers one strong objection to deliberative democratic approaches to clinical care resource allocation. Indeed, many critics believe that deliberative democracy cannot serve as a guide to resource allocation because of its inability to provide any recommendation about the rightness of substantive arguments and final allocations of resources.[47]

The relevance of the third theme of my thesis reaches beyond the debate on clinical care resource allocation. It has already been noted that clinical care resource allocation works well as a case study for phenomena reaching beyond health policy.[48] Moreover, clinical care resource allocation seems to serve well as a case study for deliberative democracy at large.[49] In my thesis, I use clinical care resource allocation to explore the tensions surrounding the

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[47] Powers and Faden (2000). Also Daniels (1999, 199–201) denies that a commitment to deliberative democracy leads to any substantive recommendation.

[48] Klein et al. (1996, 1–3).

[49] Parkinson (2006).

use of *administrative agencies and scientific experts* within a deliberative democracy.[50]

On the one hand, clinical care resource allocation effectively highlights why democratic societies should have a solid administrative apparatus and involve experts in decision-making. Administrative agencies are needed because clinical care must reach all members of the relevant population in conformity with minimal requirements of homogeneity. Furthermore, all citizens in a democratic society have an interest in seeing resource allocation decision-makers give the right answers to a plurality of scientific questions. To give a few examples, those questions range from the clinical effectiveness of new drugs to the cost of a certain intervention and the way in which it would fit within the best clinical practice. Hence, experts from relevant disciplines should be involved to maximise the probability that correct answers are provided.

On the other hand, administrative agencies that allocate clinical care resources on the basis of expert evidence may easily prompt popular outrage. Although grounded in evidence-based evaluations of cost and clinical effectiveness, NICE's recommendations have not always gone down well with the popular press and public opinion. In the U.S., one of the most classic examples dates back to 1987, when Medicaid denied the 7-year-old Coby Howard a bone marrow transplant that could have saved his life. The State of Oregon judged that there were more cost-effective ways to save lives than soft tissue transplants, and a fierce controversy followed.[51] Moreover, scientific experts and administrators are not directly authorised through popular election, and the decision-making procedures they employ are often so complex that the general public cannot possibly understand

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[50] This has been a topic of interest to democratic theorists at least since Tocqueville (1969, 691–693). For the treatment of administrative power by an author who recurs in my thesis, see Richardson (2002).

[51] Fox and Leichter (1991).

them, let alone keep them in check.

In sum, administrative agencies and scientific experts play important functions in clinical care resource allocation. At the same time, they pose a serious threat to deliberative democracy. My thesis can be read as an attempt to spell out the key desiderata that administrative agencies and scientific experts must meet to be reconciled with the ideal of deliberative democracy.

In concluding this chapter, I would like to answer an obvious objection against my thesis. This objection asks, what is the point of developing a new deliberative democratic model of clinical care resource allocation? Daniels already borrows several concepts from the framework of deliberative democracy. For a start, the focus on the process of resource allocation places AFR uniquely close to democratic theory: all democratic theories investigate the process through which collective decisions should be made. Moreover, Daniels defines fair process as a matter of reason-giving among fair-minded persons, echoing one of the main themes of the deliberative approach to democratic theory. Finally, Daniels claims that the resource allocation agencies following AFR should be seen as contributors to a broader process of public deliberation.[52]

Moving beyond Daniels, there are authors who go as far as using the label "deliberative democracy" to describe their approach to clinical care resource allocation. Amy Gutmann and Dennis Thompson examine clinical care resource allocation in the process of developing the basic principles of their influential conception of deliberative democracy.[53] Focusing more closely on clinical care, Leonard Fleck proposes a deliberative democratic framework to determine how resources should be allocated.[54] Broadly speaking, these two proposals differ from AFR in calling for greater public

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[52] Daniels (2008, 119).

[53] Gutmann and Thompson (1996) and (2002a).

[54] Fleck (2009).

involvement and claiming that fair procedures are not as devoid of substantive implications as Daniels thinks. Given that several authors already apply the tenets of deliberative democracy to clinical care resource allocation, the objection questioning the point of a new deliberative democratic proposal needs to be tackled. In short, my answer is that there are strong reasons to be unsatisfied with all existing theories of clinical care resource allocation drawing on deliberative democracy.

First, none of the existing proposals provides a satisfactory justification for a deliberative democratic approach to clinical care resource allocation. Starting with the justification of deliberative democracy in general, a greater effort to distinguish good arguments from bad ones is needed to give a determinate direction to the resulting model of deliberative democracy.[55] Turning to the application of deliberative democracy to clinical care resource allocation, none of the authors who I have mentioned discuss all major counter-arguments. For example, the reasons behind the idea that the scope of deliberative democracy should be limited to abstract questions of justice are never assessed.

Second, the content of all existing accounts of deliberative democracy in clinical care resource allocation is unsatisfactory. As explained earlier in this section, the involvement of scientific experts in a deliberative democratic process for allocating clinical care resources constitutes both a great opportunity and a serious threat. Nonetheless, an in-depth exploration of the place of scientific experts in a deliberative democratic approach to resource allocation is missing. Moreover, none of the existing accounts provides a satisfactory analysis of the relationship between procedures and substance in

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[55] Both Fleck (2009, 140-201) and Gutmann and Thompson (1996, 39-49) ground their models in a mix of justifications ranging from the idea that democratic deliberation produces better decisions to the claim that deliberative democracy expresses the equal status of citizens. In chapter 2, I argue that distinctions should be made between different lines of justifications.

deliberative democracy. Indeed, not even Fleck or Gutmann and Thompson come close to appreciating to what extent deliberative democracy constrains the substantive values that should govern clinical care resource allocation.

2. THE PROCEDURAL CASE FOR DELIBERATIVE DEMOCRACY IN CLINICAL CARE RESOURCE ALLOCATION

The aim of this chapter is to explain why societies should adopt a deliberative democratic approach to clinical care resource allocation. Specifically, this chapter goes through the main modes of justification of deliberative democracy to single out the one that provides compelling arguments that can be applied to clinical care resource allocation.

In section 1.2, I identified a few general features that are common to all conceptions of deliberative democracy. For political decisions to be legitimate, decision-makers should not pursue their own interests or the interests of a section of society. Indeed, participants should have the common good in view. Furthermore, they should be ready to change their mind in light of the arguments voiced during discussion.

Any definition of deliberative democracy is bound to be rather broad, because competing models of deliberative democracy may differ a great deal from one another. Some of the differences between those models are rooted in the mode of justification of deliberative democracy that they have adopted. Thus, to show that one mode of justification is better than the others contributes to working out a specific account of the requirements of deliberative democracy, in clinical care resource allocation as well as in any other field. In sum, the task I set for myself in this chapter is important because it helps to identify what a deliberative democratic approach to clinical care resource allocation requires.

In section 2.1, I identify two modes of justification that fight for supremacy in the field of deliberative democracy, i.e. epistemic and procedural. However, this section is, for the most part, devoted to criticising a third mode of justification, which is centred on the idea of virtue. Section 2.2 argues that, in a concrete policy field like clinical care resource allocation, the epistemic mode of justification is unconvincing. In section 2.3, I defend a procedural mode of justification that rests on the idea that deliberative democracy expresses and implements the principle of equal respect for autonomous individuals. In addition, I demonstrate that deliberative democracy requires both public reason and public involvement. Finally, section 2.4 shows that my analysis points out the inadequacy of Norman Daniels's influential case for fair procedures in clinical care resource allocation.

2.1. Right decisions, fair procedures and virtuous citizens

In Elizabeth Anderson's words, "democratic theory is caught between two modes of justification: epistemic and procedural".[56] Epistemic justifications are of an instrumental kind in that they stress the ability of democratic procedures to produce outcomes whose value is independent from the procedures themselves. In particular, epistemic democrats believe that democracy is good at tracking the right answer to the questions faced by political institutions. Conversely, proceduralists claim that the value of democracy lies in the fact that democratic procedures express and implement intrinsic values such as equality, liberty or autonomy. It is

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[56] Anderson (2008, 129). For the idea that epistemic and procedural approaches to justification dominate democratic theory, see also Estlund (2009) and List and Goodin (2001, 277–283).

sometimes said that the contrast lies between the idea that democracy leads to right decisions and the idea that democracy leads to fair decisions.[57]

The vast majority of authors who are working on the justification of deliberative democracy either rely on one of these two modes of justification or employ a combination of them.[58] It is plausible to say that the dominance of epistemic and procedural strategies reflects their strength as arguments. In light of this dominance, the main aim of this chapter is to adjudicate between epistemic and procedural justifications for a deliberative democratic approach to clinical care resource allocation.

However, in this section I quickly analyse and reject a third mode of justification, which is centred on the idea of *virtue*. The most serious problem that affects this mode of justification also plays a role in clarifying the structure and appeal of the justification that I favour, which is explored in section 2.3. Therefore, it makes sense to outline why a virtue-based approach to deliberative democracy is untenable, although some of the issues involved are so complex that a thorough analysis falls outside the scope of my work.

Like epistemic arguments, virtue-based justifications value deliberative democratic procedures instrumentally. What distinguishes them is their focus on the effects that deliberative democracy has on the character of its society members. Indeed, the supporters of virtue-based justifications believe that deliberative democracy is valuable because it promotes good ways of life and thought, both within and outside the political process.

Compared to other forms of government, democracy allows a greater number of persons to have an impact on political decisions. Moreover, citizens in a deliberative democracy are called upon to assess the arguments

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[57] List and Goodin (2001, 277).

[58] Among others, Anderson (2006) and Bohman (2006) propose epistemic arguments, while J. Cohen (1989), Rawls (1996) and Richardson (2002) fall in the procedural camp. Christiano (2008a), Estlund (2008) and Peter (2008) favour a mixed approach.

offered by others. In this context, individuals will develop the habit of thinking more carefully about the choices that they face. According to the supporters of virtue-based justifications, this habit is valuable because it is conducive to the development of a person's ability for sharp and independent judgement. Ultimately, the value of deliberative democracy lies in its capacity to create persons that are willing to call important ideas into question and assess the value of such ideas for themselves, with regard to politics as well as any other area of life.[59]

Virtue-based justifications clash with *the fact of reasonable pluralism*, which is acknowledged in one form or another by most political theorists, especially in the liberal camp. Historically, the more a society protects freedom of thought, the greater the pluralism of comprehensive doctrines, which are doctrines addressing moral, religious and philosophical questions. This fact suggests that the pluralism of comprehensive doctrines is the inevitable product of the exercise of human reason. One influential explanation of the link between human reason and pluralism draws on the notion of burdens of judgement: the evidence bearing on the question under discussion is often complex and difficult to assess; different considerations may hold on both sides of an issue; the weight that should be given to considerations that everybody accepts as relevant may produce disagreement; the concepts we use are vague and to a good extent shaped by our total experience.[60]

I argue that the alleged virtues employed in the context of the justification of deliberative democracy are object of reasonable disagreement. Consider the willingness to think through important matters

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[59] The view that democracy and deliberation are valuable because of their effects on the virtue of citizens is advanced by Mill (1991, 55–80) and (2003, 75–119). For the virtue-based approach to the justification of democracy, see also Christiano (2008b).

[60] Most of the concepts that I use to discuss reasonable pluralism are borrowed from Rawls (1996). For another influential account of reasonable pluralism, see Larmore (1996).

for oneself and exercise critical judgement. As highlighted by John Rawls, many religious persons in our societies disregard these character traits.[61] They may want to ground their opinions in their sacred books or the relevant religious hierarchy, and this disposition does not seem to place them beyond reasonableness. Indeed, they may simply value humility above all other character traits and take any strong ideal of independence to be a Promethean dream. Given the fact of reasonable pluralism, we are left with no tools to choose between incompatible accounts of virtue all of which are the product of human reason. Thus, virtue-based approaches to the justification of democracy emerge as inadequate.

Before turning to epistemic and procedural accounts of justification, I wish to consider an objection to the idea of reasonable pluralism and add a note on the residual role of virtues in deliberative democracy. I go back to reasonable pluralism is section 2.3, where the appeal and structure of my justification of deliberative democracy are explored. Given the link between reasonable pluralism and my own proposal, it is interesting to mention one possible response to my objection to virtue-based justifications of democracy. This response questions the extent to which the pluralism characterising our societies is reasonable.

Communitarian authors like Alasdair MacIntyre and Charles Taylor claim that our societies possess the necessary intellectual resources to solve many comprehensive disagreements that liberals would label as the product of free human reason. According to them, there are several ways in which a comprehensive doctrine can be shown to be more reasonable than its competitors. To start with, a doctrine may be capable of solving a difficulty of another in a way that the latter is compelled to accept.[62] Furthermore, it may be the case that a doctrine cannot possibly explain the success of

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[61] Rawls (1997, 778).

[62] MacIntyre (1988, especially 349–369).

another.[63] The transition from pre-modern to modern science is used to illustrate both strategies. Galileo demonstrated that the Copernican approach to astronomy could account for a number of observations that the Ptolemaic model could not explain. The fact that the Ptolemaic and Copernican models shared an appeal to the facts of the world made the acceptance of the Copernican approach required by the very standards governing the Ptolemaic tradition. Furthermore, the anti-mechanistic character of pre-modern science implied that human beings can only have a non-systematic manipulative understanding of nature. The fact that modern science allows us to extensively manipulate the natural world showed that every reasonable person should abandon the pre-modern doctrine. Finally, comprehensive doctrines may rest on implicit premises that their own proponents are not willing to accept. For example, Taylor discusses the case of a teenager who misbehaves because of a confused sense of deserving differential treatment by virtue of his being the eldest brother. Once this premise is made explicit, the teenager should decide to change his behaviour.[64]

I argue that all these strategies greatly downplay the differences between, on the one hand, science and family affairs and, on the other hand, virtue and other value issues as discussed in society at large. And my argument, both here and in section 2.3, is essentially about reasonable disagreement over the values that should govern political institutions. Taking the place of independence in a virtuous life as an example, there is nothing comparable to the observation of the natural world that can serve as a common ground capable of solving disagreement. When it comes to established doctrines that discuss virtue and other value considerations, pluralism appears to come down to different basic commitments that leave no space for common

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[63] Taylor (1993, 217–223).
[64] Taylor (1993, 223-225).

standards capable of pointing out a winner.[65]

If the idea of common standards is of little use, the notion of success does not fare better. If we define success by how widespread a doctrine is, one can always answer that value considerations are concerned with how we should live, and the way in which most persons live is irrelevant. Alternatively, success could be measured by how happy and fulfilled the followers of a certain doctrine feel. Once again, this strategy would miss its target because some comprehensive doctrines consider feelings of happiness and fulfilment as irrelevant to the analysis of value issues. Finally, the attempt to solve disagreement by bringing unacceptable assumptions to light is equally untenable. For example, if such disastrous assumptions had been at the basis of a Millian or a Catholic perspective on virtue, it is plausible to assume that they would have already been discovered by the centuries-long debate over the relative merits of the two positions.

At this point, it is natural to ask whether my case against virtue-based approaches to the *justification* of deliberative democracy implies that the idea of virtue should not play *any role* in a conception of deliberative democracy. My response is that while I have levelled criticism at the notion that virtues constitute the ultimate aims that are meant to justify deliberative democracy, it is possible for the idea of virtue to have different functions in a theory of deliberative democracy. Hence, there is still room to claim that certain virtues are constitutive of the way in which deliberative democracy works in pursuit of ultimate aims that are different from personal independence and any other character trait.

For example, section 2.3 aims to demonstrate that the use of public reason is required by my procedural justification for deliberative democracy, which stresses the ability of deliberative democratic procedures to express

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[65] Porter (2003, 53–56).

equal respect for individuals and, more specifically, their ability to make decisions in the light of their own intelligence. Public reason, which requires that individuals be willing to ground political decisions in rationales that all can accept, effectively constitutes a virtue of civility. Now, my acceptance of public reason as a constitutive element in the workings of deliberative democracy is consistent with my rejection of virtue-based approaches to justification because public reason is not nearly as controversial among reasonable persons as the character traits that populate virtue-based justifications. The willingness to call all important ideas into question and to then exercise critical judgement is highly controversial because it contradicts certain elements that lie at the core of widespread conceptions of the good life. In contrast, public reason is *a political virtue*, which only applies to the political sphere and embodies values that are compatible with all sorts of comprehensive doctrines. As I intend to explain in full detail in section 2.3, those values are equal respect and a political conception of autonomy that is much thinner than the idea of personal independence embraced by the proponents of the virtue-based justification of deliberative democracy.

2.2. A poor fit: the epistemic powers of deliberative democracy and concrete policy fields

The aim of this section is to demonstrate that epistemic justifications do not provide a solid case for deliberative democracy in clinical care resource allocation. The idea behind the epistemic mode of justification is that deliberative democratic procedures are likely to produce decisions that are right according to a standard that is independent from the procedures themselves. Two broad arguments are advanced in support of the epistemic powers of democratic deliberation. One of them relies on the work of Nicolas de Condorcet or, more specifically, the so-called “jury theorem”. The jury theorem demonstrates that if voters vote on the basis of what they believe to be the right decision, vote independently of one another and have an average probability of getting the right answer that is greater than 0.5, the more the number of voters increases, the more the probability that the majority vote will yield the right decision approximates 1.[66]

As for the second broad argument, its roots can be found in John Dewey’s work on democracy and social intelligence. A key assumption of all Deweyan approaches is that the intelligence relevant to solving political problems is generally dispersed throughout society. Individuals are all different and come from disparate walks of life. Depending on the political issue under discussion, varying individuals will have the best insights into the problem and its solutions. Therefore, inclusive procedures and sustained deliberation are needed to pool the dispersed intelligence of society in order to identify the best solutions to the most urgent problems.[67]

The epistemic mode of justification can be criticised by questioning the place of independent standards of rightness in the justification of political decision-making procedures. It is argued that the vast majority of political issues, and certainly the most difficult ones, involve a clash of values that, although perfectly valid if taken individually, cannot be satisfied together. Under these circumstances, speaking in terms of right decisions independently of the process for handling the plurality of relevant considerations seems like a stretch. The best we can do is to identify the decision-making procedures that allow us to navigate disagreement in a way

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[66] J. Cohen (1986) and Estlund (1997) employed the jury theorem before turning to different justifications in later works. See also Gaus (1997a).

[67] Anderson (2006), Bohman (2006) and Honneth (1998). Estlund (2008, 159-183) puts forward an argument that follows this structure, although he draws on the work of Joseph Schumpeter.

that is respectful towards all parties.[68] Furthermore, even if we accepted that it is plausible to speak of procedure-independent right decisions, one might question whether epistemic models are not missing the whole point of deliberative democracy. Does the fierce opposition aroused by non-democratic governments really boil down to the sense that an opportunity is lost to more effectively track the right decisions? Many feel that the problem with non-democratic forms of government is rooted in the total lack of respect towards those who are not allowed to participate in decision-making.[69]

To build a fully-developed criticism out of these two considerations would be a lengthy and difficult enterprise. Thus, I do not intend to take any stance on them. My rejection of the epistemic mode of justification rests on a further argument, which questions the epistemic powers of the public in fields like clinical care resource allocation. Some critics of the epistemic approach claim that, even if we grant that procedure-independent right decisions exist, democratic procedures are ill-suited to track them. It is claimed that the members of the public are easily manipulable and poorly informed. Furthermore, their reasoning abilities are plagued by biases that violate the most basic principles of rationality.[70] My case against the epistemic mode of justification draws on some elements of this classic criticism, but it adds a twist of its own.

Being focused on clinical care resource allocation, my thesis is concerned with *a concrete policy field*, not with the discussion of constitutional essentials or other general political issues. In a concrete policy field like clinical care resource allocation, sensible decisions must generally take into

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[68] Miller (1992, 56–57).

[69] J. Cohen (2009a, 5–8).

[70] For example, see Richardson (2002, 77-78) and his idea that epistemic arguments provide a “rickety” means of support, together with the response provided by Estlund (2005).

account *a great deal of scientific information*. Consider some of the decisions that a resource allocation agency has to make in the face of a new drug. Should the drug be funded? If so, which populations or sub-populations of patients should receive it, and under which circumstances? Granting that procedure-independent right decisions exist, right decisions in the face of such questions entail right decisions about a number of tough scientific issues. Decision-makers need to establish whether the drug works and how effective it is compared to available alternatives. Hence, relevant clinical trials need to be identified. Furthermore, the robustness of relevant trials needs to be analysed. To mention two more issues, decision-makers need to investigate how the drug would fit into routine clinical practice and how much it would cost to provide a course of treatment.

Those who ground the epistemic powers of democracy in the jury theorem are the first victims of my argument. Regarded by some as dubious in most circumstances, the assumption that single members of the public have *an average of greater-than-0.5 probability of being right* becomes totally implausible if pharmaceutical, clinical and economic matters are to be taken into account.[71] The supporters of the jury theorem cannot even defend their position by claiming that the members of the public should talk among themselves and with the relevant experts to improve their probability of being right. This is because the jury theorem assumes that decision-makers make their decisions independently of one another. Indeed, the jury theorem seems to sit rather uncomfortably with the deliberative dimension of democratic decision-making.[72]

If the jury theorem loses its force when applied to clinical care resource allocation, the Deweyan approach does not fare much better. The

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[71] For the idea that the assumption at the basis of the jury theorem is dubious in most circumstances, see Estlund (2008, 223-236).

[72] Anderson (2006, 10-12).

intelligence relevant to the scientific issues that we have been discussing is *not dispersed*. For example, there is no need for decision-making procedures that pool persons from all walks of life in order to tell which clinical trials are relevant and well designed. Inevitably, any procedure of that kind would end up pooling a great deal of ignorance about clinical research as well as biases that notoriously affect our attempts to think about large numbers and probabilities.[73] In sum, the ability to examine clinical effectiveness, clinical practice, costs and many other matters appears to be concentrated within specific expert communities. And those matters make up an important part of the decisions concerning clinical care resource allocation. Consequently, in a concrete field like clinical care resource allocation, the Deweyan approach fails to provide a convincing account of the ability of deliberative democracy to track the right decisions.

Before concluding, it is worth considering an objection that a supporter of the Deweyan approach may raise. It is not true, it may be said, that the intelligence relevant to scientific issues is not dispersed. Although lying outside traditional communities of expertise, patients and carers have a direct knowledge of the illnesses and treatments they have experienced. Their insight is crucial in tracking the right decisions, and this is why deliberative democratic procedures are justified on an epistemic basis even in a concrete field like clinical care resource allocation.[74] Important real-world resource allocation agencies seem to side with this objection to my argument. For example, consider NICE, which I introduced in section 1.1. Placed at arm's length from the Department of Health, NICE is a British

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[73] Within cognitive psychology, the literature on heuristics and biases is enormous. Kahneman (2011) and Thaler and Sunstein (2008) try to summarise some of its most important findings.

[74] This objection echoes arguments offered by science and technology studies scholars in fields like nuclear policy. For example, Funtowicz and Ravetz (1993) and Wynne (1996) claim that farmers and other subjects directly affected by an environmental problem may provide valuable insights that scientific experts cannot offer.

agency that is widely discussed for its legally binding recommendations concerning the funding of health technologies. At the beginning of the health technology appraisal process, NICE identifies a number of relevant patient and carer groups. Then, these groups are invited to contribute to the discussion of clinical effectiveness and other dimensions of decision-making.[75]

I do not intend to deny that patient and carer groups have a role to play in contributing evidence in the context of clinical care resource allocation.[76] Still, this objection cannot possibly rescue the epistemic case for a deliberative democratic approach to clinical care resource allocation. An epistemic argument able to support decision-making procedures that are really democratic would need to go much further. Specifically, it should show that the relevant intelligence is dispersed to such an extent that universal suffrage, universal right to be elected, appointment by lot or another authentically democratic procedure is needed to pool it. Restricting the focus to patient and carer groups relevant to the issue at hand, this objection may certainly serve as a reminder that the designers of clinical care resource allocation procedures should look beyond traditional expert communities. However, the relevant intelligence remains concentrated in a few identifiable places, falling short of providing an epistemic case for procedures that are authentically democratic.

In this section, I have demonstrated that, as far as clinical care resource allocation is concerned, the epistemic justifications of deliberative democracy are untenable.[77] This result is important because it opens the way

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[75] NICE (2013a).

[76] I expand on this point in section 10.2.

[77] A critic might object that it is unclear whether my argument succeeds in refuting the epistemic component of the mixed justification proposed by Peter (2008). Peter's "epistemic proceduralism" is different from both variants of the epistemic mode of justification. Indeed, the idea is not that deliberative democratic procedures track procedure-independent right decisions. Peter argues that basic elements of deliberative

for my procedural case for deliberative democracy, which is put forth in the next section.

Furthermore, my analysis has shown that clinical care resource allocation needs to incorporate a great deal of information which falls within the remit of scientific disciplines. Even if we abandon the epistemic perspective on deliberative democracy, there are strong reasons to attempt to find a way to tap into the relevant communities of expertise when clinical care resources are allocated. Still, this project is not without dangers. Chapters 9 and 10 refer back to these issues, exploring how scientific experts can contribute to the decision-making process in a way that is consistent with the ideal of deliberative democracy.

2.3. The case from equal respect and autonomy in the face of coercive power

This section aims to put forward a procedural case for deliberative democracy in clinical care resource allocation. The idea at the basis of the procedural mode of justification is that deliberative democracy expresses and implements intrinsic values of fundamental importance. Specifically,

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democracy such as diversity of perspectives, equal consideration and responsiveness to criticism make up a procedure of construction whose outcomes are epistemically valuable precisely because they are the product of that procedure. In other words, deliberative democratic procedures transfer their epistemic value to outcomes. I argue that with regard to a concrete policy field such as clinical care resource allocation, Peter's argument fails for reasons analogous to those employed against the jury theorem and the Deweyan approach. Many issues that fall within the remit of scientific disciplines are relevant to clinical care resource allocation. In this context, deliberative democratic elements such as diversity of perspectives, equal consideration and responsiveness to criticism do not construct epistemically valuable outcomes – those elements are likely to pool ignorance and dilute the valuable contributions of experts. Interestingly, my argument appears to be in line with Peter's recent analysis of the “circumstances” of an epistemic conception of deliberative democracy. Peter (2014) states that her epistemic-procedural case for deliberative democracy is strong when the issues under discussion are wide-ranging and relevant information is dispersed – these conditions are rarely met in a field such as clinical care resource allocation.

my argument is centred on equal respect and autonomy in the face of coercive power. While answering two objections, this section also starts to specify two general requirements of a deliberative democratic approach to clinical care resource allocation, i.e. public reason and public involvement.

The starting point of my argument is the fact of *coercive power*. Political decisions are backed by force and citizens have no real choice but to obey them. Coercion creates a burden to legitimate state actions. Subsequently, coercive power simply cannot be exercised in any way decision-makers may wish.

How should coercive power be exercised to be legitimate? The most basic principle is that individuals are to be treated as equals: no one must be treated as a mere means to the ends of others. More specifically, decision-making procedures must express and implement a principle of *equal respect* that is based on the *autonomy of individuals*. By autonomy I mean that each person is capable of reflecting upon what she should do and direct herself in the light of her intelligence. In Henry Richardson's words, it is the distinctive ability of persons to "make up their minds" on the basis of reasons that commands our respect.[78]

At this point, a critic might ask whether I could offer any consideration in support of the idea that equal respect should serve as the most fundamental principle of political legitimacy. My twofold answer draws on the influential analysis of equal respect proposed by Charles Larmore.

First, equal respect is exceptional in that it is compatible with a wide variety of comprehensive doctrines that address moral, religious and philosophical questions. Moreover, equal respect has effectively won the allegiance of the followers of an extremely broad range of comprehensive doctrines. Of course, this is not to say that there has always been a universal

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[78] Richardson (2002, 62).

acceptance of the idea of equal respect. Still, the appeal of this idea is so strong that it gained some traction even at times when societies were built on norms that flatly contradicted basic requirements of equal respect. As pointed out by Larmore, "the belief that some particular hereditary class produces those most fit to rule does not exclude equal respect, for one could feel obliged (as some such aristocrats were) to justify this belief to the other classes".[79] Turning to modern-day societies, most of us accept the idea that all persons deserve equal respect, regardless of what other moral, religious and philosophical principles we may endorse.[80] The level of consensus enjoyed by equal respect in our societies is particularly important because such consensus has emerged under conditions of considerable freedom of thought. As explained in section 2.1, the more a society protects freedom of thought, the stronger the tendency towards disagreement. Thus, the fact that the idea of equal respect has been able to defy a strong tendency towards disagreement suggests that this idea has great value.[81]

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[79] Larmore (1987, 66).

[80] While discussing contemporary political theory, Dworkin (1983) and Kymlicka (1990, 3–4) speak of an "egalitarian plateau" from which all major positions operate.

[81] The widespread support for equal respect demonstrates that my procedural case for deliberative democracy is not open to the criticism that I have levelled against virtue-based modes of justification. In fact, my case for deliberative democracy does not hinge upon any specific answer to highly divisive issues, such as whether human excellence involves personal independence. This holds true despite the fact that at first glance, the notion of autonomy that forms the basis of my idea of equal respect may seem similar to the idea of personal independence espoused by the proponents of virtue-based justifications. The idea of personal independence used by virtue-based justifications is a fully-fledged conception of the good life, which requires that individuals should call into question all important ideas and think through such ideas for themselves. Drawing on the analysis of autonomy proposed by Rawls (1997, 778), it is fair to say that this idea of personal independence constitutes a "purely moral" understanding of autonomy because it is rejected by many comprehensive doctrines, religious or otherwise, that fall within the realm of reasonableness. In contrast, my idea of autonomy is very thin; it is limited to stressing the ability of persons to direct themselves in the light of their own intelligence, without saying anything about the way in which intelligence should be used (by trusting only one's own judgement or, alternatively, by relying on one's sacred books, culture and the like). Far from providing a conception of the good life, my idea of autonomy is mainly relevant to the political process, where coercion poses a threat to it. Closely related to the Rawlsian idea that persons should share equally in the exercise of political power, the notion of autonomy that forms the basis of my idea of equal respect represents what Rawls calls a "political"

Second, Larmore uses the work of Jürgen Habermas to point out that equal respect is presupposed by linguistic practices that we all adopt and lie at the basis of our way of reflecting and talking about politics. The focus is on practices that are as basic as thinking that we have good reasons to believe that a political problem should be solved in a certain way. According to Larmore, these practices already imply that in an ideal conversation, we could vindicate our belief to others and win everyone's assent through our good reasoning. In turn, this commitment to everyone’s reasoned assent appears to imply that we are all devoted to equal respect, at least implicitly. Consequently, there is room to argue that equal respect should be placed at the basis of any account of how political decisions should be made, vindicating my choice of equal respect as the most fundamental principle of political legitimacy.[82]

Once we accept that persons are to be respected as equals who are capable of directing themselves in the light of reasons, it follows that political power can only be the power of all citizens taken as a collective body. However, to accept that every person bears an equal share of political power is not enough. The concepts of coercive power and equal respect for the autonomy of single individuals are still in tension; given that single citizens may be coerced into obedience if they do not agree with the majority, how can individuals retain their ability to direct themselves in the light of their own intelligence?

In brief, binding decisions must result from a process that ensures that everyone who is subject to the ensuing decisions can be regarded as having imposed these decisions on themselves. In this way, the principle of equal respect for the autonomy of single individuals is upheld in spite of coercion. As Jean-Jacques Rousseau puts it, the idea is that “obedience to a law one

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value, which is consistent with a wide variety of comprehensive doctrines.

[82] Larmore (1987, 55-59).

prescribes to oneself is liberty".[83] The main task for the remainder of this section is to demonstrate that deliberative democracy is the regime under which persons can be said to impose binding decisions on themselves. Before turning to that task, however, a further comment is in order.

This argument applies to the specific policy field my thesis is concerned with. The coercive power of the state reaches as far as clinical care resource allocation. Hence, decision-making procedures should embody equal respect for the autonomy of those who are subject to clinical care resource allocation decisions. The connection between political power and clinical care resource allocation is most clear where clinical care is funded through taxation and resources are allocated by public agencies. However, the burden of legitimation also applies where private or mixed clinical care systems are in place. Most notably, the decision of whether and to what extent the provision of clinical care should be left to the market is quintessentially a political one. Therefore, it should be set through a process embodying equal respect for the autonomy of individuals.

So far, I have not yet defended the idea that deliberative democracy is needed to implement the principle that decision-making procedures should be organised in such a way that all individuals can be regarded as imposing decisions on themselves. I will now address this issue, discussing the deliberative element before focusing on democracy.

Procedural justifications of deliberative democracy that start from principles like equal respect and autonomy are often associated to the ideal of *public reason*, which I am willing to endorse.[84] Public reason requires that political decisions should be grounded in rationales that all reasonable persons might be expected to accept. How this ideal follows from my

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[83] Rousseau (1968, 65). Overall, my argument owes much to the justifications of deliberative democracy offered by Cohen (1989), Rawls (1996) and Richardson (2002).

[84] Cohen (1989) and Rawls (1996).

procedural justification should be straightforward: if binding decisions were grounded in reasons that everyone is willing to accept, the autonomy of all the individuals who are subject to those decisions would be safe. Indeed, everyone would only be coerced into actions which they acknowledge they should perform.

With public reason we have come to the justification of the deliberative component of deliberative democracy. In fact, public reason requires that decision-makers should abandon the pursuit of sectional interests. Decision-makers should also be ready to change their mind if other participants come up with a different but compelling rationale centred on the common good, which is to be understood as those principles all reasonable individuals might be expected to accept.

Public reason is set to play an important role in my thesis. However, public reason is affected by a two-fold difficulty, which makes it seem like a non-starter. While addressing this difficulty, I specify a viable conception of public reason beyond the general definition provided in the previous paragraphs. First, the problem with public reason is that, as far as political debates are concerned, there is hardly ever any given reason that everyone will be willing to accept. This consideration brings us back to the fact of reasonable pluralism. Indeed, our societies are characterised by pluralism well beyond the controversies over what counts as a virtue, which are discussed in section 2.1. It is hard to imagine any political debate in which the majority is able to come up with a rationale that is accepted by everyone. To bring my discussion to bear on the main topic of my thesis, chapter 1 offered a glimpse of how divisive the issues surrounding clinical care resource allocation may be. Therefore, it is wishful thinking to believe that actual consensus can be achieved on how clinical care resources should be rationed.

Second, we have seen that public reason is intended to satisfy an ideal of autonomy as self-rule on the basis of reasons. Unfortunately, the few instances of consensus (or near consensus) that can be identified in our societies are often affected by pathologies that make them inconsistent with any principle of reasoned rule. Actual consensus may be the product of widespread bias. For example, individuals find cancer particularly dreadful and are generally willing to give cancer treatment an importance that does not take into proper consideration the impact of cancer on mortality, morbidity and any other objective factor. Alternatively, there may be consensus on the relevance of considerations that a closer analysis would rule out as violating commitments that are kept in the highest esteem by public reason. Most notably, I intend to argue that this is the case of cost effectiveness.[85]

This two-fold difficulty leads some to conclude that public reason is unfeasible.[86] I argue that this conclusion is misguided. One cannot attack public reason on the basis of the rarity and pathologies of *actual* consensus because much of the appeal of public reason lies precisely in the fact that public reason concerns *hypothetical* consensus.[87] Therefore, the feasibility of public reason does not depend on the assumption that decision-makers must be able to rely on non-pathological spaces of actual consensus.

The shift to hypothetical consensus is rooted in the distinction between *reasonable* and *unreasonable* persons. The general definition of public reason that I proposed a few paragraphs earlier states that the provision of reasons is due only to reasonable persons. However, I have not yet explained what exactly is meant by reasonableness. By definition, when the arrangements to be enforced by political institutions are being discussed,

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[85] The two examples are further explored in sections 6.4 and 6.1, respectively.

[86] Christiano (1997) and Gaus (1997b).

[87] For example, see the survey article written by Chambers (2010). In this context, both Quong (2013) and Vallier and D'Agostino (2014) speak of "idealisation".

reasonable persons are willing to propose terms of cooperation that are acceptable to all. By refusing to propose terms of cooperation that all can accept, unreasonable persons pull out of the project to uphold autonomy in the face of coercive power. Thus, public reason is justified in disregarding their perspectives.

Reasonableness is a normative standard. No one engaged in the process of reason giving can ever be sure that any real-world audience is entirely made up of reasonable persons. Therefore, decision-makers should strive to identify the arguments that all persons might be expected to accept if everyone were reasonable, highlighting the hypothetical dimension built into public reason. Also, the hypothetical dimension of public reason contains another element. Given that public reason is grounded in an ideal of autonomy as reasoned self-rule, public reasons do not need to be acceptable to persons who fall short of *good reasoning*. Roughly speaking, public reasons are reasons all might be expected to accept if no one was confused or made logical mistakes.[88]

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[88] Echoing the critique of hypothetical contractualism offered by Dworkin (1975), it might be objected that the search for consensus among *hypothetical persons* cannot possibly show respect to the autonomy of those *actual persons* who are subject to coercive power. Indeed, it is unclear whether there is a valid connection between the assent of hypothetical persons and that of their actual counterparts. My response is that in the case of public reason, the link between hypothetical and actual persons is closer than it might seem. Public reason creates its audience of hypothetical persons based on the actual persons who are subject to political decisions; it idealises them by eliminating such features as unreasonableness and confusion, if they are present. What is left at the end of this process is still *a part of each of the actual persons that public reason started with*. Therefore, to search for consensus among hypothetical persons equates to seeking the consent of a laundered version of each actual person, which demonstrates respect for those who are actually subject to coercive power. Of course, I still have to explain why public reason needs to adopt this seemingly unnatural focus on only a limited part of actual persons. We have seen that if binding decisions are grounded in rationales that a person is willing to accept, her autonomy is preserved. Now, it is extremely unlikely that political decision-makers can regard any decision and its supporting rationales as well-suited to establish consensus among a large number of persons if unreasonableness, confusion and logical mistakes are allowed to interfere. In sum, given that deliberative democracy is concerned with the *autonomy of all*, it must posit that the provision of acceptable reasons is due to *a laundered version of everyone*. Furthermore, the principles that deliberative democracy is ultimately meant to implement permit the disregard of the features of actual persons that are idealised away by

It is worth mentioning one more point about the sense in which public reason is an ideal of consensus. Even if we were sure about the reasonableness and reasoning abilities of our audience, the burdens of judgement mentioned in section 2.1 would still apply. Hence, it could still be the case that the members of our audience disagree with one another. While discussing a political issue, what looks to one reasonable person as the argument that everyone else should accept as the most compelling may not look so to another. In sum, not only does public reason trade in hypothetical consensus, it may also fall short of what is called "strong consensus", i.e. the state in which all participants, hypothetical or otherwise, recognise the same line of reasoning as the one that should be used to settle a certain issue.[89.]

Properly understood, public reason consists in the provision of rationales that draw on a pool of commitments and considerations that all reasonable persons share. By definition, reasonable persons are committed to the equality of all persons and to the idea that society is meant to serve the interests of every member. Moreover, reasonable persons share a number of other commitments and considerations – for example, section 4.3 aims to argue that when it comes to clinical care resource allocation, reasonable persons should be committed to the minimisation of the strongest complaint and the compartmentalisation of different areas of government activity.

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public reason. Deliberative democracy is not meant to show respect for the ability of persons to simply give consent to courses of action. Indeed, deliberative democracy is supposed to show respect for the autonomy of individuals, which is the ability to consent to courses of actions *in the light of one's intelligence*. Therefore, public reason is allowed to disregard sources of disagreement that stem from bad reasoning, as they imply a failure to use one's intelligence. More specifically, deliberative democracy is meant to implement *equal* respect for the autonomy *of all*. Those who behave unreasonably pull out of the project to show equal respect for the autonomy of all because they are willing to propose terms of cooperation that are unacceptable by some. In light of its most fundamental principles, public reason is therefore allowed to idealise away any instance of unreasonableness.

[89] Quong (2011, 261–265).

Public reason requires that each decision-maker strives to identify rationales that are as robust as possible and rooted in commitments and considerations that reasonable persons share – in other words, rationales that seem to be best suited for establishing strong consensus. Still, it is worth keeping in mind that strong consensus on those rationales is not guaranteed, not even in a hypothetical society populated by reasonable persons.

The distinction between actual and hypothetical consensus constitutes the core of my response to the two-fold difficulty I described above. Before changing topic, however, it is worth discussing the possibility of limited spaces of actual consensus and the role of majority rule, in order to clarify how the search for hypothetical consensus should work in practice. Although acknowledging that actual consensus on the whole rationale supporting political decisions is extremely unlikely, some claim that political debates are often characterised by actual consensus on some aspects of the rationale in question. For example, there may be consensus on the list of values relevant to a certain issue, although accompanied by disagreement over their order of priority.[90] More importantly for the sake of my overall argument, there are cases in which incompletely theorised agreement occurs. In other words, individuals may agree on concrete judgements about political issues even though they disagree over abstract foundations or are not interested in more abstract claims.[91]

From the perspective of public reason, it is sensible to start from the limited spaces of consensus that may characterise actual debates. If spaces of actual consensus have emerged in our pluralistic societies, it may be because they are grounded in reasons capable of curbing the tendency towards disagreement and able to win the consensus of reasonable persons.

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[90] Christiano (1997, 266-271).

[91] Sunstein (1995). The notion of incompletely theorised agreement is linked to the so-called "convergence" view of public reason, adopted, among others, by Gaus (2011).

Thus, it makes sense to take limited spaces of actual consensus as a starting point and investigate whether they are backed by solid public reasons. In section 5.2, I start from the widespread idea that clinical care is special and show that it is supported by excellent public reasons. However, investigations must be thorough, because actual consensus may well be pathological, i.e., rooted in bias or considerations inconsistent with public reason. As anticipated, I aim to demonstrate that this is the case when it comes to cost effectiveness and the dread of cancer.

Now consider majority rule. A deliberative democratic approach to decision-making requires that, in due course, majority rule is employed to reach a decision if actual consensus is not forthcoming. Some would object that the advocates of a procedural approach to deliberative democracy can provide no justification supporting the use of majority rule as a closure device.[92] This objection is ill-conceived: as pointed out by Jeremy Waldron, majority rule constitutes the best way to show equal respect for persons when decisions have to be made under conditions of disagreement. First, majority rule respects the wish of everyone to influence the political process. Indeed, no one is asked to leave their opinions aside in the interest of reaching unanimity. Second, majority rule gives the greatest possible weight to the views of each participant. Here the idea seems to be that, under majority rule, there is always the possibility that each vote will be decisive and make the balance tilt one way or the other.[93]

So far, I have demonstrated that a procedural justification resting on equal respect for autonomous individuals provides compelling reasons for a deliberative approach to clinical care resource allocation. However, it is yet to be demonstrated that a commitment to democracy follows from my argument. Public reason seems compatible with government by an elite or

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[92] Christiano (1997, 271-274).

[93] Waldron (1999, 88–118).

even a philosopher-king, provided that they commit themselves to the search for reasons all reasonable citizens can accept.[94]

My idea is not that public reason requires that the public or its representatives should be involved in making decisions.[95] Rather, public reason and public involvement provide *complementary* answers to the need for a decision-making process through which all reasonable citizens come to impose binding decisions on themselves. The intuitive argument to this effect is that, if the point of fair procedures is to honour the autonomy of citizens in the face of coercive power, citizens must be involved in the exercise of such power. In other words, no one can be said to have imposed binding decisions on themselves to the greatest extent possible if they did not have any chance to participate in the decision-making process.

This intuitive argument can be refined by going back to the limits of any viable conception of public reason. No viable conception of public reason can aim at actual consensus among decision-makers, let alone between decision-makers and the public at large. Moreover, not even a discussion between perfectly reasonable persons would be safe from the burdens of judgement. Thus, even if we lived in a society entirely made up of reasonable persons who are in full possession of their reasoning abilities, it would still be possible that some disagreed with a decision or its supporting rationales. This is not to deny that public reason is a precious means to express and implement equal respect for the autonomy of individuals. Regardless of who makes decisions, a commitment to public reason is needed for decision-makers to do all that is in their power to honour the autonomy of their fellow citizens. What I wish to suggest is that public involvement is needed to overcome the limits of public reason and in order to foster autonomy even further.

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[94] For a similar observation, see Machin (2009).

[95] This strategy is adopted by Estlund (2008, 206-222).

If a political decision is made on the sole basis of public reason, that decision is grounded in commitments and considerations that all reasonable persons share. Nonetheless, some reasonable persons may believe that the commitments and considerations that reasonable persons share lend stronger support to a different decision, or that the same decision could have been given a more solid rationale. After the decision is made, some reasonable persons may therefore be coerced into obeying a decision that, to a certain point, they disagree with. Therefore, as far as part of the decision is concerned, those reasonable persons could claim that public reason did not uphold their autonomy. An additional means of expressing and implementing the autonomy of individuals is needed, which can operate beyond the limits of public reason. Thus, the public or its representatives should be involved in the process through which certain public reasons are chosen over alternative combinations. Under conditions of reasonable pluralism, public involvement is needed to satisfy to the greatest extent possible the principle that all individuals should be allowed to impose binding decisions on themselves.

2.4. Against Daniels's justification of fair procedures

In the previous section, I put forward a procedural case for deliberative democracy. In one important sense, my account of the value of deliberative democracy and Norman Daniels's conception of accountability for reasonableness (AFR) are rather similar. Daniels proposes publicity, relevance, revision and regulation as principles that should govern clinical care resource allocation procedures. According to Daniels, the procedures following AFR deal with disagreement over substantive considerations in a manner that is fair to everyone.[96] Analogously, public reason, public involvement and the other general requirements that I aim to discuss in chapter 3 make up my own account of fair procedures in the face of reasonable pluralism. Going back to the divide between procedural and epistemic justifications of decision-making procedures, both Daniels and I care about procedural arrangements that lead to fair, but not right, decisions. However, given that Daniels's conception of fairness in clinical care resource allocation is hugely influential, it is important to point out that my case for deliberative democracy marks an important difference from AFR.

Daniels and I offer different justifications for fair procedures. In section 1.1, we saw that Daniels thinks of procedural fairness as some sort of *remedial* value. He turned to AFR when he realised that philosophical reflection is not fine-grained enough to solve the conflicts among the numerous substantive values relevant to clinical care resource allocation. Daniels's assumption seems to be that, if philosophy had been able to solve those conflicts, what clinical care resource allocation agencies should have done is follow the substantive conclusions of philosophical reflection.[97]

This assumption is inconsistent with the argument that I developed in section 2.3. Fair decision-making procedures are required by an intrinsic value of fundamental importance, which is equal respect for the autonomy of individuals in the face of coercive power. Thus, there is no room to argue that the philosophical analysis of substantive questions should be tried first and an account of fair procedures should enter the picture only if philosophers fail. Deliberative democracy must be the first option.[98]

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[96] Daniels (2008, 117-133).

[97] Daniels (2008, 103-110). In section 1.1, I described Daniels's argument in greater detail. Furthermore, I discussed how influential this kind of argument is.

[98] A supporter of AFR could respond by expanding on an argument that, proposed by Machin (2009), was already mentioned in section 2.3. It could be argued that at no stage did Daniels disregard the intrinsic value of fundamental importance upon which procedural fairness rests. When he attempted a philosophical analysis of the substance of clinical care

The remarks that I have just offered already reveal the inadequacy of Daniels's case for fair procedures. However, there is more to be said in support of my justificatory strategy and against Daniels's argument. This second set of remarks draws on arguments that I plan to develop throughout the thesis, especially in chapters 5, 6 and 7. Accordingly, I now outline how conclusions that are reached in later chapters can be used to direct another criticism at Daniels's justification for AFR.

We have seen that seemingly intractable conflicts between substantive values are at the basis of Daniels’s case for fair procedures. Section 2.3 pointed out that my procedural justification leads to a conception of deliberative democracy that assigns an important role to public reason. My thesis aims to demonstrate that public reason has important implications for the substantive values that should govern clinical care resource allocation. Among other things, public reason requires that decision-makers should refrain from using a large number of influential substantive values. Consequently, the frame of mind imposed by public reason confines value conflicts within much narrower limits than described by Daniels. Even the value conflicts singled out by Daniels as representative of all others, which oppose cost effectiveness to priority to the worst-off, ability to benefit and fair chances to be treated, are set to be solved by public reason – in fact, both cost effectiveness and fair chances turn out to be inconsistent with public reason.[99] In sum, besides providing more solid foundations for an

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resource allocation, Daniels was exploring the prospects of a procedural ideal that was similar to public reason in that it promised to have substantive implications. Given that ideals like public reason do not involve democracy, Daniels was justified in carrying out a philosophical analysis of substantive issues without worrying about public participation or other aspects of the decision-making process. This response to my criticism of AFR is unsatisfactory because no plausible account of fair process can take an ideal like public reason to be the only requirement of procedural fairness. As seen in section 2.3, equal respect for autonomous individuals also requires public involvement. Moreover, section 3.2 aims to demonstrate that additional criteria (i.e. transparency, accuracy and revisability) are needed to make up a convincing account of the requirements of procedural fairness.

[99] For the unsolved value conflicts singled out by Daniels, see Daniels (2008, 105-108). I

account of fair procedures, my case from equal respect and autonomy promises to ease the worry that led Daniels towards AFR. Indeed, my deliberative democratic account of fair procedures aims to offer a solution to the value conflicts that prompted Daniels to develop AFR. In one important sense, there is room to argue that my model promises to also be successful in the terms that Daniels set for his own theory.

2.5. Conclusion

The aim of this chapter has been to identify the reasons why clinical care resource allocation should be governed by deliberative democracy. To achieve that aim, I have analysed and rejected virtue-based and epistemic justifications for deliberative democracy. Clinical care resource allocation should be governed by deliberative democracy for procedural reasons: deliberative democratic procedures are needed to express and implement equal respect for autonomous individuals.

How does this chapter serve the overall aims of my thesis? The first aim of my thesis is to defend a deliberative democratic approach to clinical care resource allocation. Clearly, this aim could not be accomplished without the work done in this chapter. Furthermore, choosing between competing modes of justification helps to give shape to the general requirements of deliberative democracy. In fact, public reason and public involvement have emerged as integral parts of a deliberative democratic approach to clinical care resource allocation. This means that this chapter also serves the second aim of my thesis, which is to investigate what is required by deliberative democracy in the context of clinical care resource allocation.

What about the broad themes cutting through my work? In section 1.3, I

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explored them in greater detail in section 1.1.

explained that one of the main themes of my thesis concerns the procedural turn in the debate over clinical care resource allocation, i.e. the shift of focus from substantive issues to the principles governing decision-making procedures. This chapter should have made it clear that my critical stance towards the procedural turn does not involve the rejection of a strong concern for the procedures governing resource allocation. In fact, the ability of certain decision-making procedures to implement fundamental principles, such as equal respect and autonomy, lies at the basis of my case for deliberative democracy. However, this chapter has also prepared the ground for the argument that a well-placed concern for fair procedures has strong implications for the substantive values that should govern clinical care resource allocation. In fact, I have shown that a procedural case for deliberative democracy leads to public reason. In addition, I have suggested that public reason is able to make important distinctions between appropriate and inappropriate substantive considerations.

Furthermore, I have shown that the justification for fair procedures offered by Daniels is inadequate. This kind of justification resonates with many scholars, decision-makers and commentators who have contributed to the procedural turn, which has been found to rest on uncertain foundations.

3. GENERAL REQUIREMENTS AND SCOPE OF DELIBERATIVE DEMOCRACY

This chapter serves two purposes. First, it aims to complete the analysis of the general requirements of deliberative democracy in clinical care resource allocation started in chapter 2 – public reason and public involvement are further analysed before introducing three other requirements. Second, it tackles an important objection internal to the conception of deliberative democracy that I have been developing.

To ensure that no important component of a fair process is overlooked, and to highlight the differences from alternative conceptions of procedural fairness, I decided to gather the candidates as general requirements of deliberative democracy by considering the requirements that are taken by other procedural models to contribute to the fairness of clinical care resource allocation processes. Specifically, I consulted a) philosophical analyses aimed at identifying the procedural requirements that contribute to the fairness of resulting allocations of clinical care resources;[100] b) research carried out by health economists who argue that preferences for procedural requirements should be factored in when welfare economic evaluations are conducted;[101] and c) empirical research aimed at determining whether the

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[100] In addition to Daniels (2008, 103-139) and Daniels and Sabin (2008), see Clark and Weale (2012), Emanuel (2002a), Fleck (2009) and Gutmann and Thompson (1996) and (2002a). Although NICE's document on social value judgements is issued by a body involved in actual resource allocation, the links with AFR and the type of arguments employed create a strong resemblance with philosophical analyses - see NICE (2008) and Rawlins and Culyer (2004).

[101] Dolan et al. (2007) and Wailoo and Anand (2005).

actors actually involved in clinical care resource allocation share the ideas about procedural fairness put forward in a) or, more specifically, by Norman Daniels's accountability for reasonableness (AFR).[102]

This chapter aims to point out which candidates as requirements of procedural fairness are actually called for by deliberative democracy to express and implement equal respect for the autonomy of individuals. I intend to show that deliberative democracy upholds transparency, accuracy and revisability, which are advocated by virtually all models that I considered. Although rather popular, the adoption of a requirement of public involvement marks an important difference with influential conceptions of procedural fairness, most notably AFR. Moreover, I aim to demonstrate that my idea of public reason goes beyond any constraint on reason-giving that is proposed by alternative models of procedural fairness in clinical care resource allocation.

This chapter also aims to respond to a powerful criticism that may be raised by commentators who share most, if not all, of the conception of deliberative democracy developed in my thesis. In assigning an important role to public reason, my conception of deliberative democracy sides with John Rawls's influential model. Moreover, my account of deliberative democracy is aligned with Rawls's in grounding deliberative democracy in principles such as equal respect and autonomy. However, Rawls famously argues that only constitutional essentials and the most basic issues of justice falls within the scope of deliberative democracy.[103] Therefore, most issues concerning clinical care resource allocation should not be for deliberative democracy to settle, ruling out the project carried out by my thesis. My aim is to argue for a broad view of the scope of deliberative democracy by singling out the main arguments behind Rawls's position and demonstrating

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[102] Kapiriri et al. (2009) and Martin et al. (2002).

[103] Rawls (1996, 212-254) and (1997).

their inadequacy.

In section 3.1, I start my exploration of the general requirements of deliberative democracy by deepening the analysis of public reason and public involvement that was started in section 2.3. Section 3.2 argues that transparency, accuracy and revisability are necessary to complete the picture of what deliberative democracy requires in the allocation of clinical care resources. In addition, this section explores why a number of alleged components of procedural fairness should not be included among the requirements of deliberative democracy. Finally, section 3.3 argues that neither a case from second-order justification nor a case from incompleteness can justify restricting the scope of deliberative democracy in such a way that excludes clinical care resource allocation.

3.1. Public reason and public involvement

While defending a procedural case for deliberative democracy, section 2.3 identified public reason and public involvement as complementary answers to the need to devise a process for clinical care resource allocation that expresses and implements equal respect for the autonomy of individuals. In this section, I further analyse what these requirements of deliberative democracy involve and how they provide a marked contrast with AFR and the other accounts of fair process developed in the wake of the procedural turn.

Public reasons are reasons that all reasonable persons might be expected to accept. Simply *in virtue of its definition*, public reason distinguishes my model from all other accounts of procedural fairness in clinical care resource allocation that I examined. Public reason involves many of the constraints on the substance of reason-giving proposed by existing accounts, but *goes beyond* all of them. To start with, public reason requires that decision-makers should abandon the pursuit of vested interests.[104] If a decision was justified based on the financial interests of decision-makers or a section of society, how could that decision be acceptable to those who do not stand to receive a financial benefit from it? Also, public reason requires formal fairness, i.e., that like cases should be treated alike.[105] If two groups of patients were similar in all relevant respects, and if treatment was provided to one group only, the resource allocation decision would be reasonably rejected by the members of the other group. Moreover, public reason involves those constraints on the substance of reason-giving that are crystallised into such concepts as “fair consideration”[106] and “moral, as opposed to prudential, reasons”[107]. Indeed, decision-makers should consider the interests of all affected individuals and provide reasons that are not based on the inequalities of bargaining power that may exist.

If taken together, the idea of fair consideration and that of moral reasons point in the right direction. However, public reason goes further in dictating that a specific type of moral reasons be provided. Broadly speaking, this is also the way in which public reason differs from the relevance condition, which is used by Daniels to constrain the substance of the exchange of reasons leading to resource allocation decisions. In Daniels's words, this condition requires that rationales must be acceptable to all, but only in an “attenuated sense”.[108] Decision-makers are not required to look for those reasons that all reasonable persons might be expected to accept as most

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[104] See NICE (2008, 13-15) and Wailoo and Anand (2005), as well as what is elsewhere identified as honesty (Martin et al., 2002), impartiality (Emanuel, 2002a, 236-239) or objective, as opposed to subjective, ways of reasoning (Kapiriri et al., 2009).

[105] Clark and Weale (2012, 306-307) and Daniels and Sabin (2008, 47-49). Dolan et al. (2007), Fleck (2009, 164-171) and Kapiriri at al. (2009) subsume formal fairness under the category of consistency.

[106] Emanuel (2002a, 237).

[107] Gutmann and Thompson (2002a, 83–86).

[108] Daniels (1999, 201).

weighty. It is enough if the others can see that the reasons that are provided bear some relevance to the goal of providing “value for money” in meeting the health needs of the population. In contrast, public reason is very selective, dictating that decisions should be grounded in a fraction of the rationales that count as relevant in Daniels's sense.

Specifically, section 2.3 pointed out that public reason consists in the provision of rationales that draw on a pool of commitments and considerations that all reasonable persons share. The autonomy of individuals is honoured if and only if every decision-maker strives to identify the most reasonable among the rationales that can be built on the basis of what is shared by reasonable persons.[109]

In the field of clinical care resource allocation, the question of the content of public reason, or the arguments that fall within the pool of reasons that all reasonable persons share, is especially interesting. This special interest is rooted in the fact that, so far, the idea of public reason has mainly been applied to controversies among religious or otherwise comprehensive doctrines over the truth of moral, metaphysical and philosophical propositions. In other words, the idea of public reason has mainly been used within debates focused on issues of *liberal tolerance and state neutrality*.[110] In this context, a standard answer has emerged to the question of the content of public reason: public reasons can be characterised as reasons that do not make reference to one's religious or otherwise comprehensive doctrine.[111]

Here I do not mean to imply that issues of neutrality are irrelevant to clinical care resource allocation. However, clinical care resource allocation primarily involves controversies of a different type, concerning the

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[109] Still, it is possible that reasonable persons disagree over the decisions that are required by the commitments and considerations that all share. Alternatively, reasonable persons may disagree over the most robust justification for a decision that everyone converges on.

[110] Chambers (2010, 894–895).

[111] The locus classicus of this conception of the content of public reason is Rawls (1996, 212-254) and (1997). For a critical view, see Gaus and Vallier (2009).

distribution of common resources between competing claimants. Thus, the content of public reason is bound to look different from more traditional inquiries into state neutrality, adding interest to my analysis and highlighting the contrast with Leonard Fleck, who also uses the idea of public reason in his account of fairness in clinical care resource allocation. Indeed, Fleck upholds the definition of public reasons as reasons divorced from comprehensive doctrines. In this way, he underestimates the implications for the content of public reason of the passage from neutrality-centred to distribution-centred controversies.[112]

Now, what happens to the content of public reason once we acknowledge that the debate on clinical care resource allocation is not centred on neutrality? This question is answered in section 4.3. In brief, reasonable persons share the commitment that, under conditions of scarcity, resources should be allocated so as to minimise the strongest complaint anyone can have. Also, reasonable persons share a commitment to the compartmentalisation of different areas of government activity. This conception of the content of public reason is at the basis of my account, proposed in chapters 5, 6, 7 and 8, of the implications of deliberative democracy for the substantive values that should govern clinical care resource allocation.

Along with public reason, public involvement is also necessary in the processes leading to clinical care resource allocation decisions. Most notably, the requirement of public involvement clashes with the account of procedural fairness proposed by Daniels. To be sure, Daniels maintains that members of the public should be given the opportunity to challenge the decisions made by clinical care resource allocation agencies.[113] Nonetheless,

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[112] Fleck (2009, especially 19-21). Fleck's idea of the content of public reason forms the basis of his account of the substantive implications of deliberative democracy, which I argue are not profound enough. I return to this point in section 7.3.

[113] Daniels (2008, 131-132).

many critics convincingly argue that a right to appeal is not enough to rescue the public from an overly passive role.[114] Phrasing this criticism in my own terms, citizens can hardly be regarded as imposing resource allocation decisions on themselves if public servants and insurance companies can legitimately make all relevant choices before appeals processes. Public servants and insurance companies are, at most, indirectly connected to the public through complex authorisation and accountability chains that pass through elected politicians. This connection is not enough to implement to any satisfactory extent the autonomy-building power of public involvement.

It might be asked whether public involvement necessarily includes a commitment to engage the whole public at the same time, as with referenda. This is an important question because any commitment to engage the whole public at the same time would be affected by the so-called "problem of scale", which states that when a large number of persons is involved in discussion, well-order deliberation becomes extremely difficult, if not impossible.[115] My answer is that the requirement of public involvement should be satisfied by creating a *deliberative system*, i.e., a system of deliberative forums, each with an element of public involvement.[116]

In other words, the commitment to public involvement should be satisfied by creating *multiple opportunities* for the involvement of a *limited number* of citizens at a time, built into different stages of the chain of decision-making that leads to the distribution of clinical care resources. For instance, there should be opportunities for public involvement when

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[114] Emanuel (2002b), Friedman (2008), Rid (2009) and Sabik and Lie (2008). Although broadly supportive of AFR, NICE employs a Citizens Council in its decision-making process - see Rawlins (2005).

[115] J. Cohen (2009b, 256–257) and Parkinson (2003).

[116] For the idea of deliberative system, see Goodin (2005), Mansbridge (1999a) and the essays included in Parkinson and Mansbridge (2012). Parkinson (2003) suggests that deliberative systems can solve problems of scale.

governments set the broad contours of the system for resource allocation, when central agencies such as NICE make recommendations about optimal clinical care interventions and the use of health technologies, and when local authorities and clinical care providers face their share of resource allocation decisions. Arguably, public involvement should take different forms in different forums. At certain levels, the election of representatives may be the most suitable arrangement. Elsewhere, representation may be achieved through stratified sampling and sortition.[117] Furthermore, those who are selected as representatives of the public may either be included in broader resource allocation bodies or create a separate body interacting with more traditional clinical care resource allocation agencies.

There may be an objection that questions how the participatory procedures built into the deliberative system can create legitimacy for those who do not participate. The supporters of the deliberative system can offer a twofold answer. First, I have already mentioned that deliberative forums are supposed to achieve some form of representation of those who do not physically participate, where representation can be secured either through election or through stratified sampling and sortition. Second, the deliberative system creates multiple chances to participate in one or the other of the deliberative forums. Therefore, everyone has a very good chance to be called upon to participate, at least once, with regard to some public policy area and at some level of the decision-making chain. In turn, the fact that everyone is likely to be called upon to participate somewhere in the deliberative system contributes to legitimising any decision that comes out of the system in the eyes of those who have been left outside of the specific forum that has taken that decision.[118]

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[117] For an exploration of the extent to which selection through sortition can achieve democratic representation, see Brown (2006) and Mansbridge (2009).

[118] My account of what public involvement entails has intentionally been left abstract. However, I aim to discuss specific public involvement arrangements in chapters 8 and 10.

3.2. Transparency, accuracy and revisability

The aim of this section is to point out that, besides public reason and public involvement, additional requirements are necessary to complete the picture of what a deliberative democratic approach to clinical care resource allocation requires at a general level. I start by identifying several requirements that should *not* be included in that picture, although they are sometimes depicted as fully-fledged components of procedural fairness. Daniels's condition that the other requirements making up AFR should be implemented states something that is already implicit in the objective to lay down a set of requirements for clinical care resource allocation procedures. Therefore, that condition is redundant.[119] Other times, practical arrangements are proposed as basic requirements of procedural fairness, although their value is purely instrumental and lies in the ability to promote more fundamental requirements. This is the case with the idea that resource allocation agencies should be well-organised and forward-looking,[120] working under effective leadership[121] and providing hospitals with incentives for compliance.[122]

In contrast, I argue that transparency, accuracy and revisability are valid requirements of deliberative democracy. The reason why transparency should be included in my account of fair procedures should be straightforward. If secrecy prevents the general public from accessing decisions and their rationales, resource allocation processes express lack of respect for the ability of the members of the public to direct themselves in light of their intelligence. Indeed, the message expressed by those processes

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[119] Daniels (2008, 133).
[120] Kapiriri et al. (2009).
[121] Martin et al. (2002).
[122] Kapiriri et al. (2009).

is that the members of the public should be treated like children, who need to be protected from the fact that certain tough decisions have been made. In sum, the idea that decisions and their supporting rationales need to be addressed to the general public emerges as a prerequisite for showing equal respect towards autonomous individuals.

Transparency raises a number of stimulating questions. Is transparency of any value if it is not developed in terms of a requirement of comprehensibility?[123] Should we go as far as advocating a broad view of transparency, subjecting every aspect of the professional life of decision-makers to scrutiny?[124] Moreover, the supporters of implicit rationing famously claim that, in the context of clinical care resource allocation, much is to be gained from obfuscation and secrecy.[125] Several questions surrounding transparency cast doubts on the broader objective to subject clinical care resource allocation to deliberative democracy. However, this is not the place to engage in the in-depth analysis that is necessary to tackle them; I defend and specify the requirement of transparency in sections 4.1 and 4.2.

One point that is worth making here concerns the link between transparency and *consistency*. As convincingly argued by Daniels, to state transparently that certain reasons have led to a certain decision creates a commitment to follow the same reasons if similar cases arise in the future.[126] This presumption in favour of consistency does not involve the infallibility of past decision-makers. In actuality, the application of established reasons to new cases may well lead to the realisation that those reasons are unsatisfactory. In turn, this may lead to the revision of past decisions which

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[123] Among others, see O’Neill (2006).

[124] See the classical analysis of constitutional conventions proposed by Gutmann and Thompson (1996, 115–117).

[125] Among others, see Coast (1997), Hunter (2001) and Mechanic (1997).

[126] Daniels (2008, 119-123).

were grounded in reasons later deemed to be unsatisfactory. However, to have a presumption in favour of consistency means that especially strong reasons should be provided if the revision of established rationales and relative decisions is sought.

Accuracy concerns the use of factual information.[127] Once the substantive values that should govern clinical care resource allocation have been identified, the use of the most accurate factual information is necessary to satisfy those values to the greatest extent possible. Decision-makers need an understanding of such factors as cost considerations, clinical effectiveness of interventions and the place of these interventions in clinical practice if they intend to identify the allocation of available resources that promotes their objectives as much as possible. At this point, it seems clear that accuracy deserves a place among the general requirements of deliberative democracy in clinical care resource allocation. Let us assume that the substantive values that should govern the allocation of resources have been chosen through procedures that, satisfying public reason, public involvement, transparency and revisability, qualify as fair. From the perspective of my procedural conception of deliberative democracy, those values are worth pursuing because they result from a fair process. Given that the values governing resource allocation are worth pursuing, everyone has an interest in having the most accurate information factored into decision making. Therefore, accuracy is a requirement for equal respect for the autonomy of reasonable individuals.

However, the problem of the place of accuracy in deliberative democracy is more complex than it may seem. Communities of expertise generally possess the most accurate information concerning a number of areas

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[127] Accuracy and rigour of information are especially emphasized by the studies eliciting preferences from decision-makers or samples of the public (Dolan et al., 2007, Kapiriri et al., 2009, Martin et al., 2002 and Wailoo and Anand, 2005).

relevant to clinical care resource allocation. Now, the involvement of experts poses major threats to the fairness of clinical care resource allocation processes. First, expert knowledge is often incomprehensible to lay citizens, clashing with the requirement that decisions should be grounded in reasons that all might be expected to accept.[128] Second, experts have strong incentives to hide disagreement and uncertainty from the public and, if involved in policy-making, tend to make decisions that should be left for the public to make.[129] At this point in my argument, I can only say that my thesis aims to demonstrate that we should uphold accuracy and the idea that experts should be involved in clinical care resource allocation. I return to the tensions between deliberative democracy and accuracy in chapters 9 and 10, which are entirely devoted to their solution.

Revisability is an additional requirement involved in the principle that states that procedures for clinical care resource allocation should implement equal respect for the ability of individuals to direct themselves on the basis of their reason.[130] Given that decisions should be made on the basis of the reason of those affected, deliberative democratic processes must not ignore that human reason is fallible. Hence, procedures should be in place for the public to appeal against decisions concerning clinical care resource allocation.

If not limited, appeal procedures can easily conflict with the presumption in favour of consistency involved in the requirement of transparency. It stands to reason that if institutional designers were too generous in defining the grounds of appeal against resource allocation resolutions, decisions and their supporting rationales would be too often overturned. Furthermore, making the right to appeal too expansive would lead to a state of affairs in

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[128] Turner (2001).

[129] Beatty (2006) and Bucchi (2008, especially 61–65).

[130] Daniels (2008, 131-132) and NICE (2008, 14).

which decision-making agencies are paralysed by the sheer amount of appeals that must be considered. Here the challenge is to identify grounds of appeal that honour revisability while protecting consistency and the work of decision-making agencies at large. Surely the mere fact that someone disagrees with a decision and its supporting rationale should not count as valid ground of appeal.[131] Importantly, not even the fact that a decision violates public reason should be accepted as ground of appeal. Public reason is to be regarded as a moral duty, as opposed to a legal one.[132] If courts and other bodies of guardians were allowed to reverse a decision whenever public reason is not followed, the right to hold public office of whoever is appointed to make resource allocation decisions would be under threat. Consequently, the broad commitment to democracy that underlies my work would be violated. However, there seems to be room to argue that decisions can be flawed in more basic terms, which may provide the grounds of appeal we need. I develop this line of reasoning in section 8.1, where I aim to explore the way in which appeal procedures should be designed.

My reflections on the need to carefully specify the requirement of revisability highlights a challenge awaiting any attempt to put my deliberative democratic approach to clinical care resource allocation into practice. This challenge is rooted in the fact that, by my account, a number of requirements contribute to procedural fairness: public reason, public involvement, transparency, accuracy and revisability. Now, some of these requirements are *prone to conflict*, as we have seen with regard to revisability and the commitment to consistency involved in transparency. Earlier on, I described the tension between public reason and public involvement caused by problems of scale, and the potential conflict between public reason and accuracy over the involvement of experts. These tensions

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[131] NICE (2014a, 11).

[132] Rawls (1996, 212-213).

make the objective to implement a deliberative democratic approach to clinical care resource allocation more difficult, because institutional designers need to find a way to specify each requirement so that the frictions with other requirements are minimal.

However, the challenge under discussion is by no means exclusive to my conception of deliberative democracy. In actuality, it is something that all models of procedural fairness that propose a number of requirements need to face. Moreover, it does not appear to be an insurmountable challenge. In the course of my thesis, I return to all the tensions between requirements that have emerged in this chapter, showing that they can be eased. Therefore, there is reasonable hope that frictions can be minimised in most, if not all, cases of tensions that may arise, including those that I do not consider. Finally, it is worth stressing that, given the aims of my thesis, I do not need to commit myself to identifying all possible tensions and demonstrating that they can be solved. My thesis is a work in political philosophy. Hence, although my thesis explores implementation to a limited extent in order to add to the justification of my theoretical proposals, a detailed analysis of the way in which my arguments should be implemented falls beyond the scope of my work.

3.3. Against the narrow view of the scope of deliberative democracy

In this section, I respond to an internal criticism that might be raised by commentators who agree with most, if not all, of the conception of deliberative democracy developed in sections 3.1 and 3.2. As noted in the introduction to this chapter, my conception of deliberative democracy is close to Rawls's in such important respects as the justification for deliberative democracy and the role played by public reason. However, Rawls champions what is sometimes called the “narrow view” of the scope of deliberative democracy, according to which deliberative democracy should only be applied to constitutional essentials and issues of basic justice.[133] According to Rawls, while basic liberties and the general structure of government fall within the scope of deliberative democracy, questions of distributive justice beyond freedom of movement, free choice of occupation and the social minimum are not for deliberative democracy to settle.[134]

One of the implications of Rawls's view is that most of the issues concerning clinical care resource allocation fall outside the scope of deliberative democracy, ruling out the project carried out in my thesis. The aim of this section is to identify the two main arguments that support the narrow view of the scope of deliberative democracy and demonstrate that they are unconvincing. Given that Rawls does not discuss at length the justification of his view of scope, I also draw on a number of authors who engage with this aspect of Rawls's theory.

The two main arguments backing the narrow view of scope can be referred to as “the case from second-order justification” and “the case from incompleteness”.[135] Starting from the former, Rawls claims that constitutional essentials and issues of basic justice are most urgent.[136] The intuition behind Rawls's claim is effectively captured by such commentators as Gerald Gaus and Jonathan Quong.[137] These authors explain that the

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[133] See Quong (2004).

[134] Rawls (1996, especially 227-230). For his latest and most clear-cut comment on the scope of deliberative democracy, see Rawls (2001, 91).

[135] In his critique of Rawls's narrow view, Quong (2004, 238-241) also considers the “basic interests” argument, put forward by De Marneffe (1990). The basic interests argument is grounded in a specific definition of public reasons as reasons concerning the distribution of Rawls's primary goods. This is an overly restrictive account of which reasons count as public, far from the account I develop throughout this thesis. Therefore, I leave the basic interests argument to one side to focus on more fitting challenges to my position.

[136] Rawls (1996, 227).

[137] Gaus (2011, 491–492) and Quong (2004, 235-236).

political decisions falling outside the scope of deliberative democracy as defined by Rawls are made through a process that is sanctioned by the constitution. Furthermore, constitutional essentials and matters of basic justice also address substantive questions, and the answers that are provided are then incorporated into a variety of non-essential political decisions. Therefore, if settled by deliberative democratic means, constitutional essentials and issues of basic justice are thought to confer *derivative* legitimacy to the rest of political decisions. Using Quong's words, this "second-order" justification makes the application of deliberative democracy to non-essential questions redundant.

In implying that the derivative legitimacy provided by constitutional essentials and issues of basic justice is enough to honour the autonomy of all citizens, the case from second-order justification forgets the *sources of heteronomy* that abound in the passage from a framework of essential decisions made by deliberative democratic means to non-essential decisions. Given that there is room for coercive power to be exercised in a way that is inconsistent with the autonomy of individuals, deliberative democracy should also be applied to the questions falling beyond the scope of deliberative democracy as defined by Rawls.

The sources of heteronomy that I have in mind concern both the forces driving decision-making and the substance of decisions. Even if constitutional essentials and issues of basic justice were settled through a deliberative democratic process, various forces beyond constitutional structure could still influence how power is exercised, reducing citizens to heteronomy. To cite but one example, powerful economic interests would be able to steer decision-making processes about non-essential political issues. Thus, public reason, public involvement and the rest of the requirements of deliberative democracy would be necessary to counteract those interests.[138] Moreover, any framework of constitutional essentials and issues of basic justice is consistent with a wide variety of answers to each non-essential political question.[139] It follows that, for each non-essential question, there is a high probability that many individuals will end up coerced into obeying a decision they disagree with. As seen in section 2.3, this fact is enough to call for deliberative democracy, which is meant to reconcile coercion with equal respect and autonomy.

Having rejected the case from second-order justification, I now turn to the case from incompleteness, which starts from the idea that the scope of deliberative democracy should be limited in such a way that public reason can be complete, i.e. capable of providing an answer to all, or nearly all, the questions that are dealt with.[140] To be precise, the advocates of the narrow view of scope have in mind a specific sense in which public reason can be deemed incomplete. Their argument is that, if applied beyond constitutional essentials and issues of basic justice, public reason is unable to provide any *determinate* answer to a large number of political questions.[141] Given its tendency towards indeterminacy, public reason cannot possibly serve as a framework for making decisions about those political questions falling outside the scope of Rawls's definition of deliberative democracy. Therefore, deliberative democracy must not be applied beyond constitutional essentials and issues of basic justice.

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[138] Dryzek (1990, 17–20).

[139] Gaus (2011, 492-295).

[140] Rawls (1996, 227).

[141] Following the terminology first introduced by Gaus (1996, 150–158), the supporters of the narrow view point out the "indeterminacy" of public reason. Alternatively, public reason can be incomplete because it is inconclusive, which means that public reason yields more than one reasonable answer to a given question. As acknowledged by Rawls (1997, 797-799) and explained in the analysis of public reason provided in section 2.3, inconclusiveness is a common feature of public reason, regardless of its scope. For more on the distinction between indeterminacy and inconclusiveness, see Schwartzman (2004, 193–198).

The charge of indeterminacy also forms the basis of important objections raised against public reason at large, regardless of its scope. These objections provide the richest account of the reasons why public reason is thought to be indeterminate, which have important similarities with the somewhat sketchy arguments offered by those who use indeterminacy to justify a narrow view of the scope of deliberative democracy. In what follows, I describe what is thought to make public reason indeterminate by presenting the arguments of the supporters of the narrow view together with the arguments of the critics of public reason. In this way, I depict the target of my counter-arguments at its most appealing.

A first argument for indeterminacy starts with the claim that the substantive values upheld by public reason are often vague. Thus, it is often impossible to determine how a certain value should be applied to a particular context without resorting to judgement or other resources external to public reason. For example, Rawls argues that the Difference Principle should be left outside the scope of deliberative democracy because public reason would find it extremely difficult to ascertain whether a certain state of affairs satisfies the Difference Principle or not.[142]

Second, the substantive values accepted by public reason are numerous and prone to conflict, while public reason does not have the necessary resources to cope. In his critique of public reason, David Reidy claims that "individual liberty, happiness, political equality, equality of opportunity, distributive justice, social stability, the orderly reproduction of political society, fraternity, openness and honesty in government, economic prosperity, social diversity, liberal democratic citizenship, the common defence, the general welfare and cultural vibrancy often conflict and

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[142] Rawls (1996, 229-230). In his defence of a narrow view of the scope of impartial justification, Barry (1995, 144, quoted by Quong, 2004) speaks in terms of "implications of justice".

compete with one another".[143] The values bearing on each political issue are so numerous that only a comprehensive doctrine can provide an order of priority and reach determinate conclusions in case of conflict.

Third, public reason is silent about "background or preliminary issues" that are necessary to provide determinate answers to political questions.[144] The political status of the foetus or non-human animals can be cited as important examples of the background or preliminary issues that public reason cannot tackle.

Quong offers an excellent starting point for answering this threefold argument. According to Quong, the indeterminacy of public reason with regard to any political question cannot be proven at the level of abstract analysis at which the argument in question operates. This is because it is not possible to determine whether public reason will be able to overcome problems of vagueness, value conflicts and background or preliminary issues ahead of an in-depth discussion of the specific political question. For instance, consider the obstacles placed in the way of public reason by the status of non-human animals. Before looking at the details of specific policy issues, we cannot know whether public reason can yield a determinate answer. As an example, Quong considers construction policies that concern sites where endangered animals or plants live. The preservation of the animals and plants in question may turn out to be justifiable from within public reason because of their value for scientific and medical research.[145]

In addition to the inability of any abstract argument to prove the

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[143] Reidy (2000, 65). Rawls (1996, 225) and (1997, 777) makes reference to the need to balance conflicting values while discussing why the scope of deliberative democracy must be limited.

[144] Reidy (2000, 68). Greenawalt (1988, 144–172) and Horton (2003, 18–21) also level criticism at public reason based on similar considerations. Instead, Scanlon (2003, 163) uses the status of "unspoiled wilderness" to defend Rawls's narrow view of the scope of deliberative democracy.

[145] Quong (2004, 242-245). For the possibility to formulate environmental policies on the basis of public reason, see also Bell (2002), discussed by Quong (2004, 243-244).

indeterminacy of public reason, the arguments that stress the tendency of public reason towards indeterminacy can be criticised on the basis of similar abstract considerations that show that indeterminacy is likely to occur less frequently than claimed by the critics of public reason or the supporters of the narrow view of its scope. In offering each of these considerations, I refer to points that I intend to make later on in my thesis, when I examine how public reason shapes the substance of clinical care resource allocation. The analysis carried out in chapters 5, 6 and 7 provide novel examples of the resources that public reason can rely on to overcome the risk of indeterminacy. Therefore, my analysis of the substantive implications of a deliberative democratic approach to clinical care resource allocation makes a contribution to broader debates about the tenability of deliberative democracy and its scope.

Let us start from the vagueness of the values accepted by public reason. Pace Rawls, if the application of a given value reaches an impasse, a judgement call that cannot be explicitly justified to others is not the only option. While staying within public reason, decision-makers can attempt to further specify the value in question by looking at other values accepted by public reason and their justification. Indeed, other values might support one possible specification over the others, resolving the impasse.

This model of specification is proposed as an account of public reasoning by Henry Richardson. Specification provides a method for bringing values to bear on concrete problems and solving value conflicts. Richardson's aim is to offer an alternative to both the deductive application of values and intuitive balancing. According to Richardson, it is often possible to specify a value by looking at the mutual support among acceptable values. This is because the motivation behind the value that we wish to specify may be partially explained by another value. Unlike the use of judgement, this process of specification can be explained and justified to others.[146] Section 5.1 aims to show that Richardson's model of specification can help to define priority to the worst-off in the context of clinical care resource allocation. In brief, I argue that the specification of priority to the worst-off should be sensitive to the fact that public reason also upholds ability to benefit. Thus, priority to the worst-off does not justify funding clinical care interventions aimed at patient groups whose members can only receive trivial benefits from treatment.

Second, the suggestion that public reason is often condemned to indeterminacy by a plurality of conflicting values is in stark contrast with the account of public reason I develop throughout the thesis. As a duty to make reference to reasons that all reasonable persons might be expected to accept, public reason is aptly described as a “duty of restraint” from a variety of considerations that comprehensive doctrines may find relevant.[147] Therefore, it is often the case that, when values seem to conflict over a certain issue, many of those values are actually inconsistent with public reason. Focusing on clinical care resource allocation, chapters 5 and 6 demonstrate that public reason works as a finely-woven filter, excluding all the substantive values that are commonly proposed as relevant with the exception of priority to the worst-off, ability to benefit, specialness of clinical care and cost considerations. Moreover, section 7.2 points out that there is little room for the kind of conflict that public reason cannot solve between the four values upheld by public reason – such values lend themselves to be made into a decision-support tool that is capable of providing clear guidance in a wide variety of circumstances. In sum, my analysis shows that value conflicts pose a threat that is considerably less serious than suggested by Rawls or the critics of public reason.

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[146] Richardson (1990) and (2002, 214–230).

[147] Chambers (2010) and Macedo (2008).

Finally, public reason can sometimes reach a determinate conclusion while avoiding a background or preliminary issue that, at first glance, seemed unavoidable. For example, Samuel Freeman argues that a determinate conclusion in favour of the right to abortion can be reached without taking any stance on the political status of the foetus: given that all parties should agree that a blanket ban on abortion would interfere with the freedom of women, the burden of proof lies with anti-choice campaigners, who know that such burden cannot be discharged from within public reason.[148] Turning to clinical care resource allocation, sections 5.2 and 5.3 discuss the value that public reason should place on health and clinical care in order to assess the principle of specialness of clinical care. At that point, some may object that the specialness of clinical care is not amenable to public reason because we can only reach determinate conclusions about the value of health from within our comprehensive doctrines or, specifically, our own conception of what it means for body and mind to flourish. However, I demonstrate that, far from drawing on any comprehensive doctrine, public reason can affirm the value of health as an opportunity good, which is something that virtually everyone has reason to want, regardless of their conception of the good.

It is now time to draw together the different threads of my argument. Even at the abstract level at which they operate, the arguments stressing the indeterminacy of public reason (both in general and with regard to non-essential questions) overestimate the threat posed by the mechanisms that may prevent public reason from yielding any determinate answer. Moreover, the indeterminacy of public reason cannot be conclusively proven in the abstract, without any in-depth discussion of the specific issue to be settled.

The implication for the question of scope is that deliberative democracy

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[148] Freeman (2004, 2053–2065).

should be applied to essential and non-essential political issues alike. Decision-makers should tackle all political questions by first attempting to reach a determinate answer on the basis of public reason. As we have seen, public reason is likely to be indeterminate less frequently than suggested by its critics and the supporters of the narrow view of its scope. Furthermore, Quong rightly notes that there is nothing to lose and everything to gain if decision-makers resort to non-public reasoning only after ascertaining that public reasons capable of providing a determinate answer to a certain question really are unavailable.[149] We can extend the point made by Quong even further. Compared to excluding whole questions from the scope of deliberative democracy, much is to be gained by discovering that public reason can answer a certain question *up to a certain point* and needs to be supplemented by judgement or comprehensive doctrines beyond it. Indeed, to ground a decision in public reason *to the greatest extent possible* honours equal respect and autonomy more than settling no aspect of that decision on the basis of public reason. Although public reason is shown to be determinate with respect to almost all substantive issues explored in chapters 5, 6 and 7, we will see that a few aspects of clinical care resource allocation decisions cannot be dealt with on the basis of public reason alone. However, this is not a good reason not to follow public reason as far as possible when it comes to allocating clinical care resources.

3.4. Conclusion

This chapter completed the analysis of the general requirements that should govern the process for allocating clinical care resources in a deliberative democracy. In addition to public reason and public involvement, I argued

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[149] Quong (2004, 242–245).

that transparency, accuracy and revisability contribute to the fairness of the decision-making process. My account of the requirements of deliberative democracy and, in particular, my idea of public reason turned out to differ from all other accounts of fair procedures developed in the wake of the procedural turn.

Furthermore, this chapter responded to an important objection, which is internal to the conception of deliberative democracy that I adopt. In responding to the proponents of the narrow view of the scope of deliberative democracy, I anticipated that my idea of public reason has all the necessary resources to provide answers to a wide array of substantive issues concerning clinical care resource allocation. Chapters 5, 6 and 7 are meant to discuss those resources in full detail.

4. IN SUPPORT OF EXPLICIT RATIONING AND SUBSTANTIVE ANALYSIS: A DEFENCE OF DELIBERATIVE DEMOCRACY

This chapter addresses two families of criticisms coming from within the debate on clinical care resource allocation. The first family of criticisms attacks the commitment to transparency that was affirmed in the previous chapter. Besides being a requirement of deliberative democracy in its own right, transparency is necessary for other requirements to work. For example, public involvement procedures could hardly be put in place if the allocation of clinical care resources was unacknowledged. Similarly, no one could appeal against resource allocation decisions if decisions were not transparently stated. Thus, the objections to transparency threaten to be particularly damaging and are worthy of careful attention.

Looking at the history of clinical care services, resource allocation was for a long time characterised by lack of transparency. It was only during the 1990s that several countries began to devise systematic approaches to clinical care resource allocation that placed some decision-making areas in the open.[150] Previously, the area of clinical care resource allocation was largely unacknowledged and clinicians were at the very centre of the process of rationing. Roughly speaking, when they felt that a certain intervention would put too much strain on available resources, clinicians

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[150] See Locock (2000) and Ham and Coulter (2001) in their analysis of New Zealand, the Netherlands and the U.K.

told patients that nothing could be done or that best clinical practice recommended against intervention. As it is often the case when doctors are given resource allocation responsibilities, many clinicians did not even admit to themselves that resource constraints influenced their decisions.[151] Alongside resource allocation by clinicians, long waiting lists and rationing by deterrence were employed to mask the fact of resource allocation and its underlying rationales.[152]

Now, the so-called supporters of "implicit rationing" object to the tendency towards greater transparency that has characterised the last couple of decades. The advocates of implicit rationing put forward appealing arguments that point out the strengths of "muddling through elegantly", to quote how some of them describe their ideal.[153] The first aim of this chapter is to defend transparency from the criticisms that may be raised by the advocates of implicit rationing and other theorists.

The second aim of the chapter is to respond to those who are anxious to vindicate the role of substantive analysis in the face of the procedural turn described in section 1.1. Chapters 2 and 3 made it clear how important procedural fairness is for deliberative democracy. Critics might argue that the stress placed on fair procedures is likely to create a context in which decision-makers rush through substantive issues as if they were of secondary importance. Interestingly, this outcome appears to be the fault of those ethicists who, like me, seem to have relinquished their duty to work hard on substantive questions. My response highlights the great potential of deliberative democracy to settle controversial substantive issues. Substantive recommendations constitute a key part of deliberative democracy, which is able to accommodate them without taking away any

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[151] Aaron and Schwartz (1984, 100–102)

[152] Locock (2000, 93).

[153] See Hunter (2001) and Mechanic (1997).

authority from the public.

Taken together, the first two sections answer to the main arguments that may be used against transparency. More specifically, section 4.1 discusses the idea that a commitment to transparency is grounded in a flawed model of reasoning, while section 4.2 focuses on the consequences of transparency. Furthermore, section 4.1 provides some definitions that are necessary to clarify the position that I defend. In response to the second family of criticisms under discussion, section 4.3 argues that deliberative democracy involves a duty to fully explore substantive issues, which is to be discharged by both decision-makers and ethicists. Moreover, section 4.3 discusses three routes that can be followed to identify the substantive implications of deliberative democracy.

4.1. Transparency and models of reasoning

Before starting my critique of implicit rationing, I need to provide some definitions in order to clarify the basis of my argument. First, I need to define the *scope* of transparency. Transparency certainly requires that clinical care resource allocation decisions and their supporting rationales be made public. Furthermore, it is desirable that formal meetings in which the members of a resource allocation agency come together to make decisions are held in public. Ideally, these meetings should cover issues like agenda-setting and the definition of the main concepts employed during deliberation. Such arrangements suffice to express strong respect for the ability of citizens to direct themselves on the basis of reasons. The members of the public are not treated like children who need to be protected from the fact of clinical care resource allocation. Moreover, in-depth justifications that support resource allocation decisions are offered to them.

At the same time, clinical care resource allocation decision-makers should not be subjected to the full glare of transparency throughout every aspect of their professional lives. Here I follow those supporters of deliberative democracy who propose a two-tiered model to ease the problem of trade-offs between transparency and the desideratum that decisions be grounded in solid reasons.[154] Transparency may prompt decision-makers to uphold a position they previously endorsed even though compelling countervailing considerations have emerged. Furthermore, transparency may lead to shallowness because pandering to the feelings of the audience is often enough to attract consensus. The purpose of keeping informal communications secret is to contrast the adverse effects that transparency may have on deliberation while honouring the value of transparency at the level of formal decision-making.[155] Moreover, the analysis of the consequences of transparency offered in section 4.2 demonstrates that the scope of transparency must be limited in order to provide the public with non-illusory opportunities to keep decision-makers in check and develop trust.

The ambiguity of terms like “implicit rationing” necessitates further clarification. Although “implicit rationing” is sometimes taken to mean lack of transparency about rationing in the doctor-patient relationship, I do not intend to take any side on this issue.[156] Deliberative democracy requires *transparency towards the public* as the ultimate bearer of political authority.

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[154] See Elster (1998b) and Gutmann and Thompson (1996, 114–117) in their analyses of constitution-making. For more on the problems associated with transparency, see Chambers (2004) and Gosseries (2010).

[155] Obviously, a tier of secrecy is not the only arrangement that a deliberative democracy can employ to counter the anti-deliberative tendencies of transparent decision-making. Chapter 8 discusses a number of arrangements that are meant to encourage the use of public reason.

[156] For this use of the term, see Owen-Smith et al. (2009) and Schwappach and Koeck (2004). Also Firth (2007) and Marcus (2007) discuss transparency about rationing at the level of individual patients.

Thus, what matters is that resource allocation by clinicians is acknowledged and regulated by a web of guidelines and incentives that are transparent towards the general public.[157] Whether clinicians should inform their patients that a certain choice of treatment is rooted in the need for rationing is a different issue and the arguments developed in this chapter do not hinge upon it.

The rest of this section discusses the criticisms of transparency that are concerned with the proper way of reasoning when it comes to resource allocation. All these criticisms stress the importance of the judgement of clinicians, where judgement is the ability to strike the right balance among a plurality of relevant considerations *in a way that cannot be fully explained to others*. Two subspecies of this type of criticism can be distinguished that focus, respectively, on moral and clinical judgement. Starting with *moral judgement*, it is argued that the more we approximate the point of care delivery, the more numerous the relevant values become. Any attempt to crystallise the way in which those values should be handled by front-line clinicians into transparent guidelines is doomed to failure. Consequently, "rationing at the micro level must be left for doctors and patients to work out among themselves".[158]

The best way to respond to the argument from moral judgement is to attempt to identify the compelling values that are relevant to the allocation of resources by clinicians and cannot be handled by transparent guidelines. What are the values that can only be handled by means of judgement? If we had to answer by exploring the values that actual clinicians take into account, the situation would look grim for the supporters of implicit rationing. For instance, some clinicians allocate clinical care resources on

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[157] The limits of the use of guidelines and incentives are explored later on in this section.
[158] Mechanic (1995, 1659).

the basis of the employment and productivity of patients.[159] Other clinicians allocate resources by “creaming”, i.e. privileging the most interesting and amenable patients.[160] Relatedly, some clinicians tend to allocate more time to patients they like.[161]

If the judgement of real-world clinicians often includes highly problematic value considerations, the values identified by the theorists who object to transparency do not fare better. David Mechanic is the author who most forcefully states the idea that the need for moral judgement justifies implicit clinical care resource allocation.[162] One leitmotif of his argument is that patients have different levels of knowledge and different motivations. Indeed, there are patients who look for all available information on the internet and do not accept “no” for an answer. According to Mechanic, clinicians should take these factors into account and give priority to the patients with greater knowledge and stronger motivation. Mechanic also mentions family circumstances as a relevant consideration.

None of the considerations identified by Mechanic are suitable to govern resource allocation, regardless of whether they are employed by transparent guidelines or the judgement of clinicians. Those considerations are *discriminatory*; they focus on character traits or features of our life plan that individuals should be free to discard without fear that their entitlements to clinical care may be affected. Mechanic is effectively claiming that clinical care resource allocation should not be neutral towards curiosity, stubbornness and deference to authority. Mechanic also seems to suggest that we should discriminate against those who have chosen to build no family, even if the clinical care to be allocated has nothing to do with areas like reproductive health.

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[159] Mechanic (1995, 1657).

[160] Klein et al. (1996, 89).

[161] Ubel (2001, 103–105).

[162] Mechanic (1995) and (1997).

In sum, the critics of transparency are unable to provide a convincing account of the plurality of appealing values that, according to them, eschews transparent guidelines. Thus, deliberative democrats have reason to hope that transparent guidelines can be nuanced enough to take into account all the values that should be considered. Section 7.2 returns to this issue, demonstrating that methods are available to create transparent decision-support tools that take into account values such as priority to the worst-off, ability to benefit, specialness of clinical care and costs.

To avoid misunderstandings, it is worth stressing that my argument against the use of moral judgement on the part of clinicians does not imply that clinicians should be restricted from rationing. My argument does not even deny that clinicians should examine values along with clinical considerations while performing their resource allocation responsibilities. In fact, my only aim has been to cast doubt on existing attempts to prove that relevant values are so numerous at the point of care delivery that they cannot be dealt with by transparent guidelines.

Clinicians constitute a key interface between patients and the health service at large. Clinicians are needed to apply resource allocation guidelines, which are produced by health technology appraisal agencies, local commissioning authorities and other bodies, to individual cases of patients in need of care. Indeed, only clinicians are in a position to investigate the relevant features of a patient in order to identify the right guidelines that should govern that individual’s treatment. This is a very important function because on the account of resource allocation that my thesis aims to develop, the entire purpose of a health service should be to attend to the claims of individual patients. It is worth noticing that while performing their resource allocation responsibilities, clinicians are effectively applying value considerations because all resource allocation guidelines serve a combination of values. For example, guidelines governed by public reason are likely to recommend a relatively generous allocation of resources to treatments that satisfy values such as priority to the worst-off and ability to benefit.

Now that we have established that clinicians should be involved in rationing, I turn to the topic of clinical judgement, which allows me to identify a function that clinicians should perform beyond the sheer application of guidelines. As I said earlier in this section, the need for *clinical judgement* is sometimes used to attack transparency. The clinical conditions of patients cannot always be reduced to the average conditions that figure in the guidelines for clinical care resource allocation, including those guidelines that split patient populations into subgroups. If a patient sharply deviates from the average, clinicians should be allowed to take into account information concerning comorbidities and any other factors that make the patient exceptional. This is the only way to reach resource allocation decisions that remain faithful to the spirit of the original guidelines by strongly upholding the commitment to ability to benefit and the other values animating such guidelines. Doctors should be allowed to use clinical judgement because in many cases, there are numerous factors concerning the clinical situation of a patient that may distance her from the average condition considered in the guidelines. When a clinical situation is complex, it is fair to expect that clinicians might not be able to fully explain why they think that a certain course of action is most consistent with ability to benefit and the other values governing the original guidelines. In other words, it seems fair to say that there are times when it is necessary for doctors to use their clinical judgement.[163]

Taking sarcoidosis as an example, Peter Ubel argues that clinical

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[163] Hunter (2001).

judgement allows for more sensible resource allocation schemes than the one enacted in the early 1990s by Oregon's Medicaid programme, which simply excluded all treatments. Instead, treatment should have been limited to those patients who could have been identified by their clinicians as most likely to benefit.[164] Even Leonard Fleck, who is a staunch proponent of transparency, suggests that elderly patients should only become eligible for an artificial heart if the clinical judgement of doctors is employed to weigh the information about comorbidities and assess whether the prospective recipients are likely to survive for at least three years.[165]

On this point, I am willing to side with Fleck and take the argument from clinical judgement on board. Clinical judgement is necessary to effectively trace the ability to benefit of patients, which is a value sanctioned by public reason. Moreover, if adequately constrained by a web of transparent guidelines and incentives, the use of clinical judgement involves a very limited exception to transparency. To appreciate how limited the exception to transparency would be, we should start by recalling that transparency dictates that societies should clearly state that clinical care resources are rationed and clinicians participate in the process. Furthermore, the values governing the decisions made by clinicians should be transparently stated - we have seen that the doctor's judgement should be limited to the clinical conditions of patients. Moreover, the clinical judgement of doctors should be constrained by a framework of transparent guidelines that point out which interventions are justified in light of the values governing resource allocation and the best evidence available.[166] These guidelines should limit

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[164] Ubel (2001, 149–150).

[165] Fleck (2009, 222–224). Among the supporters of transparency, Fleck is not alone in tailoring a role for clinical judgement. For instance, Daniels and Sabin (2008, 121–133) maintain that an “explicit” approach to financial incentives for clinicians requires a transparent discussion of incentive schemes, while no mention is made of the choices that clinicians make within those schemes.

[166] For the idea of evidence-based practice, see Karanicolas et al. (2008).

the use of judgement to clinical cases sharply deviating from the average, while benchmarking and other incentives should constitute transparent attempts to steer clinicians in specific directions.

This section has demonstrated that a commitment to transparency is not grounded in a flawed conception of reasoning. The case supporting the need for moral judgement is unpersuasive, while clinical judgement can be accommodated within resource allocation processes at little cost to deliberative democracy. In the next section, I turn to explore the consequences of transparency.[167]

4.2. Disutility and instability: on the consequences of transparency

This section deals with the criticisms that are concerned with the consequences of transparency. First, I answer the charge that greater transparency in clinical care resource allocation leads to greater disutility. Second, I turn to the issue of stability. Starting from the issue of utility, it is

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[167] This section has made it clear that deliberative democracy requires that clinicians be involved in resource allocation. Therefore, this is a fitting place to discuss an interesting position that, advanced by Orr and Wolff (2013), aims to shield clinicians from resource allocation. In brief, there should be a division of moral labour between "committee-room" decision-making, which equips clinicians with clinical care resources, and clinicians "at the front line". Roughly speaking, cost effectiveness should govern committee-room decision-making, while clinicians should only take resource constraints into account when costs are strikingly excessive. Importantly, this argument is also relevant to my thesis because it casts doubts on an assumption at work in chapters 5, 6 and 7, i.e., that the same values should govern the whole chain of clinical care resource allocation decision-making. My answer to Orr and Wolff is twofold. First, the proposed division of labour appears to be unfeasible because the choices made at the front line have too profound an impact on costs. As described by Veatch (1992) with regard to appendectomy, most clinical situations involve the possibility of a great deal of such marginally beneficial actions as blood tests, repeat tests, provision of back-up support, extension of hospital stay and follow-up appointments. Hence, if we wish to give any effect to the values governing committee-room decision-making, we have no choice but to encourage clinicians to apply them at the front line. Second, Orr and Wolff's division of labour is justified in light of the damages that the doctor-patient relationship would suffer if clinicians had to admit that cost effectiveness drives their choice of treatments. However, my thesis rejects cost effectiveness as an unsuitable value. Values like priority to the worst-off and ability to benefit make up less disturbing justifications.

argued that transparency harms both patients and the population at large. In Joanna Coast's words, transparent clinical care resource allocation results in both “deprivation disutility” (the additional burden that is experienced by those patients who know that, although a beneficial treatment exists, they will not receive it) and “denial disutility” (the anguish of being involved in the denial of beneficial treatments, which is experienced by the public at large). Thus, implicit procedures for resource allocation are preferable.[168]

This argument is unconvincing for reasons both internal and external to Coast's utilitarian framework. Implicit resource allocation procedures may be discovered and exposed, spreading a sense of betrayal among patients and citizens who thought that no rationing was taking place. In addition, the mere risk of being discovered makes the work of clinicians and other actors involved in implicit resource allocation distressing.[169] Moreover, only the patients who know that their care has been rationed stand a chance of having their health-related utility improved by taking advantage of such opportunities as exceptional funding panels, internal appeal procedures and legal proceedings. Finally, lack of transparency constitutes an obstacle to coordination among the multiple actors involved in clinical care resource allocation. Efficiency in the allocation and delivery of care benefits greatly from such coordination.

Besides failing to demonstrate that a utilitarian approach favours implicit rationing, Coast's argument rests on the shaky assumption that utility should determine whether clinical care resource allocation ought to be transparent. Section 3.2 argued that transparency is a matter of equal respect for the autonomy of individuals. Specifically, transparency implements the idea that we all have the necessary abilities to be admitted into the conversation about clinical care resource allocation. Equal respect is a principle of the utmost

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[168] Coast (1997).

[169] Doyal (1997).

importance. Hence, it is fair to say that, even if the level of disutility described by Coast actually resulted from transparency, it should be tolerated.

At this point, the critics of the consequences of transparency need to change tack and focus on the stability of clinical care resource allocation institutions. It is argued that greater transparency in resource allocation would result in a huge amount of patients resorting to legal action, while the public would demonstrate and lobby for change following media coverage of resource allocation decisions. Consequently, a severe strain would be put on the legal system and courts would force resource allocation agencies to retreat from numerous decisions. In turn, the persistent dissatisfaction with resource allocation would push towards continuous reforms of the health system.[170] In brief, this argument claims that transparency is unfeasible, posing a formidable challenge to deliberative democracy. To meet this challenge, an articulated response is in order.

To start with, implicit strategies have become increasingly impractical, offering no real protection against litigations, demonstrations and, in turn, instability. As pointed out by Norman Daniels and James Sabin, the public has become suspicious of clinical care providers. Besides, information technology enables laypersons to find and disseminate a wide array of information that resource allocation decision-makers may want to fudge.[171] Now, let us contrast implicit rationing with an approach to resource allocation that implements transparency *together with the other requirements of deliberative democracy*. My aim is to show that the latter approach can rely on *important resources to ensure stability that are*

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[170] Mechanic (1995) and (1997). To a certain extent, Mechanic's argument is supported by empirical studies pointing out that, once informed that their care has been rationed, many patients are ready to fight, be that via legal action or appeal procedures internal to the resource allocation agency – see Coast (2001) and Owen-Smith et al. (2009).

[171] Daniels and Sabin (2008, 40–41 and 49–51).

unavailable to implicit rationing.

Among other things, the supporters of implicit rationing claim that transparency is bound to put a huge strain on legal systems, leading to frequent reversals of original resource allocation decisions. To assess this claim, it is useful to look at the way in which the role of courts has changed since the 1990s, when the U.K. and other countries began to allocate clinical care resources more transparently. To be sure, there have been more legal actions to contest clinical care resource allocation decisions than in previous decades. Moreover, the courts have dropped the absolute unwillingness to interfere with clinical care resource allocation that once characterised them. However, this tendency has limited importance. While examining Canada, South Africa and the U.K., Keith Syrett writes that "it remains relatively rare for decisions to be subject to challenge".[172] In other words, the huge number of litigations envisaged by the critics of transparency has failed to materialise. Moreover, when decisions are subject to challenge, courts uphold the need for rationing and are generally unwilling to interfere with the *substance* of the rationales supporting original decisions. Apart from a few exceptions, courts rule against resource allocation decisions only when important procedural requirements have not been met. For example, it may be the case that no rationale can be extrapolated from the original decision or the decision-making process was not transparent.[173] In sum, if a system of procedural requirements similar to the one developed in chapters 2 and 3 was implemented, it is likely that most legal cases would be adjudicated

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[172] Syrett (2007, 159).

[173] See the analyses of the role of courts offered by Newdick (2005) and (2007) and Syrett (2007) and (2011). While remaining in line with the sketch that I offered in the main text, Jackson (2013, 74–88) describes three cases in which British courts appear to engage to a certain extent with the substance of the rationales offered by resource allocation agencies: *R (on the application of Otley) v Barking and Dagenham NHS Primary Care Trust*, *R (Murphy) v Salford Primary Care Trust* and *Servier Laboratories v. National Institute for Health and Clinical Excellence*.

quickly and favourably to original decisions, posing no real threat to stability.

Turning to the risk that the public might demonstrate and lobby against transparent decisions, the *design* of decision-making agencies can be adjusted in such a way that clinical care resource allocation is better shielded from protests, lobbying and the vested interests that are often behind them. Chapter 8 is devoted to the design of a system that encourages resource allocation decision-makers to follow public reason while insulating them from vested interests and the misguided passions that are widespread among the public.

In brief, chapter 8 welcomes the tendency to make most clinical care resource allocation decisions at the level of administration, as opposed to representative institutions. In addition, chapter 8 argues that the most sensitive decisions should be further insulated from disruptive influences, e.g. by building resource allocation agencies that work at arm's length from ministerial control. Resource allocation agencies should establish appeal procedures to channel contestation in constructive directions and employ actors (e.g. scientific experts and members of the public if involved in deliberative exercises) who can break with the biases that are entrenched in popular passions. In the same chapter, I explore arrangements aimed at spreading a positive attitude towards deliberation within representative institutions and the media, which shape the attitude of the general public towards politics. In sum, the prevailing message is that much can be done to protect resource allocation processes from the destabilising effects of demonstrations and lobbying.

To conclude my discussion of the resources available to ensure the stability of deliberative democracy, I wish to make a point about the ability to prevent hostile reactions in the form of both legal actions and mass protests. This point draws on the idea that the current levels of willingness to contest clinical care resource allocation decisions are at least partly due to decreasing *trust* in clinicians, public servants and other actors involved.[174] While implicit rationing and the associated risk of exposure are likely to lead to diminishing trust, transparency has the potential to build greater trust and, in turn, contribute towards stability.[175] To be sure, Onora O'Neill and others level strong criticisms at the link between transparency, trustworthiness and trust. I need to show that deliberative democracy can respond to those criticisms.

O'Neill claims that, in itself, transparency just means disclosure of information. Hence, transparency may lead to a number of scenarios, including ignorance that any disclosure has taken place, bewilderment in the face of an overwhelming amount of information, or frustration when dealing with dense rationales full of jargon. To create trust, transparency must be supplemented with norms that secure effective communication with the public, most notably relevance, intelligibility and honesty. Moreover, a way must be found to extend this form of communication in order to also address expert opinions, which are often incomprehensible to the general public.[176]

I argue that the norms proposed by O'Neill are already involved in my conception of deliberative democracy, which shares O'Neill's aim of securing effective communication with the public. In section 4.1, I limited the scope of transparency to formal decision-making processes in order to protect the quality of deliberation. However, this restriction is also necessary

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[174] Syrett (2007, 134).

[175] For the link between secrecy and erosion of trust, see Levinsky (1998).

[176] O'Neill (2002) and (2006). In suggesting that transparency is worthless if not coupled with understandability and veracity, Etzioni (2010) offers an argument that is analogous to O'Neill's. However, Etzioni also claims that widespread cognitive bias prevents the public from making good decisions about the information that is made public. In response to the latter claim, deliberative democracy has many ways to bypass the cognitive biases affecting our reasoning faculties. Indeed, chapter 8 discusses a number of arrangements aimed at encouraging the use of public reason over bias.

to select a core of fundamental information for the public to focus on instead of being flooded with an unmanageable amount of material. Moreover, public reason imposes demanding standards of deliberation, culminating with the command that decisions should be grounded in reasons that all reasonable persons might be expected to accept. Such norms as relevance, intelligibility and honesty are certainly involved in public reason, highlighting how close deliberative democracy and O'Neill's position are. As already noted in section 3.2, deliberative democracy acknowledges that the commitment to widely-intelligible arguments is limited by the need to ground decisions in the best scientific expertise available. In this context, effective communication can be ensured by using widely-accessible strategies for assessing the expertise and honesty of those who put forward incomprehensible expert opinions.[177]

According to O'Neill's own standards, deliberative democracy is in an excellent position to build trust in the actors involved in clinical care resource allocation. The public can check whether decisions and supporting rationales are actually implemented. Moreover, the public can appreciate that decision-makers are forced to make tough decisions by the scarcity of resources. Repeated contacts with any such system for clinical care resource allocation promise to build trust and, in turn, lead to a reduction in hostile reactions to resource allocation decisions.[178]

In conclusion to this section, I respond to an objection to my treatment of stability. At this point, a critic might argue that the mix of empirical evidence and more theoretical arguments offered in the previous paragraphs is not enough to demonstrate that a deliberative democratic approach to clinical care resource allocation can be stable *in the long run*. Indeed, our *social psychology* constitutes an obstacle that cannot be overcome. This

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[177] Such strategies are explored in section 9.2.
[178] See also de Fine Licht (2011, 196).

point is famously made by Guido Calabresi and Philip Bobbitt, who discuss situations in which societies routinely trade off human life for other values – for example, they examine the commissioning of dialysis machines. Although necessary, the decisions concerning those trade-offs should never be made transparently because, over time, the sense of the values that are sacrificed more often would be eroded.[179] On a similar note, Alan Fiske and Philip Tetlock maintain that every society places its values into separate spheres, which stand in a specific order of priority. Clinical care resource allocation involves trade-offs between health and market efficiency, which belong to spheres that are far apart along our order of priority. Now, this type of trade-offs is taboo. It does not matter if institutions have excellent reasons to make those trade-offs - no system that dealt with them in the open could last.[180]

To distinguish this kind of objections from the instability arguments that I have already tackled, I do not consider Calabresi and Bobbitt's and Fiske and Tetlock's arguments to be about the number of hostile reactions that transparent resource allocation has attracted in the real world or what, if anything, promises to further diminish such reactions. I take Calabresi and Bobbitt's and Fiske and Tetlock's arguments to work at a different level: no matter what is suggested by the empirical evidence and theoretical considerations that I have already discussed, the irrational mechanisms of our social psychology are still at work and, sooner or later, their consequences will be felt.

How can we answer this objection? To start with, most clinical care resource allocation decisions do not involve the type of trade-offs described by Calabresi and Bobbitt or Fiske and Tetlock. Most decision-making agencies have strong budgetary constraints. Thus, what they are supposed to

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[179] Calabresi and Bobbitt (1978).

[180] Fiske and Tetlock (1997).

do is distribute available money so that competing claims to life-saving and health-improving interventions are ranked and addressed in a fair manner. This fact suggests a first strategy for easing the worries voiced by Calabresi and Bobbitt or Fiske and Tetlock: whenever possible, clinical care resource allocation decisions should be framed so as to place centre-stage the fact that the real trade-off is life and health for life and health, not life and health for market efficiency. Of course, if we look at the level where the national budget for clinical care provision is fixed, life and health are traded off against other values, including market efficiency. However, my argument supporting the feasibility of transparency is strengthened by the fact that this level of decisions has traditionally been left in the open and the public seems rather comfortable with it.

Moreover, the most fundamental weakness in the objection under discussion comes down to the unsupported acceptance of an irrationalistic attitude towards the powers of persons in the face of social norms. In fact, neither Calabresi and Bobbitt nor Fiske and Tetlock provide any real evidence that, although certain choices are perfectly justified, individuals cannot stand to see those choices infringe on the social norms they have inherited. Here I do not need to deny that established norms play a role in political debates. However, we have no reason to believe that our social psychology would condemn to failure any system that regularly engaged the public in a transparent discussion of the need for rationing clinical care resources, the workings of resource allocation and the values that should govern it. In fact, it seems fair to claim that, over time, the majority of the public would simply be convinced by arguments that are perfectly reasonable without descending into any state of moral decay similar to the one envisaged by Calabresi and Bobbitt.[181]

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[181] Barry (1984, 303–309) puts forward a critique of Calabresi and Bobbitt that has important similarities with mine.

In sum, neither the consequences of transparency nor its inherent conception of reasoning pose challenges that deliberative democracy cannot counter. However, the supporters of implicit rationing are not the only theorists of clinical care resource allocation who may be willing to take issue with the proposal I develop in my thesis. Hence, the next section responds to the objections that may be raised against the stress that I place on procedural fairness.

4.3. Can substantive analysis fit within a theory of deliberative democracy?

The critique of procedural fairness that I wish to tackle is effectively stated by Richard Ashcroft. Procedural approaches to clinical care resource allocation posit that a decision is just if it results from a fair process. Moreover, Ashcroft notes that procedural approaches are often grounded in a "presumption of undecidability" of intricate substantive issues. Therefore, from the perspective of a procedural approach, the goal to ground resource allocation decisions in the best balance of substantive values sounds both *redundant* and *infeasible*. When a procedural approach to resource allocation is put into practice, the analysis of substantive values will therefore be hurried. Consultations and discussions will not go deep enough and the resulting treatment of substantive issues will provide a sub-optimal basis for decisions. Ashcroft is rather clear in placing blame; to a great extent, the problems associated with the procedural turn are the fault of ethicists, who seem to have given up their most distinctive task, which is to face intricate value issues head-on.[182]

This is a stimulating objection, which helps to see how different my

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[182] Ashcroft (2008).

conception of deliberative democracy is from the models of procedural fairness that Ashcroft has in mind. Specifically, I argue that my proposal accommodates the concerns forming the basis of Ashcroft's argument. For starters, the undecidability of substantive issues was rejected as a justification for procedural fairness in section 2.4, where I contrasted deliberative democracy with Daniels's accountability for reasonableness. In fact, the whole point of adopting the procedural requirements that make up my conception of deliberative democracy is to express and implement due respect to individuals.

Moreover, the provision of public reasons figures among the procedural requirements that I propose. Public reason requires that clinical care resource allocation decisions be based in well-constructed rationales, as opposed to bias and unsupported beliefs. Moreover, decision-makers must strive to identify those reasons that all reasonable persons might be expected to accept. If there is more than one such reason, participants must try their best to identify the single reason that they deem to be most reasonable. Given that the reasons at the centre of this process of deliberation centrally involve substantive values, my conception of deliberative democracy dictates that substantive values should receive an in-depth treatment, far from the type of treatment denounced by Ashcroft.

However, my proposal could still be attacked by the supporters of the role of substantive analysis in clinical care resource allocation. My response to Ashcroft did not take any stance about the *specific* substantive values that should govern resource allocation. Thus, as far as specific substantive values are concerned, it seems that anything goes. Political philosophy, moral philosophy and bioethics have traditionally been concerned with identifying which substantive values are valid and which substantive values are not. Consequently, real-world resource allocation decision-makers have reason to expect philosophical contributions to suggest which substantive values are suitable to govern resource allocation. As a procedural model, however, deliberative democracy seems condemned to fall short of such expectations, creating a problem of insufficient guidance.[183]

The response that I should give might seem straightforward. As stated several times in the previous chapters, my thesis intends to point out a number of substantive implications of deliberative democracy so that, in turn, these implications can be translated into clear guidance for decision-makers. However, there is little doubt that my plan would be greeted with scepticism by many. It might be argued that, at most, substantive recommendations constitute an *external* limit on deliberative democracy, because a theory of democracy only has the resources to deal with decision-making procedures. Although the specific content of my substantive recommendations is explored in chapters 5, 6 and 7, it is appropriate to respond here to the sceptics by outlining how deliberative democracy can have substantive implications and defending this function as part of a theory of democracy.

In brief, it is public reason that makes procedural fairness and substantive recommendations parts of the same package. As discussed in chapters 2 and 3, public reason requires that resource allocation decisions should be the result of a process in which participants exchange reasons that all reasonable persons might be expected to accept. If such a process were to take place, certain substantive values would be *affirmed by all* participants, while other substantive values would be *always rejected*. Thus, the former kind of values should be endorsed by the supporters of deliberative democracy, while values of the latter kind should be rejected as inconsistent with public reason. In fact, that decision-makers use and put aside the right substantive

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[183] For a similar critique of deliberative democracy, see Powers and Faden (2000). See also the criticism levelled at Daniels by Hasman and Holm (2005).

values contributes to measuring the extent to which a process for allocating resources upholds a fundamental requirement of deliberative democracy.[184] The analysis of which substantive values would be accepted (and rejected) during an exchange of public reasons assigns an important role to ethicists. In response to Ashcroft, deliberative democracy calls upon ethicists to engage with substantive issues in order to establish how such issues would be settled under the hypothetical conditions dictated by public reason.[185]

Now, what routes could be followed to identify the values that would be accepted by all and those that would be rejected during a discussion governed by public reason? To start with, the idea that *reasons* must be public excludes those substantive considerations that, as popular as they may be, are rooted in bias instead of well-supported rationales. For instance, section 6.4 argues that this is the case of the dread of cancer.

Two additional routes to substantive recommendations are especially prominent in a field like clinical care resource allocation. As we saw at the beginning of chapter 1, the rationing of clinical care resources is inevitable and not all beneficial interventions can be provided. Consequently, not all the health needs that could technically be addressed can be met in reality. This fact poses a serious challenge to public reason. In fact, one may doubt that reasonable persons whose health needs have deliberately been left aside can ever be expected to accept *any* resource allocation decision.

In response to this doubt, I reiterate that, by definition, reasonable persons are committed to proposing terms of cooperation that all can accept and, therefore, grounding decisions on rationales that take their own perspective into account on the same footing as everyone else's. Thus, each

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[184] J. Cohen (1993) and (1997) and Gutmann and Thompson (2002b) offer similar justifications in support of the view that deliberative democracy has substantive implications. For some critical perspectives, see Daniels (1999), Sunstein (1999) and Young (1999).

[185] The hypothetical dimension of public reason is discussed in section 2.3.

reasonable individual should be ready to give up her prospect of treatment if someone else has a stronger claim to treatment and the two treatments cannot both be delivered.[186] In turn, this means that public reason requires that clinical care resources should be allocated according to the strength of the claims to treatment that individuals can make. In sum, a prominent route to substantive recommendations is provided by the notion that rationing can only be acceptable to all reasonable persons if the *strongest complaint anyone can make* against the allocation of resources is made as weak as possible. Once the strongest claim to treatment has been attended to,

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[186] A critic could question this step in my argument by drawing on Scanlon's idea of a personal prerogative. Scanlon builds his contractualist moral theory on a notion of universal justifiability that is similar to my interpretation of public reason. However, he maintains that (at least in most circumstances) our duty to aid others stops with the "rescue principle", which states: "if you are presented with a situation in which you can prevent something very bad from happening, or alleviate someone's dire plight, by making only a small (or even moderate) sacrifice, then it would be wrong not to do so" (Scanlon, 1998, 224). According to Scanlon, reasonable persons are not required to give the same weight to their own interests and the interests of others in all their decisions - any such requirement would be too intrusive. Now, this idea of a personal prerogative clashes with my claim that reasonable persons should be ready to give up their prospect of treatment whenever someone else has a stronger claim to it. Is there anything that can be said against the personal prerogative? I start by noticing that this prerogative seems somewhat *out of place* within Scanlon's moral theory. Like my model of public reason, Scanlon's theory incorporates a strong commitment to impartiality, understood as the idea that when it comes to determining moral and political principles, each person matters just as much as any other. In my model, impartiality is reflected in the notion of *equal* respect that ultimately justifies public reason. Moreover, impartiality is reflected at two levels in the centrality of reasonableness, which is a commitment to proposing terms of cooperation that *all* can accept as long as each person is committed to finding terms that are acceptable to *everyone*. Analogously, Scanlon claims that a decision is wrong if it is grounded in a system of principles that *anyone* could reasonably reject. Now, this strong commitment to impartiality sits very uncomfortably with a prerogative lamenting possible intrusions on the part of moral and political principles into the freedom to value one's interests more than the interests of anyone else. Perhaps more importantly, much of the appeal of the personal prerogative seems rooted in the fact that Scanlon discusses scenarios where persons are considering whether they should contribute something which is presently *in their own possession* – e.g. a certain piece of information or a healthy limb. However, my thesis only discusses the allocation of clinical care resources, which are *held in common*. Even if we grant that it would be too intrusive to reject the personal prerogative in general or when it comes to re-distributing goods that are in an individual's possession, there is room to argue that universal justifiability is inconsistent with that prerogative in the case of clinical care resource allocation.

resource allocation decision-makers should turn to the second strongest claim, and so forth until resources run out. There are no perspectives from which such a resource allocation scheme could be reasonably rejected. Even those who hold the strongest complaint against that scheme should admit that theirs is the weakest strongest complaint anyone can have.

This route to substantive recommendations has much in common with the method of pairwise comparisons as proposed by Thomas Nagel. Pairwise comparisons are like my conception of public reason in that they constitute an ideal of universal acceptability grounded in equal and separate concern for individuals. The supporters of pairwise comparisons maintain that, when it comes to allocating scarce resources, the perspective of each affected individual should be compared with the perspective of everyone else, searching for the strongest complaint that any individual may have.[187] Section 5.1 explores what form the strongest complaint can take in the field of clinical care resource allocation, proposing a combination of priority to the worst-off and ability to benefit.

A further prominent route to substantive recommendations is provided by the strong presumption for *compartmentalisation* that is involved in public reason.[188] This presumption can be justified starting with John Rawls's argument that a satisfactory theory of distributive justice must not embrace intuitionism. According to Rawls, intuitionists claim that a plurality of substantive values apply to political issues and there is no explicit criterion to balance those values in case of conflict. If we cannot employ any explicit criterion to specify a complete order of priority or, at least, confine

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[187] Nagel (1991, 63–74). See also the arguments offered by J. Cohen (1997, 420–422) to derive priority to the worst-off from an ideal of legitimacy as exchange of public reasons.

[188] The notion of compartmentalisation has important points of contact with those philosophical proposals centred on such ideas as "spheres of justice" (Walzer, 1983) and "local justice" (Elster, 1992). Furthermore, my argument lends support to a view that is often voiced in policy debates, i.e., that agencies belonging to a government department should not concern themselves with tasks that are the business of other departments.

intractable value conflicts within narrow limits, we must accept that intuitions will do a lot of work in settling the numerous value conflicts involved in the distribution of resources. In this context, vested interests and sheer custom are free to influence how value conflicts are solved. Indeed, these factors can hide behind the opacity of intuitive judgements in a way that, given the absence of explicit criteria, is virtually impossible to detect.[189] The appeal of Rawls's argument becomes even greater when placed against the background of my conception of deliberative democracy. Deliberative democracy is meant to implement equal respect for the autonomy of individuals, i.e. their ability to impose decisions on themselves in light of their own reason. Now, if clinical care resource allocation decisions are steered by powerful lobbies or are based on the inertia of the status quo, the autonomy of citizens is blatantly violated.

One of the implications of the argument against intuitionism is that deliberative democracy should embrace a strong presumption for the compartmentalisation of the different areas of resource allocation that governments are responsible for. Given the link between the proliferation of substantive values and the violation of the autonomy of citizens, decision-makers should be extremely wary of allowing objectives of other government departments to flood into clinical care resource allocation processes.[190] As argued in section 6.5, the commitment to

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[189] Rawls (1999, 30–46).

[190] It might be objected that the presumption for compartmentalisation is in tension with my critique of Rawls's narrow view of the scope of deliberative democracy, offered in section 3.3. I have argued that if we do not endorse compartmentalisation, the values bearing on each issue will be too numerous for public reason to cope. Also, the supporters of the narrow view maintain that if we enlarge the scope of deliberative democracy, the values bearing on many political issue will be too numerous for public reason to cope. How is it possible that the abundance of values is not a problem when I discuss scope, but becomes a problem when I turn to compartmentalisation? To demonstrate that this tension is only apparent, it is enough to look more closely at my response to the narrow view of scope. My response was that public reason can filter out a large number of substantive values that are commonly proposed as suitable to govern clinical care resource allocation and other political issues. Therefore, even if we accept a broad view of the scope of

compartmentalisation is conducive to the rejection of substantive considerations concerning medical and scientific research.

Now that I have shown that argumentative strategies are available to draw substantive implications from deliberative democracy, it is time to respond to a final objection. In a sense, this objection is the mirror image of the criticism levelled by Ashcroft at the role of ethicists within procedural approaches. The idea is that substantive recommendations will always be out of place in a theory of democracy because they effectively usurp the authority of the public to the benefit of ethicists.

Perhaps the most obvious example of this alleged usurpation is provided by the conflict between the substantive implications of public reason and the requirement of public involvement. Regardless of the proposed substantive implications of public reason, involving members of the public in clinical care resource allocation is likely to lead to decisions that, at least sometimes and in certain respects, contradict those implications. Truthfully, the problem reaches beyond public involvement, because any real-world clinical care resource allocation decision-maker is likely to make some decisions that deviate from the recommendations of public reason. Hence, the tension is with the freedom of expression and the right to hold public office of whoever is appointed to make resource allocation decisions.

The objection under consideration is of particular concern because my thesis aims to demonstrate that public reason provides answers to numerous substantive questions with the resulting recommendations sometimes being inconsistent with the beliefs held by a large number of the citizens living within our societies. In fact, I aim to demonstrate that a significant number of potentially controversial substantive recommendations are the product of

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deliberative democracy, the number of values bearing on each political issue will be limited. In sum, my critique of the narrow view of scope is consistent with the idea that decision-makers should be extremely wary of pursuing aims that belong to other government departments.

an attitude of reasonableness that is enacted by proposing terms of cooperation that all can accept, which section 2.3 showed to be an integral part of the way in which deliberative democracy works.

My response to this objection is twofold. First, Rawls effectively pre-empts this type of criticism by pointing out that public reason is a *moral*, not a *legal*, duty. In other words, the requirement of decision-makers to use public reasons must not be enforced by the law.[191] Therefore, deliberative democracy denies that procedures should be in place to reverse the decisions that are simply inconsistent with the substantive implications of public reason.[192] Provided that courts and other bodies of guardians are forbidden from stepping in when public reason is not followed, no amount of controversial substantive recommendations can possibly usurp any authority from the public and other legitimate decision-makers.

In other words, as long as persons who are not fully reasonable and disagree with the substantive recommendations of public reason exist within societies, such persons will play a central role in political life as understood by my conception of deliberative democracy. Some of them will be involved in clinical care resource allocation as members of the public, while others will simply be appointed as decision-makers. In this way, persons who disagree with the substantive recommendations of public reason will be free to participate at all levels of discussion and decision-making, trying their best to ensure that clinical care resource allocation decisions are consistent with their own ideas. Given that courts are forbidden from stepping in when public reason is not followed, to accept a requirement of public reason does not equate to limiting or removing the authority of the public.

Second, no substantive recommendation should be considered to be the

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[191] Rawls (1996, 212–213).

[192] Section 8.1 discusses the grounds of appeal that are suitable for a deliberative democratic approach to clinical care resource allocation.

final word concerning the particular matter at hand; substantive recommendations are nothing more than contributions to a *continuing* process that is *inclusive* of a wide range of actors. Indeed, all substantive recommendations made by ethicists must be thought of as something that is offered for consideration to academics, clinical care resource allocation decision-makers and the public at large. No matter how controversial one's recommendations may sound at first, the hope is that they withstand criticism and are found to be compelling interpretations of what public reason requires, gaining momentum and convincing decision-makers and members of the public that they should be put into practice by resource allocation agencies. Moreover, no matter how established it may be, any recommendation is always open to discussion, refinement and rejection, reinforcing the conclusion that no authority is taken away from the public by the effort to work out the substantive implications of deliberative democracy.[193] All the substantive recommendations that I intend to make in my thesis are meant to be a contribution to the ongoing inclusive process that I have just outlined.

4.4. Conclusion

This chapter has been devoted to the defence of deliberative democracy from two criticisms coming from within the debate over clinical care resource allocation. Specifically, I have dealt with a family of arguments that, by attacking transparency, casts doubts on the tenability of much of my model of deliberative democracy. Also, I have answered the objection that deliberative democracy involves lack of attention towards substantive questions. In answering this objection, I have highlighted the great potential

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[193] Gutmann and Thompson (2002b).

of deliberative democracy to settle substantive issues. Chapters 5, 6 and 7 build upon the analysis carried out in this chapter in order to explore the ability of deliberative democracy to provide determinate answers to issues concerning the substantive values that should govern resource allocation.

5. SUBSTANTIVE VALUES I: IN SUPPORT OF PRIORITY TO THE WORST-OFF, ABILITY TO BENEFIT AND SPECIALNESS OF CLINICAL CARE

One of the recurring themes of my thesis is to show that my conception of deliberative democracy has the necessary resources to provide a good deal of recommendations concerning the substantive values that should govern clinical care resource allocation. Four chapters are devoted to the broad issue of the substantive recommendations of deliberative democracy. This chapter and the next aim to explore, one by one, a number of substantive values that have been proposed as suitable to govern clinical care resource allocation, so as to determine which values are affirmed and which ones are rejected by public reason.

Proposals concerning which substantive values should be employed can be drawn from a number of contexts: academic literature in the ethics of clinical care resource allocation; the preferences of the public; and documents issued by bodies engaged in actual resource allocation, like NICE and Clinical Commissioning Groups within the NHS. A great many values are proposed in these contexts, and I do not have the space to discuss them all. Thus, this chapter and the next focus on exploring the values that enjoy *the greatest support*.[194] In circumscribing the range of values to be discussed, a specific sort of *representativeness* should also be sought.

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[194] The support enjoyed by the values that I examine is discussed when I analyse them one by one.

Accordingly, the values under discussion should embed a wide array of concerns and conceptions of the goals of clinical care resource allocation. The list of values resulting from my search for widespread support and representativeness is the following: priority to the worst-off; ability to benefit; specialness of clinical care; aggregation of benefits; cost; fair chances to be treated; individual responsibility for health; dread; government and stakeholder priorities; innovation; lack of alternative treatments; and rarity.

At the end of the analysis developed in this chapter and the next, it is determined that deliberative democracy does not require that one single value should govern resource allocation. However, public reason filters out a great deal of values that are commonly proposed as relevant. This result is in line with the idea that public reason constitutes a "duty of restraint" from a good deal of considerations that may be appealing to those who do not operate from within public reason.[195] Indeed, public reason only endorses priority to the worst-off and ability to benefit, framed by the idea of specialness and constrained by cost considerations. Chapter 7 pulls together the different parts of the analysis carried out in this chapter and the next, exploring the underlying spirit of my framework of values, how to use it to create a decision-support tool and why the filtering ability of public reason constitutes a strength of my approach. Instead, chapter 8 discusses how to implement the use of public reason in dealing with substantive values.

This chapter focuses on three values that are affirmed by public reason, which are priority to the worst-off, ability to benefit and specialness of clinical care. In contrast, the arguments proposed in chapter 6 are mainly negative. Section 5.1 demonstrates that priority to the worst-off and ability to benefit give concrete shape to the commitment to minimise the strongest

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[195] Macedo (2008).

complaint. In section 5.2, I argue that widely-held intuitions and a solid abstract principle support the idea that clinical care is special and, therefore, should be distributed in isolation from other social goods and more equally than the majority of them. Next, section 5.3 defends the specialness thesis from an objection rooted in the research on the social determinants of health. Finally, section 5.4 discusses the implications of my argument. In particular, I argue that priority to the worst-off and ability to benefit should be understood in terms of health, not overall well-being, opening the door to the use of Quality-Adjusted Life Years.

5.1. The case for priority to the worst-off and ability to benefit

This section starts by showing that priority to the worst-off and ability to benefit are upheld by public reason because they are capable of giving concrete shape to the strongest complaint against resource allocation. Next, I discuss whether there are other possible shapes that the strongest complaint may take. Questions concerning the way in which priority to the worst-off and ability to benefit should be understood are considered at the end of the section.

Section 4.3 discussed how it is possible that rationing decisions can ever be acceptable to all, including those whose health needs are not met. I argued that any reasonable person should be ready to give up her prospect of treatment if some other individual has a stronger claim to treatment in the case that the two treatments cannot both be delivered. Thus, the minimisation of the strongest complaint anyone may have against resource allocation arrangements emerged as a key component of the exercise of public reason. Given this strong conclusion, it makes sense to start my analysis of substantive values with the question, what are the shapes that the strongest complaint can take in clinical care resource allocation?

Being *the worst-off* is probably the most natural answer. The link between universal acceptability and priority to the worst-off is defended at a general level by Thomas Nagel. Public policies should be acceptable to each individual. This means that pairwise comparisons between each person and all other affected individuals are in order to determine whose claim is stronger and, therefore, should be favoured. In turn, pairwise comparisons lead to paying special attention to the lower member of each pair, giving priority to the worst-off.[196] Focusing on the clinical care context, the patient who is in a poor condition, with a bad prognosis if not treated, strikes us as having an extremely strong complaint against resource allocation arrangements that do not help her.

Arguably, the major objection to the idea that priority to the worst-off should be used to specify the strongest complaint is rooted in the so-called "bottomless pit" problem.[197] Even when no full recovery or even substantial benefit is possible, medical technology can often do something. For example, it is often the case that we can offer marginal gains in life expectancy to terminally ill patients, or small improvements in quality of life to patients suffering from debilitating diseases. In many cases, the door is always open for some additional intervention. Hence, it seems that, if we accept priority to the worst-off, we are committed to consuming huge amounts of resources to attend to such patients even though they only benefit minimally from treatment.

The bottomless pit problem can be solved from within my model of deliberative democracy. Being badly-off is not the only basis for complaint against resource allocation. In fact, there is also *ability to benefit*, i.e., the

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[196] Nagel (1991, 63–74)

[197] Arrow (1973) provides an early example of this critique. See also Brock (2002, 370–371).

size of the gain that individual patients can realise from treatment. That a patient could have greatly benefited from a treatment that has not been delivered imposes itself as a strong complaint against the way in which resources have been allocated. This is a different complaint from the one grounded in how badly-off the patient is – indeed, it seems fair to argue that if two patients are equally badly-off, but one can benefit more than the other, the former has stronger reason to complain against an unfavourable resource allocation arrangement.[198] Therefore, public reason dictates that, when faced with a patient with great ability to benefit, many should be ready to acknowledge that they are behind in the order of priority.

The exact trade-offs between priority to the worst-off and ability to benefit are difficult to settle.[199] However, it seems fair to say that, if a patient is denied a treatment that could have provided her with considerable benefits, her complaint is stronger than that of a patient who, although among the worst-off, can only receive trivial benefits from treatment. This idea is confirmed by a number of empirical studies in which members of the public appear to withdraw support for the worst-off when the worst-off cannot benefit significantly from treatment.[200] I argue that the widely-held intuitions identified by those studies are in a sort of reflective equilibrium with the outputs of the process of specification of priority to the worst-off. As discussed in section 3.3, Henry Richardson's idea of specification is a model of public reasoning that is grounded in the notion that the point behind a value may be partially explained by other values that we accept.[201] Crucially, this relation of mutual support appears to occur between priority

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[198] Scanlon's contractualism is the locus classicus for the argument that the degree to which individuals can benefit is a crucial component to the strongest complaint against a decision - see Scanlon (1998, 223–229).

[199] Section 7.2 explores in greater detail how to handle conflicts among values accepted by public reason.

[200] See the studies collected in Dolan et al. (2005, 201).

[201] Richardson (1990) and (2002, 214–230).

to the worst-off and ability to benefit. What could the motivation behind a concern for the worst-off be if not the willingness to *give help* to those who are badly-off? Thus, if the magnitude of the help we can give is trivial, the motivation behind priority to the worst-off loses force, clearing the way for the conclusion that, if the worst-off is capable only of receiving marginal benefits, ability to benefit should receive priority. In turn, this conclusion allays the concerns at the basis of the bottomless pit problem.

Are being badly-off and having a considerable ability to benefit the *only* bases for a complaint against clinical care resource allocation? I cannot provide an affirmative answer with absolute certainty. My analysis only discusses the most strongly supported and most representative among the substantive values that are proposed. Therefore, I cannot exclude that someone might come up with an additional value that I do not consider, claiming that it should contribute to shaping the idea of the strongest complaint.

However, we have reason to believe that priority to the worst-off and ability to benefit are most likely to remain the core of any account of the strongest complaint in clinical care resource allocation. Several authors in moral and political philosophy have recently discussed the distribution of scarce aid resources using methods that, based on pairwise comparisons or the search for the strongest complaint, have much in common with my idea of public reason. Besides the already-mentioned Thomas Nagel, at least Frances Kamm and Thomas Scanlon certainly deserve a mention. Well, in support of my account of the strongest complaint, values analogous to priority to the worst-off and ability to benefit dominate their proposals.[202]

To be honest, clinical care resource allocation seems to provide a natural

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[202] Kamm (2007, 11–77), Nagel (1991, 63–74) and Scanlon (1998, 189–247). A supporter of Scanlon's contractualism may object that personal responsibility should count as additional basis for complaint. However, section 6.4 shows that the appeal to personal responsibility is untenable.

candidate as an additional component of the strongest complaint that is likely to be missed by abstract investigations into moral and political philosophy: discrimination against those who are affected by disabilities that pre-exist to the disease that is considered for treatment. In the case of life-saving treatments, pre-existing disabilities seem to reduce the ability to benefit of patients. This is because pre-existing disabilities reduce the quality of life that a person can enjoy after treatment and, sometimes, reduce life expectancy. Moreover, to treat persons with pre-existing disabilities may be more expensive than treating the non-disabled. For example, to treat obese patients may lead to extra costs going down to the need for extra staff and equipment of the right dimension and strength.[203] We have seen that deliberative democracy puts a premium on ability to benefit, while section 6.2 aims to demonstrate that public reason supports cost considerations, at least as tie-breakers. Thus, instead of taking extra care of those patients who are so unfortunate as to suffer from pre-existing disabilities, my model seems to put them at a further disadvantage by according higher priority to the non-disabled. In John Harris's words, this “double jeopardy” may strike some as an additional basis for complaint.[204]

My response is that discrimination against pre-existing disabilities is not well understood as a further basis for complaint in addition to priority to the worst-off and ability to benefit. Indeed, whether or not any double jeopardy takes place is a function of how the worst-off and ability to benefit are understood. Some believe that ability to benefit should be calculated by “zooming in” on the condition to be treated, leading to a *treatment-specific conception* of ability to benefit. Using Dan Brock's example, if a treatment for severe allergic reactions promises to be equally effective in protecting the airways of both a disabled and a non-disabled patient, the two patients

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[203] Brock (2009, 30).

[204] Harris (1987) and (1995). For a critical perspective, see Singer et al. (1995).

should count as equally able to benefit.[205] Moreover, it is argued that the worst-off should be understood as those whose *life as a whole* will have been worst affected if untreated. According to this conception of the worst-off, the impact that pre-existing disabilities have had on past quality of life contributes to determining how badly-off patients should be considered to be for the purposes of resource allocation.[206] If any of these proposals was accepted, the discrimination against pre-existing disabilities would be minimised, if not completely eliminated.

Unfortunately, these proposals provide examples of the definitional issues that I have to place beyond the scope of my argument. The aim of my analysis of substantive values is to determine which values should be affirmed and which ones should be rejected starting from the list that I identified at the beginning of the chapter. Given their complexity, I simply do not have the space to address numerous issues concerning the way in which the values that I accept should be understood. Thus, I have to bracket the issue of non-discrimination against pre-existing disabilities. However, I have argued that the risk of discrimination against pre-existing disabilities is a function of how the worst-off and ability to benefit are understood. And this argument suffices to respond to those who might think that discrimination against pre-existing disabilities constitutes an additional basis for complaint.[207]

Despite my remarks about the need to keep clear of most definitional issues, there is one such issue, that of evaluative space, that cannot be

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[205] Brock (2009, 40–42).

[206] Brock (2002, 369–370) and Persad et al. (2009, 424–425). For a different view of the way in which past, present and future states of need should be factored in to determine who the worst-off are, see Kerstein and Bognar (2010) and Nord (2005).

[207] As a prominent example of those definitional issues that fall beyond the scope of my argument, it is worth mentioning the question of who should be called upon to rate how bad a certain condition is. Should members of the public do the ratings, or should we ask actual patients? Menzel et al. (2002) and Ubel et al. (2003) discuss the arguments for and against each option.

bracketed. Should the worst-off and ability to benefit be understood in terms of health or overall well-being? This question lies at the centre of the controversy over the specialness of clinical care, which falls within the list of values provided at the beginning of the chapter. The next two sections are devoted to the defence of the specialness thesis. As I intend to discuss in full detail in section 5.4, the specialness thesis supports the idea that health provides the appropriate evaluative space.

5.2. The specialness thesis: intuitions and abstract principles

This section and the next aim to demonstrate that decision-makers committed to public reason should uphold the idea that clinical care is special. The idea that clinical care is special means believing that clinical care should be distributed *in isolation* from other social goods and more *equally* than most of them.[208] As anticipated at the end of the previous section, the specialness thesis works as a frame within which to understand other substantive values. Moreover, the specialness thesis provides negative recommendations, excluding such considerations as wealth and social position from the substantive values that should govern clinical care resource allocation.

My argument for the specialness thesis starts with the intuitions that, widely shared in our societies, support isolation and equality in clinical care resource allocation. The public would be uncomfortable with any allocation of clinical care resources based on the way in which other social goods are distributed. This attitude is particularly evident in the case of wealth and works in both possible ways. First, the proposal that lower priority for treatment should be given to the rich would be received as counter-

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[208] Segall (2007).

intuitive.[209] Second, in Norman Daniels's words, "people who tolerate vast inequalities in wealth and power are often morally outraged when those who are ill cannot get care because they cannot pay for it".[210]

Widely-held intuitions go some way towards justifying the specialness thesis as a substantive value accepted by public reason. When spaces of consensus emerge in our deeply pluralistic societies, it is often because they are grounded in solid reasons capable of winning the consensus of reasonable persons. By themselves, however, widely-held intuitions do not yet amount to public reasons. Indeed, widely-held intuitions may well rest on entrenched bias. Thus, I need to demonstrate that our intuitions about specialness fit within a wider context of further intuitions and abstract principles that are compelling to those engaged in the search for public reasons.

Daniels provides a compelling account of the abstract grounds of our intuitions. His account links the value of health and clinical care to the protection of *opportunities*; good health protects the range of life plans open to individuals, while bad health threatens the individual's ability to pursue a wide variety of activities. In Daniels's words, "the impairment of normal functioning by significant pathology, such as serious disease, injury, or disability, restricts individuals' opportunity relative to the portion of the normal range that their skills and talents would have made available to them

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[209] Arrow (1973) and Brock (2002). In examining a series of empirical studies, Dolan et al. (2005, 203) find that respondents are generally unwilling to discriminate in favour of the poor.

[210] Daniels (2008, 18). It might be objected that the case of the U.S. shows that the intuitions supporting the specialness thesis do not hold in all liberal-democratic societies. Many U.S. residents are covered by private insurance, or have to pay out of pocket, for all non-emergency treatments. Moreover, Barack Obama's attempt to extend access to clinical care has been met with considerable resistance. Nonetheless, I argue that the common culture of the U.S. shares the intuitions supporting the specialness thesis. First, equal access is granted to everyone in the case of emergency treatments. Second, a core of clinical care interventions is isolated from ability to pay in the case of the poor, the elderly and the veteran. Third, there is the outrage routinely generated by the media coverage of stories in which someone is denied intervention on the basis of ability to pay.

were they healthy".[211] In turn, clinical care is said to protect health.

Having the opportunity to choose from a range of life plans and to pursue the life plan one prefers is something of great importance. How should opportunities be distributed by a society committed to public reason? No one who is committed to proposing reasons that each reasonable person can accept would recommend an unequal distribution of opportunities, at least among individuals who are born with a similar level of natural talents and skills. If someone is given an extra share of opportunities on top of what everyone else is given, this is bound to reduce someone else's opportunities. This view is crystallised in John Rawls's principle of fair equality of opportunity (FEO) in the competition for jobs and offices, which states that the only arrangement that is acceptable to all is equality of opportunity among persons who have the same level of natural talents and skills.[212]

Before completing the description of Daniels's case for the specialness of clinical care, I pause to consider a possible objection. A critic might claim that it is false that the only universally acceptable pattern of distribution of opportunity is equality. She may assert that inequality can sometimes produce a greater sum-total of opportunities, which creates conditions for *everyone* to enjoy a wider range of opportunities than under equality of opportunity. Consider an example from education, which provides the most classic case of social good protecting opportunities. Imagine that a society needs to choose whether to permit a private education sector or to keep the prohibition on private education in the context of a low-quality state school system that is free for all. If private education was allowed, fees for private schools could be heavily taxed, creating resources that could be used to improve the education of everyone attending state schools.

The first problem with this kind of example is that although it may seem

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[211] Daniels (2008, 44).

[212] Rawls (1999, 73–78).

obvious that the life plans available to those attending public schools would benefit from the taxes supplied by the private schools, that is not necessarily the case. Individuals attending private schools would have better chances to get the best jobs than those attending state schools. As I intend to discuss in a few paragraphs, the pursuit of one's career is not the whole picture of opportunity, but it certainly represents an important component of the life plans of individuals. Although individuals attending state schools would have the chance to develop greater skills and abilities than before, it is not clear that *on balance* the range of opportunities available to them would be wider than when private education was prohibited.

A second problem with this objection holds even if we assume that in the example above, the opportunities available to every state school attendee are lower when private education is prohibited. Even if we grant this assumption, the example does not refute the idea that giving a more-than-equal share of opportunities to someone is bound to reduce the opportunities of someone else. Indeed, we have seen that the introduction of private schools takes away opportunities to get the best jobs from the individuals attending state schools. The opportunities of those attending state schools increase only because *a further choice* has been made - in this case, deciding that the money paid to private schools should be heavily taxed, so that revenues can be used to boost the performance of state schools. Hence, the opportunities of those educated at state schools are greater than when private education was prohibited only because society has decided that *an extra amount of money* should be spent on state education and, thereby, the fostering of opportunities. It is this extra money, not the unequal distribution of opportunities, that does all the work in creating the conditions for everyone to enjoy greater opportunities than before.

Methodologically, it is highly questionable to compare the opportunities produced by two systems of institutions that invest considerably different amounts of money in education and, thereby, the fostering of opportunities. The difference in the money spent is bound to interfere with and invalidate any conclusion we may want to draw about the impact of patterns of distribution of opportunities or any other variable. If society has reason to believe that state education deserves the amount of money that would be collected by permitting private education and taxing the fees for private schools, that amount of money should have been allocated for state education from the beginning, for example by raising taxes on income. If this had been done, it would have been clear that giving a more-than-equal share of opportunities to someone is bound to reduce the opportunities of someone else, clashing with the commitment to universal justifiability.

Having defended the link between universal acceptability and an egalitarian pattern of distribution of opportunities, let us return to Daniels's analysis of FEO and health. Daniels convincingly argues that FEO should be extended beyond the competition for jobs and offices. The life plans of virtually all individuals include numerous strategic objectives above and beyond the pursuit of one's career. Therefore, we should endorse FEO in the choice and pursuit of life plans *in general*. Importantly, the scope of the revised version of FEO includes a wider variety of situations in which bad health may interfere with the opportunities of individuals.[213]

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[213] Daniels (2008, 57–60). It might be asked why my argument refers to FEO and not another principle of equality of opportunity – for some criticisms that can be levelled at FEO, see Arneson (1999). I use FEO because my argument builds upon the work done by Daniels, and that is his main focus. Daniels justifies his choice of focus by saying that Rawls's theory of justice, which includes FEO, is currently the most well-developed general theory of justice. Furthermore, FEO is animated by concerns that sit very well with the role that public reason plays in my thesis. As I mentioned in the main text, Rawls thinks of FEO as the principle of opportunity that every person can accept. In any case, little in my argument depends on my choice of referring to FEO. Indeed, Daniels (2008, 63-77) demonstrates that when it comes to establishing the value that health and clinical care have for justice, it would not make much difference if I abandoned FEO and switched to either the capability approach or luck egalitarianism, which provide alternative accounts of equality of opportunity. Health is valuable because it protects the ability of individuals to

Now that the case for FEO has been made, the question becomes, how should we distribute the social goods protecting the opportunities of individuals? Daniels seems to think that each of those goods should be treated as special, excluding the possibility that the provision of more of one of them can compensate for less of another one. Still, this thought is in need of justification – in what follows, I put forward two considerations in support of Daniels's idea.

A first consideration is provided by our intuitions concerning the paradigmatic case of education. I have already mentioned that the knowledge, skills and qualifications obtained through education are the most classic example of goods protecting the range of life plans open to individuals. In fact, we have strong intuitions that equality and isolation from other social goods should regulate access to education. All Western

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pursue life plans. Given that to pursue a life plan is to do and be what that plan requires, Daniels's analysis identifies a capability space that Sen (1992) and the other followers of the capability approach should be concerned with. Moreover, Sen argues that the pursuit of equality must be limited for reasons that include the need to balance equality against efficiency and liberty. According to Daniels, this shows that the capability approach has to limit the range of unjustified inequalities in a way that is likely to be similar to Rawls's use of the natural distribution of talents and skills as a baseline. Turning to the luck egalitarian approach to equality of opportunity, authors such as Arneson (1989) and G. A. Cohen (1989) claim that the aim should be to eliminate inequalities in advantage or welfare that are not the responsibility of the individuals involved. Given that disease can lead to disadvantage and a loss of welfare, luck egalitarians should be concerned with health. However, Daniels points out that health is different from other targets of equality of opportunity. Consequently, even those who support a luck egalitarian approach to equality of opportunity should drop any reference to responsibility when it comes to health (for some of the reasons why the idea of responsibility becomes unviable when applied to health, see my own argument in section 6.4). Daniels concludes that the only relevant difference between FEO and a luck egalitarian approach lies in the fact that luck egalitarians reject the use of natural talents and skills as a baseline, therefore advancing a more expansive view of equality of opportunity. A society endorsing a luck egalitarian approach would be more willing than a Rawlsian society to fund the enhancement of non-pathological traits of persons who have a low level of natural talents and skills, although enhancement would be limited to cases in which non-pathological traits prevent an individual from pursuing all life plans that have the same pay-off (in preference satisfaction or advantage) as the best life plan that is available to anyone else. Importantly, neither my case for the specialness thesis nor any other argument in my work hinges upon the rejection of the idea that equality of opportunity should be concerned with the enhancement of non-pathological traits when enhancement heavily contributes towards equality of opportunity.

countries share the idea that everyone must receive an education up to a certain level. In numerous European countries, higher education is also heavily subsidised by the state, so that access to university is either completely or largely insulated from ability to pay.[214] Even in countries where university fees are high and private primary and secondary schools offer a better education than their public counterparts, it is clear from the public debate that many are outraged by the way in which ability to pay is allowed to interfere with the allocation of a good such as education.[215] Now, we have already seen that similar to the knowledge, skills and qualifications obtained through education, good health safeguards the range of activities open to individuals. Let us assume that clinical care protects health and postpone until the next section the argument that clinical care is but one among many factors affecting health. Consequently, clinical care should be treated as special.

Are widely-held intuitions enough to prove that societies are not allowed to, for example, provide some individuals with access to an extra amount of clinical care in exchange for less education? A further argument is that education and clinical care counter different threats to FEO. In brief, education is about building a set of "positive" abilities that allow individuals to cope with a range of different activities, while clinical care makes sure that this process of construction can start and what has been built does not break into pieces. To trade off more clinical care for less education (or vice versa) is likely to lead away from FEO, showing that education and clinical care are each to be treated as special.

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[214] http://europa.eu/youreurope/citizens/education/university/fees-and-financial-help/index_en.htm (last accessed 14/10/2014).

[215] Focusing on the U.K., it is worth mentioning the protests following the government's choice to raise university tuition fees in 2010. Moreover, there is the endless debate over the problem of the performance gap between state and private schools, which has recently developed around the decisions of the Prime Minister and the Secretary of State for Education to send their children to state schools – see Adams (2014) and Shipman (2014).

In sum, the widely-held intuitions supporting the specialness thesis are in reflective equilibrium with other widely-held intuitions (about education, for example) and a solid abstract principle, i.e. FEO. This principle nicely fits within the frame of mind imposed by public reason, which involves an individualised concern for each affected party. This individualised concern sits well with a principle explaining specialness in terms of the opportunities that each individual is entitled to.[216]

5.3. The objection from the social determinants of health

This section aims to respond to a formidable challenge to the specialness thesis, posed by the social determinants of health.[217] Until a few decades ago, it was widely assumed that universal access to comprehensive and good-quality clinical care (at least if coupled with public health programmes) was all that was needed to improve aggregate population health and create greater health equality among groups. This assumption was dealt a major blow in 1980, when the Black Report was published in the U.K. Although more than 30 years had passed since the establishment of the

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[216] Segall (2009, 32–34) points out that large amounts of resources are currently spent on patients in the twilight of their lives - for example, around 30 percent of the U.S. clinical care expenditure is spent on patients who are within the last six months of life. Given that these patients do not seem to be in a position to pursue life plans, FEO fails to justify the resources spent on them. Thus, the relief of extreme pain or some other principle should be proposed alongside FEO to explain the specialness of clinical care – on the last point, see also Schramme (2009). A threefold response demonstrates that this criticism is not as damaging as it might initially look. First, that an intervention is administered to someone within the last six months of life is something that, in many cases, can only be known post factum. Thus, the aim of many such interventions is to restore patients to a state in which they can pursue their life plans for much longer than six months. Second, a good deal of resources should be spent on patients within the last months of life precisely because FEO focuses on life plans. Indeed, it is important that patients are enabled to bring their life plans to a fitting conclusion. Third, there is room to argue that we are spending too many resources on patients at the end of their lives and, therefore, part of these resources should be directed elsewhere.

[217] For the definition of social determinants of health, public health and clinical care, see section 1.3.

NHS, health inequalities between socio-economic groups had been growing rather than diminishing.[218] Over the following decades, research carried out by epidemiologists such as Michael Marmot and Richard Wilkinson established that to a large extent, health inequalities among groups are determined by socio-economic factors such as income, housing, employment and place in the workplace hierarchy, education level and social inclusion.[219]

The same socio-economic factors have been shown to be by far the most important contributor to aggregate population health. Taken together, clinical care and public health are estimated to account for no more than one fifth of the life years gained in the last century, which means that the contribution of clinical care alone has been even smaller.[220] Socio-economic factors strongly affect our propensity to disease and injury. Furthermore, the fact that the ill have access to clinical care has a much smaller impact on population health than the socio-economic factors that make individuals ill in the first place.

In the previous section, I argued that the specialness of clinical care is grounded in the ability of clinical care to protect health. However, the research into the social determinants of health has demonstrated that many factors other than clinical care protect health. Shlomi Segall and James Wilson employ such research to argue that many goods other than clinical care are to be valued on a par with it. What are the implications for the specialness thesis? A choice needs to be made between two equally problematic options.

On the one hand, *each determinant of health* might be taken to be special. The problem is that, from the perspective of justice, we have reasons to care

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[218] Department of Health and Social Security (1980).

[219] Marmot and Wilkinson (2006).

[220] Segall (2007, 353–354).

for virtually all the social determinants of health in themselves and not only because they protect health. Thus, the idea that equality and isolation should govern the distribution of each social determinant is implausible because it implies that the just distribution of, say, income as it affects health should override what justice would require for it if considered on its own.[221] Moreover, the idea that all determinants of health should be distributed in isolation is inconsistent with the egalitarian willingness to allocate more of a particular resource to those who have less of other social or natural goods.[222]

On the other hand, *health* might be considered to be special. Thus, clinical care, public health and social determinants should be allocated so as to create an egalitarian distribution of health. However, an egalitarian distribution of health can only be achieved if the distribution of each determinant of health is sensitive to the way in which the other determinants are distributed.[223] Consequently, those who are disadvantaged with respect to some social determinant can now be compensated by means of extra rights to clinical care, contradicting the idea that clinical care is special. Even the complete exclusion of a group from clinical care may result in the reduction of health inequalities, provided that those excluded from clinical care are compensated by means of a generous distribution of the social determinants.[224]

In sum, it seems that epidemiology has refuted the specialness thesis. In answer to this critique, I argue that Segall and Wilson fail to notice that clinical care has *a different function* from public health and social determinants. Clinical care is important beyond its contribution to aggregate health and the reduction of health inequalities between groups. Indeed, clinical care protects health by attending to complaints that a) come from

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[221] Wilson (2009, 5).

[222] Segall (2007, 359–360).

[223] Segall (2007, 358–359).

[224] Sreenivasan (2007, 27–28).

individuals and b) include the strongest complaints that anyone may have in relation to health. The function played by clinical care places it *uniquely close to public reason*, proving that only clinical care should be regarded as special.[225]

Imagine that a society has decided to commit a great deal of resources to public health and the social determinants. Consequently, aggregate population health has greatly improved and we are close to health equality among groups. Would this state of affairs satisfy FEO? Considering that we are looking at FEO through the lens of public reason, the answer is negative. Public reason articulates a concern for *individuals*, not for the population at large or groups. Regarding the distribution of scarce resources, public reason requires that the strongest complaint that any individual may have should be minimised. Thus, regardless of how much is invested in public health and social determinants, there will always be instances of the core problem that public reason has with with poor health – namely, an individual complaining that, without further intervention, she will have many less opportunities than most other individuals. In other words, regardless of how much is spent on public health and social determinants, there will always be individuals falling seriously ill. Facing premature death or severe disability, each of them is in a position to make a very powerful complaint based on her lack of opportunities.

Now, public health and social determinants cannot possibly react to any instance of the core problem that public reason has with bad health. In contrast, clinical care can try and enhance the health prospects of those individuals who turn out to be ill. Clinical care can avoid premature death and make recovery from extremely serious disabilities possible, including

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[225] For an attempt to respond to the critics of specialness from the perspectve of care ethics, see Engster (2014).

pain so extreme as to make many activities impossible.[226] In sum, special importance should be placed on clinical care because clinical care appears to be unique in being able to attend to the complaints of individuals as such and, therefore, give effect to the project of public reason.

One answer is available to the critics of specialness. Imagine that we know that a redistributive scheme aimed at increasing the wealth of those at the bottom of the income ladder will reduce the deaths from cardiovascular disease over the next decades. If decision-makers decide against the scheme, is not the complaint raised by each statistical individual who could have been saved by it as strong as the one raised by, for example, a patient whose life could have been saved by dialysis? It seems that not only do public health and interventions on the social determinants respond to individual complaints, but also some of these complaints qualify as the strongest health-related complaint that anyone may have.

This answer overlooks a difference in the concentration of risks and probabilities.[227] Importantly, the concentration of risks and probabilities marks a key difference under both possible approaches to the point in time when complaints against a resource allocation arrangement should be evaluated. A first approach is to evaluate complaints *ex ante*, i.e., before the resource allocation arrangement is implemented. Alternatively, resource allocation arrangements could be evaluated *ex post*, which would mean focusing on the complaints that individuals will end up having after an arrangement has been put in place and has taken effect. Whether decision-makers should adopt an ex ante or an ex post approach is a subject of debate and falls beyond the scope of this thesis.[228] Therefore, I intend to

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[226] Fleck (2009, 39).

[227] The concentration of risks and probability of benefitting is used to distinguish prevention from treatment by Daniels (2012, 187–190) and Menzel (2012, 201–202).

[228] Among others, see Fleurbaey and Voorhoeve (2013), John (2014) and Otsuka and Voorhoeve (2009, 195-198).

demonstrate that regardless of which approach is adopted, the concentration of risks and probabilities sets clinical care apart from public health and social determinants. Before examining the ex ante and ex post perspectives in turn, I wish to add two notes clarifying what my argument aims to show and what does not qualify as a valid objection to it.

First, it is important to draw attention to the fact that when I argue that clinical care is special while public health and social determinants are not, I mean to point out a difference between *broad areas* of government activity. As anticipated a few paragraphs earlier, the idea is that the provision of clinical care is unique because it responds to particularly strong complaints that most clearly come from individuals. Identifying the differences between broad areas of activity is meant to translate into identifying the differences in the rules governing the allocation of resources *within* each area. Specifically, equality and isolation appear to be suitable for clinical care but not for public health and social determinants. Even for critics such as Segall and Wilson, the specialness thesis only concerns the rules for the allocation of resources within broad areas of activity; to reject the specialness thesis is to deny that clinical care provision should be governed by equality and isolation. The aim is not to contrast *single interventions* from different areas and suggest that there are interventions on the social determinants that should take priority over clinical care interventions.

It should now be clear that to endorse the specialness of clinical care is not to say that decision-makers should always favour the clinical care intervention if forced to prioritize between it and any single preventative measure. More in general, it seems misguided to use as a counterexample to my conclusions about specialness any pro-prevention intuition that we might have about a case in which decision-makers are forced to choose between a clinical care treatment and an intervention on public health or social determinants. For example, it would seem wrong to make reference to a hypothetical choice between a lung cancer treatment and an anti-smoking advertising campaign that, for the same money, promises to save many more lives. For once, the issue of how to handle these sorts of one-to-one contrasts seems distinct from the question of the rules governing clinical care resource allocation or public health resource allocation taken as wholes. Moreover, one-to-one contrasts appear to have been taken off the table by the very conclusion that I aim to reach, namely, that there is a difference between the broad areas of activity under consideration and, therefore, clinical care resource allocation should be set apart and subject to a different set of rules from public health and social determinants.

Also the second note that I wish to add is related to my focus on broad areas of government activity. While developing the argument that a different concentration of risks and probabilities creates an imbalance between complaints against clinical care and complaints against interventions on public health and social determinants, I will often speak in terms of *typical* preventative interventions. Hence, a critic could point out that someone might come up with an example of preventative intervention that differs from typical cases in some of the respects highlighted by my argument, therefore resembling clinical care treatments in precisely those respects that contribute to my explanation of why clinical care is special.

I argue that we should not be concerned about this possibility. Pointing out the exceptional characteristics of outliers seems an unfair objection not only to my argument, but also to any attempt to draw a distinction between the principles regulating different areas of government activity. In other words, it seems fair to say that a focus on typical cases is justified when we wish to explore the broad principles that should govern different areas of government activity, which are complex and non-homogeneous domains.

Indeed, it seems very unlikely that *any* area of government activity could ever include only those interventions that meet the whole set of necessary and sufficient conditions for a certain principle to be fully satisfied. Consider education; can we really say that *everything* that is covered by fairly standard school programmes (e.g. civic education, music activities and physical exercise) fosters FEO? Still, there seems to be no need to investigate which other principle should govern the pattern of distribution of, say, civic education. Thus, in the case of education as well as clinical care, public health and social determinants of health, the question is one of identifying the principles that are fully satisfied by paradigmatic cases. Those principles should be taken to govern both paradigmatic cases and the penumbra of cases that, although different from paradigmatic cases in some respects, still strike us as belonging in education, clinical care, public health or social determinants.

There are good pragmatic reasons to follow our intuitions about the need to focus on typical cases when we discuss areas of government activity. It would be very cumbersome to identify all instances of, say, public health interventions that differ from typical cases and devise rules that are specifically suitable for each of them, according to the way in which they deviate from typical cases. Furthermore, it would be confusing for public health resource allocation decision-makers to be expected to apply a unique set of rules to each different group of public health interventions. Moving beyond pragmatic considerations, to deny that we should extend to all cases what is fully satisfied by typical instances of public health interventions appears to be wrong for philosophical reasons. Indeed, this position applies to the principles governing clinical care, public health and social determinants a classic approach to what falls under a concept, according to which a concept only includes what satisfies a specific set of necessary and sufficient conditions. However, this approach is widely regarded to be untenable because it is simply too stringent to produce plausible results in the vast majority of cases.[229]

Having clarified what my argument aims to demonstrate, I can go back to the example of the redistributive scheme and the idea that interventions on public health and social determinants respond to some of the strongest health-related complaints that any individual may have. My aim is to refute this idea, starting with an ex ante approach before turning to an ex post perspective. When interventions on public health and social determinants are planned, both the risk of bad outcomes and the expected benefit from intervention are *spread* throughout a group, typically a large group. In the case of clinical care, the risk is typically concentrated, to the point that some patients are virtually certain that, if they do not receive a particular treatment, they will die. Also, single individuals can expect benefits that are typically greater than what can be expected by any recipient of interventions on public health and social determinants.

This difference in the concentration of risks and probabilities is crucial. In their search for the strongest complaint against not enacting a certain resource allocation arrangement, decision-makers committed to public reason are supposed to look at the problem from the perspective of every affected individual in order to measure the implications that the failure to enact the arrangement in question would have for each of them. The example of the redistributive scheme was meant to suggest that if we first applied this process to the redistribution of money and then to the provision of dialysis, we would find that the strongest health-related complaint against not redistributing is just as weighty as the strongest complaint against not covering dialysis. In what follows, I demonstrate that this suggestion is

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[229] Margolis and Laurence (2014).

mistaken.

Let us start by considering the choice not to enact the redistributive scheme. Among the perspectives of all affected individuals, there is no position from which one can raise a complaint based on the loss of a *whole* statistical life and the ability to be saved. All individuals are in a position where, at most, each can point out a small risk of premature death by cardiovascular disease – the expected sum-total of lives lost discounted by the improbability that the individual in question will be one of the victims. Relatedly, no individual can point out more than a modest expected benefit from intervention – a decrease in one's (already limited) chance of death from cardiovascular disease. Now, consider the complaints that individuals can raise in the case of dialysis. The patient in need of dialysis can point out a very high risk, perhaps even a 100% risk, that she will die if untreated. Moreover, she may be in a position to demonstrate a solid ability to benefit. In sum, even though public health and interventions on the social determinants can be depicted as reactions to individual complaints, there is *a deep imbalance* between the strongest of these complaints and the strongest complaints that clinical care can respond to.[230] Hence, only clinical

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[230] Some might wonder whether ex ante complaints against not redistributing really are as weak as I have depicted them. In fact, it seems that each member of the lowest income bracket whose health prospects can still be improved by redistributing wealth has a complaint that sounds stronger than the one described in the main text, at least when it comes to the risk of bad health outcomes without intervention. Here I am thinking of a complaint that makes reference to the relatively small number of years that the individual in question, although free from major health problems at the moment, can expect to have lived from birth when the time of her death comes. Referring back to a telling example that was mentioned in section 1.2, life expectancy at birth in one of the most depressed neighbourhoods of Glasgow is 54 years, although it can reach as high as 82 years in the most affluent areas. For the sake of the argument, let us grant that the whole-lifetime approach to the relationship between time and "badly-offness" adopted by this complaint is the correct one or, at least, is consistent with public reason – section 5.1 explained that such a relationship constitutes an issue that must be placed beyond the scope of my thesis for reasons of space. Still, there are a great many clinical care interventions that promise major benefits (if not complete recovery) to individuals who, without intervention, would expect to die after living a much shorter life than any member of the lowest income bracket can expect in virtue of their membership in a disadvantaged group. For example, consider the

care can attend to *the strongest complaint that any individual may have* in relation to health, giving full effect to the project of public reason.

It might be suggested that the imbalance that I have described disappears as soon as we abandon the ex ante approach. If we look at the choice not to enact the redistributive scheme *ex post*, there seem to be positions from which an individual can build a complaint based on the fact that she is dying of cardiovascular disease and the scheme could have saved her. Several philosophical analyses seem to support the idea that individual claims to typical preventative measures are greatly strengthened by the adoption of an ex post approach, which relegates ex ante concentrations of risks to irrelevance. For example, Sophia Reibetanz discusses an example in which a field contains a landmine. If nothing is done, one out of 100 peasants will lose a limb. However, the only technician decides not to intervene because to go out into the field would give her pneumonia, which is 10 times better than losing a limb. From an ex ante perspective, the technician's complaint against going out is stronger than the complaint that any peasant can have against the technician not intervening. However, if we adopt an ex post approach, the peasant who turns out to step on the mine is in a position to raise an extremely powerful complaint, based on the loss of a whole limb and the claim that the technician could have prevented the accident.[231]

Reibetanz's example differs from typical interventions on public health and social determinants in at least one fundamental respect. Although the *recipients* of interventions on public health and social determinants may be identifiable, *beneficiaries* remain generally unknown, even if we look at them ex post.[232] Going back to my example, imagine that a drop in deaths

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case of a young patient who would expect to die at 20 without dialysis. Again, a greater concentration of risk in the case of clinical care makes the difference, preserving the imbalance between the strongest complaints that clinical care responds to and the strongest complaints that are dealt with by interventions on the social determinants.

[231] Reibetanz (1998, 301–304). See also Hope (2001, 183–184).

[232] For the idea that the knowledge of beneficiaries is almost exclusively the "province" of

from cardiovascular disease has resulted from the adoption of the redistributive scheme. We cannot know specifically who has benefited since each person who has not suffered from cardiovascular disease could have been free from disease anyhow. Can we identify beneficiaries counterfactually by looking at the scenario in which the redistributive scheme has not been enacted? The answer is still negative. Typically, interventions on public health and social determinants do not aim to eliminate a cause of death or disease altogether. Thus, if we have decided against redistribution and a person dies of cardiovascular disease, we cannot know whether she would have died of the same disease regardless.

To stress that beneficiaries are unidentifiable does not take anything away from the fact that there are individuals who can complain that without the redistributive scheme, they have ended up losing their life to cardiovascular disease and, therefore, being very badly-off. Of course, this fact makes ex post complaints against the scheme stronger than their ex ante counterparts. However, the point that I aim to make in the following paragraphs is that, even ex post, many recipients of clinical care can point out a *concentration of ability to benefit* that is unavailable to the recipients of interventions on public health and social determinants.[233] Hence, such interventions do not react to individual complaints that are as strong as the ones that clinical care reacts to. This is a key difference from the perspective of public reason, which is committed to the minimisation of the strongest complaint.

Given that the beneficiaries of interventions on the social determinants are unidentifiable, the ex post probability that one would have been spared

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medical treatment, see Menzel (2012, 199–201). Dawson and Verweij (2007) stress the fact that, even with hindsight, it is often impossible to know who has benefited from public health interventions.

[233] See also the "Prevention Paradox", famously formulated by Rose (1985, 37–38): "a preventive measure which brings much benefit to the population offers little to each participating individual".

from death if the redistributive scheme had been enacted remains thinly spread among the numerous victims of cardiovascular disease who fall in the lowest income bracket, giving rise to relatively weak complaints. Each victim can only point out that the redistributive scheme would have brought a limited decrease in one's chance of death, which is not comparable with the size of the benefits that access to dialysis would have provided to each victim of certain forms of renal failure in a society that has not been covering the treatment in question.[234]

In other words, given that no one can be certain who the beneficiaries of the redistributive scheme would have been, all complaints that individuals can raise ex post must resort to a certain probability that one's life would have been saved by the scheme. However, we have seen from the analysis of the ex ante approach that when compared to clinical care interventions, preventative measures do not fare well when it comes to the concentration of probabilities of benefit. Even when a preventative measure can save a large number of lives, it generally works by targeting a much larger amount

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[234] As a last line of defence, the critics of specialness might suggest that the probability that one would have been spared from death had the scheme been enacted is not *really* spread over the victims of cardiovascular disease – this probability only *looks* spread because of our ignorance. Assume that, had the scheme been enacted, 100 individuals would have been saved. It might be suggested that each of the 100 people who would have been saved was predetermined to respond positively to the scheme, while it was objectively determined that no one else could benefit. Thus, the thinly spread probability of being saved is only an "epistemic" probability, i.e., a probability that, instead of being grounded in an "objective risk with which the world confronts us", is the product of our ignorance of the identity of who is bound to benefit – see Otsuka (2012, 379–380). Also, it seems that merely epistemic probabilities should not diminish the strength of the complaint of each of the 100 persons who were fated to respond positively to the scheme. My answer is that, if there is anything like objective probabilities, the probability of benefiting from public health and interventions on the social determinants is certainly objective. As influential as our genes and social background may be, I doubt that many would say that each of us is predetermined to react in a very specific way to each preventative intervention. To a good extent, individuals are faced with objective risks, coming down to the way in which the world is; those risks may or may not translate into bad outcomes, depending on chance and the way in which individuals decide to act. Thus, if the scheme is not enacted, there will be a crowd of victims of cardiovascular disease, each of whom would have had a *thinly spread* and *objective* chance to be saved.

of persons who are at risk of death from certain causes, many of whom will end up dying from those causes regardless. Therefore, the ex post probability that one would have been spared from death if that preventative measure had been enacted will be spread rather thinly throughout a large group of victims of a certain cause of death.

In sum, clinical care has a different function from public health and the social determinants. Clinical care protects health by attending to complaints that a) come from individuals and b) include the strongest complaints that anyone may have in relation to health. This function places clinical care uniquely close to public reason, which involves a commitment to the minimisation of the strongest complaint. Consequently, only clinical care should be regarded as special.

5.4. Implications of my argument

This section aims to discuss the implications of the arguments advanced in the previous sections for two important topics: 1) the residual role of public health and social determinants of health as areas of government activity; and 2) the evaluative space for measuring priority to the worst-off and ability to benefit.

I concluded section 5.3 by saying that public health and social determinants should not be regarded as special. This was not to say that public health and the social determinants are not legitimate areas of government activity. Indeed, public health and the interventions on the social determinants can be thought of as reactions to individual complaints. Coming from individuals who will end up quite badly-off if not helped, some complaints appear to have a considerable strength, although the dispersal of ability to benefit prevents them from being as strong as many of the complaints that clinical care reacts to. Therefore, public reason requires that resources be spent on public health and social determinants, although neither of them is to be regarded as special. Public health and interventions addressing the social determinants could be treated as parts of a unified distributive system aimed at improving population health and reducing health inequalities. Importantly, to claim that neither social determinants nor public health interventions are special does not have the same counterintuitive implications as the idea that clinical care resource allocation should be sensitive to income, social inclusion and other social goods. For example, it makes intuitive sense to address such public health programmes as those tackling smoking or workplace hazards to those socio-economic groups that are disproportionately hit by the problem in question.

It is now time to draw together the arguments concerning priority to the worst-off, ability to benefit and specialness. The specialness thesis provides a frame within which to understand other substantive values governing clinical care resource allocation. Specifically, I argue that the specialness thesis has implications for the evaluative space to be adopted, dictating that priority to the worst-off and ability to benefit should be understood in terms of *health, as opposed to overall well-being*. Consider first priority to the worst-off. If the worst-off were defined as those with the worst well-being, the poor and those who are discriminated against on the basis of race, ethnicity or gender should receive higher priority than other patients when clinical care resources are allocated.[235] However, my discussion of specialness has demonstrated that clinical care resource allocation should be

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[235] Starting from a conception of health as one of a number of functionings constituting well-being, Powers and Faden (2006, 156–158) argue that, if a racial group experiences non-health-related disadvantages, we should put a premium on clinical care interventions addressing conditions that affect them more than other groups. Along similar lines, Coast et al. (2008) propose a capability approach to health economics that evaluates clinical care interventions based on their impact on a number of dimensions of well-being that include, but are not limited, to health.

isolated from the distribution of other social goods. Thus, the worst-off should be defined as those with the worst health.

Turning to ability to benefit, some might think that clinical care resource allocation decision-makers should take into account that a patient with a well-paid job can obtain larger economic benefits from recovery than a patient who earns less. Furthermore, being restored to good health may accrue extra benefits to those who are part of rewarding social networks and regularly embark in social activities. On a similar note, it might be argued that resource allocation should be sensitive to the family-life benefits enjoyed by a patient who, if restored to good health or having some time added to her life expectancy, can see her daughter grow, graduate or get married.[236]

However, clinical care resources should be allocated in isolation from other social goods. Consequently, clinical care resource allocation should not be sensitive to income. Given that social exclusion is a problem of justice, resource allocation should also be isolated from the enjoyment of social activities. As for family-life benefits, the issue of who is allowed to have children (and can effectively build a family) is replete with considerations of justice. For example, societies impose rules which constrain the access to in-vitro fertilization and adoption procedures. Moreover, my account of specialness is grounded in a certain relationship between clinical care and health, not clinical care and other components of well-being. Thus, to interpret ability to benefit in terms of health constitutes a matter of internal consistency. It is now clear that my idea of ability to benefit is analogous to the substantive value called “clinical effectiveness”. Indeed, clinical effectiveness describes the extent to which each patient is

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[236] According to Labelle and Hurley (1992), clinical care resource allocation decision-makers should consider that utility derives from a variety of sources. More specifically, Brock (2003) and Lippert-Rasmussen and Lauridsen (2010) criticise the idea that non-health benefits should not play a role in resource allocation.

expected to secure a health gain from treatment.[237]

My idea that priority to the worst-off and ability to benefit should be understood in terms of health makes public reason consistent with the dominant approach to the evaluative space in clinical care resource allocation, i.e., *Quality-Adjusted Life Years* (QALYs). However, as I intend to argue in section 6.1, public reason is inconsistent with a value that is often employed together with QALYs. Here I am thinking about cost effectiveness, which requires that at least one of the aims of resource allocation should be to maximise the QALYs gained across the relevant population. Hence, I wish to clarify that while I believe that QALYs can be used to measure how well-off a patient is and how much she can benefit from treatment, I do not mean to endorse any aggregative value that may be used in conjunction with QALYs.

QALYs are a measure of health that integrates life expectancy and quality of life. Depending on health-related quality of life, each life year is assigned a value between 1 (full health) and 0 (death). A two-step process is employed to determine how much worse a life year is if lived with a particular less-than-optimal health-related quality of life. First, individual health states are classified in terms of several dimensions that are meant to capture the essence of good health. To this end, surveys of patients with particular conditions are conducted. The EQ–5D, which is the classification system employed by NICE, asks respondents to classify their health states along the following dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension is scored from one to three, based on the level of impairment, which results in 243 possible health states. Second, the quality of life associated to each health state is rated. This is done by working out what fraction of a healthy year should be

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[237] For example, see Buyx et al. (2011).

counted as equivalent to a year lived in the state of impaired health that is being considered. Another survey is conducted and such methods as Standard Gamble, Time Trade-off or Visual Analogue are employed to elicit a rating of the quality of life associated to individual health states.[238]

Importantly, QALYs enable public reason to compare the complaints raised by patients affected by all sorts of diseases. The amount of QALYs that a patient expects to live after treatment minus the amount of QALYs that she expects to live without treatment can measure her ability to benefit. Moreover, it is possible to measure how many QALYs a patient will live without treatment, as well as the number of QALYs that she has enjoyed so far, in order to quantify complaints based on how badly-off a patient is.

QALYs are the object of a number of critiques.[239] For example, it is argued that the QALY would benefit if the two-step process currently employed to classify and rate health states were reformed so as to better capture the impact of health on opportunities.[240] It would be impractical and fall beyond the scope of my argument to try and assess such critiques. I only say that the supporters of the current approach to QALYs have a point when they claim that, at present, such approach is the most well-developed overall measure of health available. Should anyone propose a well-developed refined approach to QALYs or a better measure of health, public reason would be open to such changes.

5.5. Conclusion

The arguments proposed in this chapter are highly relevant to at least two of the three main themes underlying my thesis. One theme is that deliberative

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[238] Cookson and Culyer (2010, 150–159).

[239] Among others, see Alan Williams (1996).

[240] Hausman (2010).

democracy can keep together procedural fairness and a commitment to providing determinate answers to substantive questions. In arguing that priority to the worst-off, ability to benefit and specialness are upheld by public reason, I have taken a first step in the analysis of which substantive values are consistent with deliberative democracy and which values are not.

Moreover, my defence of the specialness thesis has demonstrated that not only does clinical care play a different function from public health and interventions on the social determinants, but the function played by clinical care should be given primacy. Section 1.1 identified the tendency to question the special attention traditionally paid to clinical care as a component of the population-level perspective on health resource allocation. Thus, my defence of the specialness thesis is highly relevant to another theme cutting through my thesis, which is the idea that several components of the population-level perspective are misguided.

6. SUBSTANTIVE VALUES II: THE FILTERING ABILITY OF PUBLIC REASON

This chapter and the previous one critically analyse a number of substantive values that are proposed as suitable to govern clinical care resource allocation. The aim is to determine which values are affirmed and which ones are rejected by public reason. The previous chapter played a largely positive role, demonstrating that priority to the worst-off, ability to benefit and specialness of clinical care are upheld by public reason. The arguments proposed in this chapter are mainly negative: apart from cost considerations, public reason is shown to filter out all substantive values that are discussed.

Section 6.1 argues that aggregative values are inconsistent with public reason. Section 6.2 demonstrates that the rejection of aggregation does not make my conception of deliberative democracy implausible – most importantly, deliberative democracy has no difficulties acknowledging the relevance of cost considerations. In section 6.3, I show that there is no room for the idea of fair chances among the values governing resource allocation. Section 6.4 demonstrates that three important values are in tension with the requirement of reasoned decision-making: dread, government and stakeholder priorities, and personal responsibility for health. Finally, section 6.5 turns to innovation, lack of alternative treatments and rarity, which run counter to the commitment to compartmentalisation that is intrinsic to public reason.

6.1. Against cost-effectiveness analysis and other aggregative values

Aggregative values combine the gains and losses of different individuals into the gain and loss of a group.[241] In the context of clinical care resource allocation, the most important example of aggregative value is provided by cost-effectiveness analysis (CEA). The idea at the basis of CEA is that resources should be allocated so as to maximise the net health benefits aggregated across the relevant population. Health benefits are commonly measured in terms of Quality-Adjusted Life Years (QALYs), integrating life expectancy and health-related quality of life.[242]

CEA is so influential that it is hard to find any conception of clinical care resource allocation that denies that CEA should at least be employed on the same footing as the other relevant substantive values.[243] According to some, CEA deserves more than that and should be used as the sole criterion for allocating resources.[244] Others believe that CEA is the most important among the substantive values that decision-makers should apply; other values should only be employed if CEA results fall within a grey area. This two-stage approach is employed by NICE when appraising health technologies. CEA is used to determine the incremental cost-effectiveness ratio (ICER) of the technology under appraisal. In NICE's words, “the ICER is the ratio of the difference in the mean costs of an intervention compared with the next best alternative (which could be no action or treatment) to the differences in the mean health outcomes”.[245] At this point, the intervention under appraisal can be classified in relation to the broad cost-effectiveness threshold employed by NICE (£20000-£30000 per QALY). NICE is unlikely to reject

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[241] Hirose (2013, 184–188).

[242] For the ethical issues raised by CEA, see Brock (2004).

[243] For example, virtually all the multi-criteria decision analysis frameworks discussed in section 7.3 depict the maximisation of aggregate health as one aim of resource allocation.

[244] Eddy (1991), Stein (2012) and Alan Williams (1985).

[245] NICE (2008, 18).

any intervention whose ICER is lower than £20000 per QALY, while the so-called "equity weightings" (severity of disease, end-of-life considerations, stakeholder persuasion, innovation, disadvantaged population and children premium) should be factored in to decide whether an intervention whose ICER lies between £20000 and £30000 per QALY should be covered. Above an ICER of £30000 per QALY, decision-makers need to make a particularly strong case for funding the technology under discussion based on the equity weightings listed above.[246]

CEA is not the only value that involves aggregation. It is sometimes proposed that higher priority should be assigned to common diseases qua common diseases.[247] Besides, there are values that are concerned with increasing society's aggregate economic output. Some believe that clinical care resources should be allocated with an eye to the spillover effects on the growth of the domestic industry.[248] Others argue that a premium should be placed on treating working-age patients because the diseases of such patients exact a heavier toll on the economy.[249]

There are at least two reasons why aggregative values are inconsistent with deliberative democracy. The first reason draws on a classic critique of aggregation, i.e., the idea that aggregation violates the separateness of persons.[250] Aggregative values treat the desires and interests of different individuals as if they were the desires and interests *of a single person*. The claims of the conglomerate resulting from this process of amalgamation are

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246 Rawlins et al. (2010).

247 A “common disease” premium figures in many versions of the Portsmouth Scorecard, a support tool employed by numerous Clinical Commissioning Groups in the U.K. - I. Williams et al. (2012, 70-71).

248 For example, see D. Goldman et al. (2010).

249 Working-age years are given extra weight when Disability-Adjusted Life Years are used instead of QALYs to measure the effectiveness of intervention – see Murray et al. (2000). Focusing on decision-making for vaccines against varicella-zoster virus and pandemic influenza, Beutels et al. (2008) claim that negative externalities on the economy should be considered.

250 Nagel (1970, 125–140) and Rawls (1999, 19–24).

what counts when it comes to determining what should be done – in other words, this conglomerate has effectively become an independent unit of concern. Given that the whole point of deliberative democracy is to implement equal concern *for individuals*, there can be no room for values that elevate conglomerates to the rank of independent units of concern.[251]

At this point, it might be objected that the separateness of persons is only violated if an aggregative value, such as CEA, is employed as the sole criterion for allocating clinical care resources. Indeed, if there are cases in which other considerations are allowed to trump aggregative values, the allocation of available clinical care resources is bound to fall short of creating the greatest possible amount of benefits aggregated throughout the relevant population. Therefore, the trade-offs between the interests of different potential recipients of treatment are not made *exactly in the same way* as the trade-offs between the interests of a single individual. This difference between inter-personal and intra-personal trade-offs means that the separateness of persons has been acknowledged.

In response to this objection, I argue that when aggregative values are employed alongside other considerations, resource allocation decision-makers still violate the separateness of persons; the work done by non-aggregative considerations only ensures that the separateness of persons is violated *to a more limited degree*. To the very extent that an aggregative value contributes to determining how resources should be allocated, decision-makers combine the gains and losses of different individuals into

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[251] Hirose (2013, 195–197) states that the utilitarian principle that the well-being of everyone should count for one and no more than one expresses a commitment to the separateness of persons. He might therefore claim that aggregative values simply have their own way of respecting the separateness of persons. However, it is hard to see how the principle that everyone's well-being should count for one has anything to do with separateness, as opposed to non-discrimination between desires. Indeed, I can accept a principle of rational choice requiring that the satisfaction of each of my desires should count for one without making them into desires that, instead of being part of my life plan, belong to different individuals.

the gain and loss of a conglomerate, allow the potential gain and loss of the conglomerate to have an impact on resource allocation as the claim of a conglomerate and, therefore, effectively create an independent unit of concern besides individuals. As argued a few paragraphs earlier, there is no room for values that elevate conglomerates to the rank of independent units of concern in a model of deliberative democracy whose whole point is to implement equal respect for individuals. In sum, an aggregative value violates the separateness of persons even when balanced against considerations that embed a strong concern for the claims of individuals. It is simply traded off against values that do not make the same mistake.

The second reason why aggregative values are inconsistent with deliberative democracy is that there are perspectives from which aggregative values can be *reasonably rejected*. Rationing decisions can only be acceptable to all reasonable individuals if resources are allocated so as to minimise the strongest complaint anyone can make. Aggregative values are blind towards the distribution of benefits; to the extent that aggregative values are used to allocate clinical care resources (whether by themselves or alongside other substantive values), there will be cases in which priority is given to providing each member of a larger group with certain benefits rather than offering greater benefits to each member of a smaller group. In these cases, aggregative values dictate that each member of the smaller group should make a sacrifice to avoid more modest losses to each member of the larger group. However, assuming that the members of the two groups are equally badly-off, the members of the smaller group have the strongest complaint, which demonstrates that there are reasonable persons who cannot be expected to accept aggregation. Therefore, this shows that aggregative values are incompatible with public reason and the attitude of reasonableness that forms its basis. Indeed, reasonable persons are those who are committed to proposing decisions that are grounded in considerations that any other reasonable person can accept.

The previous paragraph suggested that persons who are fully reasonable should acknowledge that aggregative values must not be used to allocate clinical care resources. However, most real-world persons have an intuition that CEA or another measure of health "bang for their buck" should play a role in clinical care resource allocation.[252] I acknowledge that the idea that so many persons are unreasonable (at least in one respect) sounds extreme. Therefore, I would like to provide further considerations in support of the idea that aggregative values are beyond reasonableness.

I have defined reasonableness as the willingness to identify terms of cooperation that are acceptable to all those who are committed to finding decisions that everyone can accept. I have not limited myself to assuming this idea of reasonableness; section 2.3 defended it as the suitable frame of mind for participating in political decision-making within a deliberative democracy that is meant to implement equal respect for the autonomy of individuals. Moreover, it is worth noting that I have not proposed an eccentric definition of reasonableness. My idea of reasonableness echoes other definitions of the term given in the context of political decision-making, most notably the influential definition provided by John Rawls.[253]

There is room to argue that the persons who support aggregative values are not fully reasonable because there is *very little logical distance* between reasonableness as I understand it and the minimisation of the strongest complaint when it comes to allocating scarce resources among many potential beneficiaries. As we saw in section 4.3, reasonable persons can only accept that they will not receive any potentially beneficial clinical care resources if this renounce is necessary to ensure that someone with a

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[252] Daniels (2008, 127–128).

[253] Rawls (1996, 48-50).

stronger claim to intervention can be treated. This effort to make the strongest complaint against distributive arrangements as weak as possible imposes itself as an immediate implication of looking at a distributive problem by taking one's own and everyone else's perspective into account on the same footing. In turn, it is necessary to look at political decisions from the perspective of each person in order to identify decisions that are acceptable to all. Thus, reasonableness and minimisation of the strongest complaint can almost be considered one and the same thing, at least with regard to distribution.

As I argued earlier in this section, the use of aggregative values runs counter to the minimisation of the strongest complaint, condemning aggregation to unreasonableness. Therefore, aggregative values are determined to be beyond reasonableness, even though many people think that they should be used to govern clinical care resource allocation. Public reason does not exclude these sorts of outcomes; for example, the proponents of public reason can certainly believe that slavery was unreasonable even at times when many people supported it. The supporters of public reason should therefore argue against CEA and other aggregative values in the hope that the idea of rejecting aggregation will gain momentum and build consensus over time.

6.2. Where public reason and aggregation overlap: cost and other considerations

It might be objected that the rejection of aggregation makes my model of resource allocation implausible in at least two ways. First, there are cases in which aggregative values give intuitively compelling answers while non-aggregative approaches appear to struggle.[254] Most importantly in the context of clinical care resource allocation, aggregation seems uniquely suited to acknowledge the relevance of cost considerations. Second, while aggregative values are effectively concerned with the claims of groups, deliberative democracy is meant to implement equal respect for individuals. However, this ideal of equal respect for individuals sits uncomfortably with the simplifications that certain resource allocation agencies have to make. This section aims to show that, with one exception regarding the relevance of costs, deliberative democracy arrives at the same plausible conclusions reached by aggregative values without resorting to aggregation.

Starting from cost considerations, no resource allocation agency has an unlimited amount of money to allocate. Furthermore, the labour-intensive nature of clinical care, the sheer amount of medical needs and the array of available interventions can quickly consume one's budget. Hence, it seems a platitude to say that decision-makers must keep an eye on costs. However, this platitude appears to be incompatible with deliberative democracy.

To explain why, I draw on an argument proposed by Albert Weale. Weale aims to demonstrate that those approaches to resource allocation based exclusively on a theory of individual rights are inconsistent with the use of cost considerations. However, his argument works well against any theory requiring that resources be allocated in a way that expresses equal concern for individuals. According to Weale, this commitment to equal concern is in tension with decision-makers approving a treatment for someone and denying a treatment to someone else on the basis of cost considerations. Weale anticipates that the supporters of individual rights might attempt to answer this difficulty by making reference to the notion of *opportunity costs*, i.e. the benefits foregone when an allocation of resources is chosen

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[254] For example, see Freiman (2013, 258–265).

over the other available options. If a large part of available resources has been carelessly spent on a group of patients, there is less to be spent on others, who should be of equal concern as those who benefited from the lavish spending. According to Weale, however, this answer fails. Many believe that considering the opportunity costs of alternative allocations of resources is good because this enables decision-makers to choose the allocation that treats the greatest number of patients. Yet, it is a matter of controversy whether higher priority should be assigned to the greater number if a non-aggregative method is adopted.[255]

A twofold response to Weale's criticism demonstrates that decision-makers devoted to deliberative democracy should take the cost of interventions into account. First, and most importantly, to consider opportunity costs is necessary to uphold the commitment to the strongest complaint *over and above helping the greater number.* Costs must be monitored to ensure that funding a certain intervention does not deprive the resource allocation agency of the necessary funds to cover interventions that respond to *a stronger individual complaint*. In other words, costs must be taken into account to ensure that available funds are allocated so as to create the greatest value, which comes down to the strength of the complaints of potential recipients. In a similar way, if a treatment approved by public reason is made cheaper while achieving the same outcomes, the savings can be used to attend to the strongest complaint among those that have so far gone unmet.

Second, there is room to argue that numbers should count, although only as *tie-breakers*, even if we reject aggregation. Consider two clinical care interventions that tackle two groups of patients who are as badly-off as each other and who can all benefit the same from treatment. The only difference

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[255] Weale (2012, 483–488).

is that one intervention addresses a larger patient population. The individualised concern imposed by public reason seems to dictate that the complaint of each member of the small group is as worthy of our attention as the complaint of any member of the larger group, recommending equal priority. However, Frances Kamm's and Thomas Scanlon's appealing arguments lead to a different conclusion.[256]

Each member of the larger group has a complaint against equal priority that is stronger than the complaint that each member of the smaller group has against assigning priority to the larger group. How is this possible? Patients from both groups have a complaint based on how badly-off they are and their ability to benefit. However, any such complaint advanced by a patient in the smaller group is “silenced” through the comparison with an equally strong complaint advanced by a patient in the larger group. Conversely, each member of the larger group can regard her own complaint as one of those that have not been silenced by any complaint from the other group. Thus, each member of the larger group can claim that, if the two clinical care interventions were assigned equal priority, her presence would not be acknowledged. Indeed, decision-makers assigning equal priority would behave as if there was no one in the larger group besides those silenced by the members of the other group.[257]

We can now return to costs. Imagine two patient groups, whose members

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[256] Kamm (1993, 114–119) and Scanlon (1998, 231–235).

[257] Otsuka (2000) objects that the complaint of each individual in the larger group can be stronger than its competitors only if aggregated with the other complaints from the same group. Although this is not the place for a thorough analysis of this issue, it seems that Kamm (2007, 53–61) is right in answering that Otsuka's objection simply highlights that individual complaints should be assessed in a “context-aware manner”. This context-awareness, however, does not ever involve the *combination* of the complaints of different individuals so as to create a group complaint that is strong enough to outweigh any complaint from the other group. Hence, no aggregation is involved. Kamm also points out that the argument for helping the greater number can be formalised as the combination of two conditions, none of which involves aggregation: Pareto optimality and impartiality towards two options that differ only in the identities of the persons helped. On the latter point, see also Hirose (2001).

are similar in all relevant respects apart from one thing: the cost of treatment of a patient is greater in one group than in the other. If decision-makers do not have the necessary resources to treat both groups, giving priority to the cheaper treatment results in more patients being helped. Given that numbers count, the number of patients helped breaks the tie in favour of the cheaper treatment, demonstrating that public reason admits the use of the cost of treatment as a tie-breaker.

An obvious question to ask is whether the cost of treatment of a patient should only be used to prioritise an intervention over another when the members of the two patient groups are *exactly* as badly-off as each other and could benefit *exactly* the same from treatment. It may be argued that decision-makers should give priority to helping the greater number when the members of the larger group can raise complaints based on how badly-off they are and how much they can benefit from intervention that, although weaker than the complaints of the smaller group's members, are strong enough to be *relevant* to them. A classic example is provided by the conflict between individuals who can be saved from being paralysed for life and individuals who can be saved from death. In turn, if we accept that numbers count in these sorts of cases, we must also accept that decision-makers should use the cost of a course of treatment to prioritise between two interventions that respond to complaints that, although of different strength, are relevant to one another.

This proposal seems plausible and surveys reveal that many persons believe that priority should be given to helping the greater number when the individual complaints coming from the larger group are strong enough to be relevant to the ones coming from the smaller group.[258] Moreover, the idea that numbers count also in the case of relevant complaints is accepted by

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[258] Cowell et al. (2010, quoted by Voorhoeve, 2014).

both Kamm and Scanlon, whose non-aggregative arguments were employed earlier in this section to explain why public reason should use numbers to break a tie between two groups of patients who are similar in all relevant respects.[259] In particular, Scanlon suggests that the same non-aggregative argument that I described a few paragraphs earlier can also be used to explain why decision-makers should give priority to helping the greater number in the case of relevant complaints. If each member of the larger group is so badly-off and can benefit so much from treatment that her complaint is at least relevant to the complaint of every member of the other group, any complaint advanced by a patient in the smaller group is to be considered silenced through the comparison with a complaint advanced by a patient in the larger group. Thus, assigning priority to helping the greater number is necessary to acknowledge the presence of every member of the larger group.

Despite the support enjoyed by the idea that numbers count also in the case of relevant complaints, I argue that this idea is inconsistent with public reason and that the role of the cost of a course of treatment should be limited to the case in which the members of two patient groups can raise complaints that, as far as priority to the worst-off and ability to benefit are concerned, are of the same strength. Similar to the argument against aggregation that was put forward in section 6.1, my view on this topic may sound extreme; however, a careful analysis demonstrates that it is *reasonableness* that leads away from the idea that resource allocation decision-makers should give priority to the greater number in the case of relevant claims.

In section 2.3, I defended a specific understanding of reasonableness as the suitable frame of mind for participating in decision-making processes that are consistent with my procedural case for deliberative democracy.

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[259] Kamm (2007, 484-486) and Scanlon (1998, 238-241).

Echoing Rawls's and other influential definitions of the term, I characterised reasonableness as the willingness to propose terms of cooperation that can be accepted by everyone who is committed to identifying decisions that are acceptable to all. This willingness involves making the effort to look at a problem from the perspective of every individual before making a decision. When it comes to allocating scarce resources among numerous possible beneficiaries, this effort leads to the conclusion that available resources should be allocated so as to make the strongest complaint that any individual can raise as weak as possible. In sum, as I have argued in several places in this thesis, there is very little logical distance between reasonableness and the idea that priority should be assigned according to the strength of the complaints of individuals; when it comes to distributive issues, reasonableness and minimisation of the strongest complaint can almost be considered one and the same thing.[260]

Now, the question is: can Scanlon's argument for giving priority to the greater number in the case of relevant claims fit within my conception of public reason, which is rooted in reasonableness and endorses the idea of priority according to the strength of individual complaints? To illustrate why the answer is negative, let us return to the example of the conflict between saving a large number of persons from permanent paralysis and saving a smaller number of persons from death. The claim to be saved from death is stronger than the claim to be saved from paralysis, even if decision-makers are ready to admit that the latter claim is quite strong. Therefore, no patient from the larger group has a claim that can actually equal and, therefore, silence the claim of any of the patients who will die if untreated. This means that there is no way that any of the larger group’s members can raise an equally strong complaint against being assigned lower priority as the

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[260] See sections 4.3 and 6.1.

complaint available to each of the smaller group’s members. In the case of relevant claims, the minimisation of the strongest complaint requires that priority should be given to the group whose members can raise the strongest claim based on how badly-off they are and how much they can benefit from treatment, regardless of numbers.

It is important to notice that the problem is not limited to Scanlon's attempt to adapt his tie-breaker argument to the case of relevant claims. From within a conception of public reason that is committed to the minimisation of the strongest complaint, there appears to be no way to place a patient group higher than another in the order of priority if the members of the latter group are so badly-off and can benefit so much from treatment that each of them can raise a stronger complaint than any of the members of the former group. To further support this impossibility, I wish to reject two proposals that attempt to explain how public reason could sidestep the difficulties that I have mentioned and give priority to the greater number also in the case of relevant claims.

Some may propose that the claims of those who face permanent paralysis if untreated should be combined into the claim of a group in order to create a tie with, or even possibly outweigh, any claim coming from the group of patients facing death. However, section 6.1 made it clear that aggregation is incompatible with public reason and the notion of reasonableness that forms its basis.

An argument recently advanced by Alex Voorhoeve goes some way towards proposing an alternative justification that public reason could use to give priority to the greater number also in the case of relevant claims.[261] I have written that Voorhoeve's argument cannot go all the way because at a certain point of the argument, aggregation plays a role. Still, aggregation

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[261] Voorhoeve (2014).

enters the picture only after a non-aggregative approach has been applied and shown to reach an impasse. Moreover, Voorhoeve's non-aggregative approach has many points of contact with the frame of mind imposed by my conception of reasonableness; in fact, both draw explicitly on the method of pairwise comparisons as proposed by Thomas Nagel.

Voorhoeve's non-aggregative approach requires that when allocating aid, decision-makers place themselves in the shoes of every affected individual, one affected individual at a time. While occupying the perspective of one individual, decision-makers should make a series of one-to-one comparisons between the claim of the individual in question and the claims of every other affected individual. This process should be repeated from the perspective of every affected individual in the hope of reaching a unanimous decision about which individual has the strongest claim and, therefore, deserves priority.

Regarding the issue of whether numbers count also in the case of relevant claims, the non-aggregative approach reaches an impasse because unanimity cannot be achieved. This is because Voorhoeve endorses what he calls "permissible personal prerogative", i.e., the idea that each individual is (to some extent) allowed to be more concerned about their own claims than the claims of anyone else. Going back to my example, if decision-makers look from the perspective of an individual who will die if untreated at a one-to-one comparison with someone who faces permanent paralysis, saving the first individual from death clearly takes priority because not only is her claim to treatment objectively stronger but also it is augmented by the personal prerogative. Now, what happens when decision-makers place themselves in the shoes of one of those individuals who face permanent paralysis if untreated? We have seen that an individual is allowed to place extra importance on their own claim to help. Although objectively weaker than the claim of an individual who can be saved from death, the claim of someone who can be saved from permanent paralysis is strong enough for the personal prerogative to fill the gap. Therefore, an individual who faces permanent paralysis can legitimately consider their own claim to be stronger than the claim of each individual who will die if untreated, giving priority to saving themselves from paralysis. According to Voorhoeve, aggregation should be employed when these kinds of disagreements result from the non-aggregative approach, opening the door to the idea that numbers count also in the case of relevant claims.

Voorhoeve's account provides an interesting justification for giving priority to the greater number in the case of relevant claims. However, this justification is in tension with my understanding of reasonableness for reasons that are not limited to the role played by aggregation. Specifically, I find the use of the personal prerogative problematic, at least when considered from within public reason.

In my thesis, I have already expressed scepticism about the possibility of fitting the personal prerogative into an approach to clinical care resource allocation such as public reason.[262] I have argued that the freedom to value one's own claims more than the claims of others is in tension with a model of decision-making that is built on impartiality at many levels. For example, notice that the idea of reasonableness alone incorporates a commitment to impartiality at two levels, which are a) the willingness to propose terms of cooperation that are acceptable to everyone, and b) the condition that those terms only need to be acceptable to persons who are themselves committed to identifying decisions that all can accept. Moreover, I have suggested that the personal prerogative seems particularly out of place when it comes to determining how to allocate resources that are presently held in common, as

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[262] See footnote 186.

opposed to other aspects of morality, such as deciding how to manage what is currently in one's private possession.

What of the argument that deliberative democracy should not allow the ability to make simplifications and ignore a certain amount of difference between patients in the way that resource allocation agencies commonly do? Consider NICE's work on health technology appraisal. NICE issues recommendations for or against whole technologies or, at most, distinguishes between a few sub-groups of patients. Still, within each sub-group there is bound to be a certain amount of variation regarding how badly-off patients are and their ability to benefit. It seems that my model of deliberative democracy should not work with this kind of simplifications. The whole point of deliberative democracy is to implement equal concern for *individuals*. Hence, some might think that resource allocation agencies must strive to measure and evaluate the strength of each complaint *in all its particularity.*

If we wanted to eliminate simplifications, virtually all resource allocation responsibilities should be assumed by front-line clinicians because they are the only ones who are in a position to appreciate the exact strength of the complaint of each patient. However, front-line clinicians cannot carry out activities that are integral to any minimally well-functioning deliberative democratic system for resource allocation.[263] Specifically, clinicians cannot make any systematic comparison between the complaints raised by their own patients and those raised by patients treated in the rest of the health service - clinicians cannot be expected to know that much about parts of the health service that are not their own.

The comparison between the complaints of patients belonging to

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[263] Moreover, clinicians would be governed by a much thinner web of guidelines and incentives than possible under a different regime. As argued in section 4.1, this outcome would be detrimental to transparency.

different parts of a given health service is a key part of the goal to subject that health service to public reason. If decision-makers did not explore the relative strength of the complaints coming from different parts of the health service, it would be impossible to allocate resources between those parts in accordance with public reason – the process of allocating clinical care resources on the basis of public reason could not even start. Thus, a good deal of resource allocation responsibilities must remain with decision-makers who are far from the front line, in a position to look at the big picture and compare complaints coming from different parts of the health service. Those decision-makers have no choice but to work with simplifications.[264]

In sum, letting many resource allocation agencies work with simplifications constitutes the *least damaging route* open to deliberative democracy. The whole point of the procedural and substantive values governing a deliberative democratic system for clinical care resource allocation is to implement equal and separate concern for individuals. Simplifications are needed to make such a complex system work *at all*. In other words, simplifications are a price that must be paid to have clinical care resource allocation governed as much as possible by a strong concern for individuals.

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[264] This is not to say that simplifications should not be reduced to a minimum. First, front-line clinicians should certainly have resource allocation responsibilities, which ought to be characterised by sensitivity to difference. As argued in section 4.1, clinical judgement should play a role when the clinical conditions of patients sharply deviate from the average conditions covered by resource allocation guidelines. Second, NICE and similar agencies should only work with simplifications to the extent that simplifications are necessary to carry out their resource allocation responsibilities. Third, all health services should consider whether to follow the NHS's lead in requiring that commissioning authorities establish exceptional funding panels. Such panels are responsible for deciding whether patients with unusual characteristics should be treated as an exception to previous rationing decisions - see National Prescribing Centre (2009, 23).

6.3. Fair chances to be treated: an interference with public reason

Dan Brock and Daniel Wikler discuss the example of a ward with 100 patients. The patients are similar in all relevant respects, except for the fact that 50 of them need one pill and 50 of them two pills to recover. If the hospital only had 50 pills, how should they be allocated?[265] Section 6.2 argued that cost works as a valid tie-breaker. Thus, those who need one pill should receive the treatment. However, many would object that a lottery should be used to give those who need two pills a fair chance to be treated. This section demonstrates that there is no room for lotteries and fair chances among the substantive values accepted by deliberative democracy.

The main rationale underlying the idea of fair chances is grounded in the equality of all patients. For example, some maintain that it is intuitively wrong to discriminate among patients who have their psycho-physical integrity in danger, while others stress that clinical care resources have not been donated to any patient in particular.[266] How can resource allocation procedures *show equal respect* to patients? Giving everyone a chance to be treated is considered to be the best answer, although opinions differ as to whether each patient should have an equal chance or whether chances should be proportional to the ability to benefit from treatment.[267]

I argue that, far from being the only way of showing equal respect to patients, lotteries interfere with the most compelling account of respectful procedures for resource allocation.[268] One of the main aims of my thesis is to develop an account of fair procedures for resource allocation that expresses equal respect for all affected individuals. Public reason is one of the general

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[265] Brock and Wikler (2006, 264). Also Johansson and Norheim (2011, 37–38) discuss a similar example.

[266] Brock (1988, 93) and Persad et al. (2009, 423).

[267] See Broome (1990) and Brock (1988), respectively.

[268] See Hirose (2007, 55) for the point that there are many ways to show equal respect to the potential beneficiaries of one's actions.

requirements of procedural fairness that make up such an account. Under a regime of rationing, public reason requires that resources be allocated so as to minimise the strongest complaint that any individual may have. This commitment to minimising the strongest complaint shows equal respect to all by weighing the complaint of *each* patient against *every other person*'s complaint. Importantly, the commitment to the strongest complaint that is integral to public reason is in conflict with the idea of fair chances; by giving patients with a relatively weak complaint a chance to be treated, lotteries hinder the process of using available resources to minimise the strongest complaint.

Why should we choose public reason over fair chances as the best way of showing equal respect when it comes to clinical care resource allocation? Clinical care resource allocation decisions are essentially political decisions and, therefore, every citizen bears an equal share of authority over them. While asking how to honour the authority of citizens, we must keep in mind that citizens should be treated as capable of autonomy, i.e. capable of directing themselves on the basis of reasons. Therefore, the authority of citizens is honoured only if political decisions are made through a process of reasoned justifications to everyone.[269] Unlike lotteries, public reason acknowledges both the *authority and capacity for autonomy of citizens* by regarding a process of reasoned justification to all as a basic source of fairness.

A supporter of fair chances could still argue that deliberative democrats should accept a degree of interference with the minimisation of the strongest complaint to ensure that *small* differences between patients do not *drastically* affect who receives treatment and who does not. Interventions that are technically available form a continuum ranging from those that

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[269] See also section 2.3.

respond to extremely strong complaints to those that respond to very weak complaints. Given that resources are limited, decision-makers are bound to reach a point in which a small difference in how badly-off patients are or how much they can benefit from treatment determines which patient group receives treatment and which group does not. Moreover, when front-line clinicians are allowed to exercise their judgement to appraise such factors as the ability to benefit of patients, these "bedside rationers" will end up responding positively to prognoses that differ only slightly from prognoses that are deemed to be bad. In contrast, lotteries ensure that small differences do not drastically affect entitlements by providing a larger number of patients with a chance of treatment.[270]

No supporter of fair chances subscribes to the unappealing idea that lotteries should govern clinical care resource allocation on their own. At least, it is argued that those patients who fail to meet a minimal threshold of ability to benefit should not be given any chance to be treated. Thus, fair chances are affected by the same difficulty that they were supposed to solve.[271] Consider the use of lotteries in the case of organ transplantation. What is the maximum age at which patients should be given a chance to receive an organ? In general, what is the minimum ability to benefit that a patient should display? In the case of weighted lotteries, we also need to ask at what point patients should be given more chances than those who have a worse prognosis but still are given a chance. To answer any of these questions involves identifying a cut-off point or otherwise allowing small differences to make the whole difference between those who are given a chance to be treated and those who are not. In sum, cases in which small differences drastically affect entitlements are inevitable. Lotteries do not

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[270] Brock and Wikler (2006, 264) and Persad et al. (2009, 423).

[271] Here I apply to a different issue a criticism originally advanced by Alan Williams (1995, 223): at some point, lotteries bring resource allocation back to the problems they were supposed to solve.

make any exception and, therefore, there is no reason why fair chances should be allowed to interfere with public reason.[272]

6.4. Unreasoned decision-making: dread, government and stakeholder priorities, personal responsibility for health

This section focuses on dread, government and stakeholder priorities and personal responsibility for health. My aim is to show that each of these values is inconsistent with the commitment to reasoned decision-making that is intrinsic to public reason. Starting from dread, I use the term to refer to those conditions feared by the general public beyond their actual impact on morbidity and mortality. Cancer is by far the most important example of dreadful disease, and the popular dread of cancer puts pressure on resource allocation decision-makers to regard cancer with a favourable eye.[273] In 2011, the British government decided to ring-fence funding for cancer

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[272] It might be objected that I have not discussed all arguments for fair chances. According to Fleurbaey and Voorhoeve (2013), a plausible explanation of the value of lotteries is provided by the so-called "distributive view", which is first described by Wasserman (1996, quoted by Fleurbaey and Voorhoeve, 2013). Wasserman explains that according to the distributive view, a chance to receive a scarce good constitutes a good in itself, which is conceived as a "unit" of the scarce good in question. Of course, chances constitute a different kind of good from the scarce good that someone will ultimately receive – chances are intangible goods, produced by a merely symbolic division of the scarce good. Still, according to the distributive view, the whole point of lotteries is to mitigate the inequality that will be created when the scarce good is distributed to some and not to others. In brief, lotteries work towards greater "outcome equality" by distributing a very specific sort of good equally. The distributive view can be criticised in several ways - for example, see Wasserman (1996, 43–45). For my purposes, it suffices to recall that section 5.4 demonstrated that the only goods that should influence clinical care resource allocation are *health benefits*. Even if we grant that a chance to be treated constitutes a good of the same value as a certain unit of the health benefits that our scarce resources can produce, the relation between that good and health benefits is only symbolic. Clearly, a chance to receive treatment does not provide a patient with health benefits in the same way as the actual treatment would. Therefore, even if we grant the plausibility of the distributive view, chances constitute goods that are unsuitable to govern clinical care resource allocation.

[273] The term "dread" is borrowed from risk perception analysis - for example, see Slovic et al. (1982). Savage (1993) identifies stomach cancer as an object of dread. In their classic analysis of the NHS, Aaron and Schwartz (1984) note that clinical care is rationed less severely in the case of cancer and other objects of dread.

treatments that do not meet NICE's cost-effectiveness threshold, creating the Cancer Drugs Fund.[274] This decision was made even though NICE had already introduced the so-called “end-of-life premium” in response to controversies over its reluctance to recommend life-extending drugs for terminal cancer. The end-of-life premium assigns extra weight to the QALYs gained from treatment if three conditions occur: patients have less than 24 months of life expectancy; the treatment offers at least 3 months of life extension; and only a small patient population can benefit from treatment.[275] Shortly after the introduction of the end-of-life premium, NICE recommended Sunitinib, a drug for renal cancer which costs around £50000 per QALY, considerably higher than the £20000-30000 per QALY threshold normally employed by NICE.

Deliberative democrats might seem to have no choice but to accept dread as one of the substantive values that should govern resource allocation. Indeed, it seems that a democratic theory should follow public attitudes. More specifically, public reason requires that decisions be grounded in widely-acceptable ideas, and the dread of cancer is very pervasive. Still, the search for actual consensus does not exhaust the task of decision-makers committed to deliberative democracy and public reason. Deliberative democracy is an ideal of reasoned decision-making: widely-held ideas may count as public reasons only if they rest on *well-constructed rationales*, while the dread of cancer strikes us as an example of *entrenched bias*.

Apart from blind fear, there appears to be no basis for the claim that cancer patients are worse-off than patients who have the same quality-adjusted life expectancy but are affected by a different disease. Consequently, any decision grounded in the dread of cancer would not be based on well-constructed rationales, violating public reason. In risk

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[274] In this way, the government fulfilled an election pledge – see Donnelly (2010).

[275] NICE (2009).

perception analysis, it is argued that public attitudes and formal assessment may constitute different but equally reasonable ways of evaluating risk factors. Focusing on the much-discussed example of nuclear power, some maintain that public attitudes embed a wide array of considerations ranging from the uncertainty of available scientific knowledge to the equitable distribution of risk and the effects on future generations.[276] No such richness of reasonable considerations explains the dread of cancer. The fact of the4.4. matter appears to be that, in our culture, cancer has become the archetype of the terrifying fatal disease. Hence, dread turns out to be incompatible with the commitment to reasoned decision-making that is integral to deliberative democracy.

The example of cancer is also relevant to another candidate as substantive value, i.e. the declaration of priorities by the government. With the creation of the Cancer Drugs Fund and other announcements, the British government made it clear that the treatment of cancer constitutes a government priority.[277] Should NICE and Clinical Commissioning Groups give higher priority to cancer because of the announcements made by the Prime Minister, the Health Secretary and other prominent figures in the Department of Health? Whether a condition is a government priority already constitutes an independent value in various versions of the Portsmouth Scorecard, which is used by many Clinical Commissioning Groups to guide resource allocation.[278]

I do not mean to argue that health ministers and other members of government should offer no guidance to lower-level agencies. However, the government should offer guidance through the same deliberative process as lower-level agencies. Consequently, recommendations should be grounded

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[276] Slovic (1987, 285).

[277] Another important example is the reduction of waiting times for appointments, which has been a government priority in many European countries – see Goddard et al. (2006, 84).

[278] I. Williams et al. (2012, 70–71).

in public reasons. It is the public reasons highlighted by the government that should be endorsed by such agencies as NICE or Clinical Commissioning Groups. Thus, if the government grounds its recommendations in public reasons, to add a government priority criterion prompts resource allocation agencies to *double-count* the arguments supporting the assignment of priority to a certain area. If the government does not ground its recommendations in public reasons, the government priority criterion opens the door to *unreasonable decisions*. Either way, the government priority criterion damages the deliberative process.

The proposal that resource allocation agencies should put a premium on the priorities of relevant stakeholders is caught in a similar lose-lose situation.[279] Moreover, the visibility of stakeholders is a function of the money, time and other resources that they can invest. Hence, if a stakeholder priority criterion was accepted, resource allocation decisions would be swayed by the richest and most well-organised among the relevant interest groups, with the pharmaceutical industry being the most obvious and troubling example. It might be objected that my argument does not apply to patient advocacy groups, which appear to be disengaged from the aforementioned struggle for influence. However, patient advocacy groups are often funded by pharmaceutical companies. Also, some patient advocacy groups are richer and better organised than others, securing greater visibility for their priorities.[280]

Turning to personal responsibility for health, some claim that lower priority should be assigned to the treatment of patients who have contributed to their disease.[281] Those who smoke, drink heavily and over-eat know that they are increasing their risk of needing certain treatments. Those treatments

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[279] For example, see the EVIDEM's list of values proposed by Goetghebeur et al. (2010).

[280] For the links between pharmaceutical industry and patient advocacy groups, see Ferner and McDowell (2006, 1269–1270).

[281] Among others, see Glannon (1998), Smart (1994) and Walker (2010).

have a cost and resources are scarce. Therefore, it appears that the lifestyle choices of some individuals deprive the system of the necessary resources to treat other patients. Presumably, at least some of the patients left with no treatment are in a position to complain that, unlike smokers, drinkers and over-eaters, they have not done anything to deserve their disease. Thus, it seems that personal responsibility contributes to giving concrete shape to the minimisation of the strongest complaint and, therefore, should be upheld by public reason.

I argue that the use of personal responsibility is inconsistent with the idea that resource allocation should be governed by public reason and, therefore, by a certain *responsiveness* to the difficulties associated to alternative courses of action. More specifically, the problem with personal responsibility is rooted in the often-stressed fact that, as soon as we start thinking of how to make a personal responsibility criterion operative, an exceptionally large amount of practical difficulties arise. Such difficulties affect key aspects of the idea of personal responsibility for health, blocking any attempt to make use of personal responsibility that is not ready to turn a blind eye to its own problems. Importantly, a cavalier attitude towards the problems affecting any candidate as substantive value is inconsistent with the idea that resource allocation should be governed by our *reason*.

A first practical difficulty concerns the extent to which our lifestyle choices can be regarded as voluntary and, therefore, our own responsibility. Given that habits like smoking and drinking are addictive, quitting is extremely difficult. In many cases, such habits are taken up at a young age, when individuals are not fully responsible for their choices. Moreover, there are social contexts that pressurise individuals into making unhealthy lifestyle choices. Generally speaking, the pressure is stronger the more disadvantaged one's social group is, to the point that some underprivileged individuals do not have any real choice but to start smoking or drinking.[282]

Second, where should we draw the line defining that a disease-inducing choice has been made? How many cigarettes per day over what period of time are enough to make one's lung cancer self-inflicted? If smoking counts, how about choosing to live in a highly trafficked neighbourhood of the city centre? The problem is compounded by the fact that genetic differences have a major impact on the health risks associated to smoking and many other lifestyles. Thus, even if we knew how to draw the line defining that a certain individual has adopted a disease-inducing lifestyle, this result would not help to evaluate the lifestyle of others.[283]

Third, it is implausible to assign lower priority to patients who have made certain lifestyle choices, even though these choices increase the chances of needing expensive treatments. For example, Alena Buyx mentions the decision to become pregnant or to care for a person with dementia.[284] How can we single out the disease-inducing lifestyles that must not lead to lower priority for treatment? This question adds an extra layer of complexity to the issue of personal responsibility. Moreover, the risk is high that decision-makers would end up using the idea of personal responsibility against lifestyle choices that are generally taken to be vicious, violating the commitment to liberal neutrality.[285]

Fourth, it has not been proven that those individuals indulging in disease-inducing habits are imposing an exceptional burden on the health service. Given that prudent persons live longer and geriatric care is rather expensive, there is evidence suggesting that such habits as smoking and eating fats may actually be good for the clinical care budget.[286]

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[282] Wikler (2004).

[283] Fleck (2012, 7–8).

[284] Buyx (2008, 872).

[285] Wilkinson (1999).

[286] Van Baal et al. (2008) and Gillies and Sheehan (2006).

A critic might still object that a small number of cases may circumvent all of the practical difficulties that I have listed, justifying lower priority for treatment. Consider the case of Jane, who comes from a privileged background in which the pressure towards unhealthy lifestyles is not strong. She took up a number of extreme sports in adult age, devoting most of her time to them and, therefore, adopting a lifestyle that clearly makes any sport injury that she may suffer self-inflicted. To assign lower priority to the treatment of injuries caused by extreme sports is not nearly as implausible as in the case of pregnancy or care work. For the sake of the argument, let us also bracket the counter-objection that the increased risk of sudden death makes Jane a likely source of savings for clinical care providers.

I argue that, even in the case of Jane, to assign lower priority to any injury that she may suffer would be mistaken. I have already discussed the practical difficulties concerning voluntariness, the presence of disease-inducing choices, lifestyles which it would be implausible to target and financial impact. These factors are so difficult to manage that it is often impossible to tell whether specific patients should be held responsible for their health states. Now, it is unacceptable to rely on a substantive value that can only assign lower priority to a small number of individuals not because everyone else lacks some relevant characteristic, but because there is a vast grey area in which it is virtually impossible to determine which individuals have all the relevant characteristics. In this context, to assign lower priority to Jane would violate on a large scale a basic principle of reasonableness, which is that two persons with the same relevant characteristics should be treated alike.[287]

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[287] This principle is often called “formal fairness“ and was shown to be consistent with public reason in section 3.1.

6.5. On compartmentalisation: against innovation, lack of alternative treatments and rarity

This section focuses on three further values: innovation, lack of alternative treatments and rarity. I argue that they should be rejected out of the same drive for the compartmentalisation of different areas of government activity.

Especially in the U.K., the debate over the role of innovation in clinical care resource allocation was fuelled by the publication of Sir Ian Kennedy's report on the issue, commissioned by NICE in 2009.[288] Innovation has been high on the agenda ever since. For example, the fact that the current regime "does not promote innovation" constitutes one of the main motivations behind the plan to turn to a value-based approach to the pricing of branded pharmaceuticals to be used in the NHS.[289] According to the original plan, the maximum price that the NHS should be prepared to pay for a drug ought to depend on the value that the drug can offer. According to the consultation paper issued by the Department of Health in 2010, the NHS should set a range of maximum prices and commissioners should be ready to pay comparatively high prices for innovative drugs.[290]

There are at least two senses in which the term "innovation" is used in the debate. I discuss them in turn, showing that public reason rejects both. First, resource allocation may help foster "strict-sense" innovation, understood as the project to pave the way for *future* breakthroughs. There are cases in which drugs and other health technologies operate through novel mechanisms. If these technologies are widely used, they might play a

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[288] Kennedy (2009).

[289] Department of Health (2010, 5).

[290] Department of Health (2010, 13). At the end of 2013, it became clear thar the project to turn to value-based pricing would be scaled down - according to the new plan, no agency within the NHS will set maximum acceptable prices. See NICE's board paper from January 2014 at http://www.nice.org.uk/media/default/Get-involved/Meetings-In-Public/Public-board-meetings/Public-board-meeting-agenda-and-papers-22-January-2014.pdf (last accessed 14/10/2014).

part in the incremental process leading to scientific advancements of great value. Thus, even if the technologies in question are not particularly valuable in themselves, it is claimed that they should nonetheless receive higher priority.[291]

To place a premium on strict-sense innovation is meant to support scientific and medical research. However, supporting research is a key part of the mission of government agencies other than those in charge of clinical care resource allocation – for example, Research Councils and the rest of the Department for Business, Innovation and Skills in the U.K. Given the existence of dedicated agencies, there is no point in stretching the mission of clinical care resource allocation agencies so as to include the establishment of a fertile research environment. As Kennedy puts it, to reward a "promise of innovation" with NHS money would threaten the overall reasonableness of the allocation of the clinical care budget.[292]

More importantly, section 4.3 argued that a strong presumption for the *compartmentalisation* of different areas of government activity is one of the main sources of substantive recommendations of public reason. Cases in which numerous substantive values conflict with one another provide an excellent opportunity for vested interests and sheer custom to influence resource allocation. Given that deliberative democracy is meant to implement equal respect for the ability of everyone to impose decisions on themselves in light of their own reason, the impact of vested interests and sheer custom is to be minimised. Hence, we must resist the proliferation of substantive values in the decision-making process leading to the allocation of resources. Given that borrowing goals from other areas of government activity is a sure way of multiplying the value conflicts that decision-makers

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[291] D. Goldman et al. (2010). A concept akin to strict-sense innovation received considerable support when NICE's Citizens Council was asked to discuss when NICE should depart from its cost-effectiveness threshold – see NICE Citizens Council (2008).

[292] Kennedy (2009, 44–50).

have to face, deliberative democrats should be committed to the compartmentalisation of different areas of government activity. Therefore, there is no room for strict-sense innovation in a deliberative democratic approach to clinical care resource allocation.

In a broader sense of the term, "innovation" refers to new technologies that are particularly valuable in themselves and not because of their ability to lead to future breakthroughs. Specifically, technologies that are innovative in this sense produce an improvement over older technologies that qualifies as a *step change*.[293] For example, Robin Ferner and colleagues claim that technologies are most innovative when they tackle conditions with no existing treatment.[294] Other interventions that are said to provide a step change include drugs for rare diseases and treatments offering a significant health gain to patients affected by serious conditions.[295]

The notion of step change is the key to the idea of innovation in its broader sense. However, the notion of step change is parasitic on concepts that are generally discussed on their own as substantive values suitable to govern resource allocation: lack of alternative treatments, rarity, ability to benefit and severity of illness. To put a premium on broad-sense innovation would effectively reward technologies for their ability to pursue other values than innovation. Broad-sense innovation as an independent value is *redundant and conducive to double-counting*, while our attention should turn to the question, what should be done with each value defining the notion of step change?

Section 5.1 demonstrated that ability to benefit is endorsed by public reason. Severity is linked to priority to the worst-off, which is also consistent with public reason. I now turn to lack of alternative treatments

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[293] Kennedy (2009, 37–39).

[294] Ferner et al. (2010).

[295] Ferner et al. (2010) and Kennedy (2009, 39 and 47–48).

and rarity, starting from the former. It seems fair to say that, at least where access to clinical care is declared to be universal, no one should be left without decent treatment for their conditions. Thus, higher priority should be assigned to interventions if no other minimally satisfactory treatment for the same condition is available under the relevant health service.[296]

However, the logic behind priority to the lack of alternative treatments comes apart if placed against the background of *rationing*. All health services are forced to ration clinical care, which is to allocate resources through a process involving the withholding of beneficial interventions. Therefore, we must accept as a fact that all health services are bound to leave some patients without any minimally satisfactory treatment even though beneficial interventions are technically available.

If we regarded the lack of alternative treatments as a valid basis for complaint, decision-makers should divert resources from other interventions in order to respond to that complaint. However, given that we operate under a regime of rationing, this diversion of resources is likely to leave someone else without any satisfactory treatment and, therefore, in a position to make *the very same complaint that we started with*. In this context, more information describing the various patients who risk being left without treatment is needed to determine who is in a position to complain and who is not. From the perspective of public reason, what matters is that those who are so badly-off and capable of benefiting as to make a strong complaint should not be left without treatment. Conversely, if someone is left without treatment but cannot raise a stronger complaint than anyone who has been treated, resource allocation decision-makers should not be moved. In itself, the lack of alternative treatments should not make any difference.

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[296] Golan et al. (2011). In the consultation paper about value-based pricing, the Department of Health (2010, 13) suggests that the NHS should be ready to pay a premium for drugs addressing areas of “unmet needs“.

Some might object that deliberative democracy should put a premium on the lack of alternative treatments because pharmaceutical industries invest too much money on “me-too drugs”, which are pharmaceuticals that offer a trivial improvement over existing treatments for common and, therefore, highly profitable diseases. From a societal point of view, me-too drugs do not offer much value for the money spent on research and development (R&D). Thus, to give higher priority to the lack of alternative treatments would serve as an incentive for industries to divert resources from the R&D of me-too interventions.[297]

This objection brings us back to the overarching theme of this section. Disincentivising the R&D of me-too drugs is a valuable aim that governments should certainly pursue. However, dedicated agencies focus on the way in which research should be promoted and directed. We have seen that clinical care resource allocation bodies should be extremely wary of endorsing the aims of other government agencies. Therefore, disincentivising me-too drugs should not be an aim of clinical care resource allocation agencies and should not be funded through clinical care resources.

Turning to rarity, the term covers orphan and ultra-orphan diseases, which have a prevalence lower than 5 in 10000 inhabitants and 1 in 50000 inhabitants respectively. Patient populations are so small that it is hard for pharmaceutical industries to recoup the costs involved in the R&D of drugs. Therefore, the purchase prices set by pharmaceutical companies tend to be extremely high, making many drugs for orphan and ultra-orphan diseases not cost effective. To assign higher priority to rare diseases when clinical care resources are allocated seems necessary to ensure that at least some drugs for rare conditions are funded. Along these lines, the members of

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[297] The British Office of Fair Trading (2007, 99) suggests that we should intervene on the demand side to disincentivise me-too drugs.

NICE's Citizens Council suggest that the NHS should pay premium prices for ultra-orphan drugs, provided that certain conditions are met.[298] The Advisory Group for National Specialised Services (AGNSS), which assessed until 2013 which treatments for ultra-orphan conditions should be commissioned by the NHS, routinely approved treatments falling much beyond NICE's cost-effectiveness threshold.[299] For example, AGNSS recommended Eculizumab, which is a drug for for atypical haemolytic uraemic syndrome whose cost may reach a staggering £500000 per QALY.[300]

Not everyone believes that rare diseases should be given priority. Some argue that the prevalence of a disease is a feature of no moral relevance. Thus, it would be unfair if government agencies discriminated in favour of treatments for rare diseases and against treatments that are expensive for some other reason.[301] This argument is faulty and misses the real problem of assigning higher priority to rare diseases when clinical care resource are allocated. Prevalence is morally relevant because low prevalence is likely to lead to the abandonment of whole groups of patients.[302] If the state did not intervene, pharmaceutical industries would be likely to never invest in patients affected by rare diseases – because of their numbers, large patient populations are much more profitable. Moreover, if any industry ever decided to do research into rare diseases, the need to recoup R&D costs would lead to extremely high prices for the resulting products, placing such products beyond the reach of many clinical care providers. In sum, the

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[298] NICE Citizens Council (2004).

[299] In 2013, AGNSS ceased to exist and its work was taken over by NICE. Although NICE is still in the process of adjusting its methods to the new role, it appears that the criteria for making decisions about ultra-orphan drugs will draw more on AGNSS's past work than on NICE's traditional health technology appraisals. For example, NICE (2013b) does not mention any cost-effectiveness threshold.

[300] AGNSS (2012) and NHS England (2013).

[301] McCabe et al. (2005).

[302] For similar arguments, see Hughes et al. (2005) and Sheehan (2005).

patients affected by rare diseases would be systematically neglected in the process starting from the R&D of drugs, violating any idea of equal concern.[303]

However, the risk of abandonment does not justify placing higher priority on rarity *when clinical care resources are allocated*. This is because the risk of abandonment is rooted in the *priorities and costs of research* as they face pharmaceutical industries in the absence of government intervention. Indeed, the problem springs from the fact that industries would hardly ever invest in the R&D of drugs for rare diseases and, if they ever focused on such diseases, there would be huge R&D costs to recoup. Once again, we have come across a problem rooted in the behaviour of research companies, as opposed to the bodies engaged in clinical care resource allocation and provision. Thus, as in the case of strict-sense innovation and me-too drugs, the abandonment of patients with rare diseases should not be for clinical care resource allocation agencies to handle. Deliberative democracy requires that clinical care resource allocation agencies should be extremely wary of borrowing values from other areas of government activity, including those from the allocation of research funding.

In practical terms, my argument means that, instead of demand-side incentives paid with clinical care resources, governments should work with supply-side incentives funded by the agencies responsible for industry and research. Several incentives of this kind are already in place; for example,

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[303] At this point, a critic might object that the abandonment of those affected by rare diseases poses the same kind of problem as the lack of alternative treatments, which has been discussed earlier. Thus, if we must accept that, under a regime of rationing, some patients will be left without treatment, we must also accept that those affected by rare diseases are likely to be abandoned. However, the parallel between rarity and lack of alternative treatments is misleading. If the state did not intervene, the patients affected by rare diseases would be systematically neglected regardless of how *badly-off* they are and the extent to which they could *benefit* from treatment under a different regime. Thus, those patients would be abandoned regardless of the strength of their complaint. In contrast, I have only argued that we must accept that patients with relatively weak complaints may end up without any satisfactory treatment.

the European Union offers waivers for market authorisation fees, extended market exclusivity and R&D subsidies. In this way, research into rare diseases is stimulated and governments shoulder part of the R&D costs, creating the possibility for lower prices for orphan and ultra-orphan drugs.[304]

In closing, it is worth noticing that, even though clinical care resource allocation agencies should not assign higher priority to rarity, my model promises to be rather friendly towards the claims of patients affected by rare diseases. Orphan and ultra-orphan drugs rank particularly badly when CEA governs resource allocation. This is because CEA involves aggregation. Hence, all orphan and ultra-orphan drugs must face the competition of treatments for minor and moderate conditions that, in virtue of their being common, are inexpensive to treat. However, public reason rejects aggregation, while priority to the worst-off and ability to benefit are upheld. Therefore, treatments for rare diseases that can save lives or greatly improve the quality of life of patients are bound to rank rather high, even though a treatment that can do the same for a lower cost should obtain higher priority.[305]

6.6. Conclusion

Like the previous chapter, this chapter has made great progress in the exploration of two of the three main themes underlying my thesis. One of the themes underlying my thesis is that, despite the scepticism surrounding the idea of substantive implications of deliberative democracy, my model of democratic deliberation has the necessary resources to provide determinate answers to difficult substantive questions. The sheer amount of values that

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[304] European Parliament and the Council of the European Union (1999). See also Gericke et al. (2005) and Pinxten et al. (2012).

[305] For more on the way in which cost and other substantive values should be operationalised, see section 7.2.

this chapter has demonstrated to be inconsistent with public reason is proof of the ability of deliberative democracy to engage with substantive issues.

Another theme of my thesis is that several components of the population-level perspective dominating the debate on clinical care resource allocation are misguided. In particular, this chapter has demonstrated that CEA should never be used to allocate resources and, therefore, decision-makers should find another way to factor in cost considerations. The most fitting way to factor in cost considerations is one of the issues to be discussed in the next chapter, which draws together the different parts of the substantive analysis carried out thus far.

7. SUBSTANTIVE VALUES III: WHAT THE RECOMMENDATIONS OF PUBLIC REASON LEAD TO

The aim of this chapter is to pull together the different parts of the analysis carried out in chapters 5 and 6 . Out of a long list of values, chapters 5 and 6 demonstrated that only priority to the worst-off and ability to benefit, if framed by the specialness of clinical care and constrained by cost considerations, are consistent with deliberative democracy. This chapter shows that the ability of public reason to provide determinate answers to hard substantive questions goes beyond the conclusions reached in the previous two chapters. Based on the values that have been shown to be consistent with deliberative democracy, section 7.1 draws the broad contours of a system of clinical care resource allocation decisions made by agencies governed by public reason. Section 7.2 demonstrates that there is scope for converting the substantive values consistent with deliberative democracy into a decision-support tool that is capable of providing guidance to resource allocation decision-makers. Finally, section 7.3 points out that, in virtue of the substantive recommendations of public reason, my model of deliberative democracy strikes a middle way between a utilitarian and an intuitionistic approach to political decision-making. Drawing on an appealing argument advanced by John Rawls, this outcome is shown to be a great strength of my model.

7.1. The spirit of my framework of values

This section sketches the broad contours of a system of clinical care resource allocation decisions made by agencies governed by public reason. In a sense, the aim of this section is to capture the spirit of the framework of substantive values constructed in chapters 5 and 6. To accomplish such a broad aim, I need to leave a number of concepts somewhat vague and underspecified. However, vagueness is overcome in section 7.2, where my focus shifts to the construction of a rather formalised decision-support tool.

Chapters 5 and 6 showed that four values are consistent with deliberative democracy. However, two of them (i.e. cost and specialness of clinical care) turned out to play only a *constraining* or a *framing* function. With some simplification, the cost of interventions should only be taken into account to ensure that available funds are allocated so as to create the greatest value.[306] Specifically, the value that decision-makers should consider concerns the strength of the complaints of the potential recipients of interventions. In turn, the strength of someone's complaint is determined by a combination of how badly-off she is and how much she can benefit from treatment. Apart from providing negative advice, the specialness of clinical care only serves as a frame within which to understand other values. Specifically, specialness requires that priority to the worst-off and ability to benefit should be understood in terms of health. In sum, as long as resource allocation agencies work within the right constraints and the right frame, their *real objects of concern* should be the worst-off and those who are capable of benefiting the most from treatment. What does this conclusion mean for the broad contours of the decisions that should be made?

The *top priority* of agencies governed by public reason should be to fund

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[306] The simplification is eliminated in section 7.2, where it becomes relevant that cost should also be allowed to break ties.

interventions providing the largest individual benefits to patients who are among the worst-off. Public reason requires that resources should be allocated so as to minimise the strongest complaint any individual may have. Given that being badly-off and having a considerable ability to benefit from treatment are the two bases for complaint that I have identified, there can be no stronger complaint than the one raised by patients who are both extremely badly-off and capable of greatly benefiting from treatment.

The example of antiretroviral treatments for HIV/AIDS may help to clarify what I mean by interventions that are both highly beneficial and addressed at patients who are extremely badly-off. Especially in the 1990s and early 2000s, antiretroviral treatments have been an object of discussion in the context of clinical care resource allocation because of their high cost. The most serious challenges have been posed by antiretroviral drugs that are used in special cases or when patients are resistant to standard treatments.[307] Be that as it may, antiretroviral treatments are very effective in suppressing the viral load in the blood. Vulnerability to cancer and deadly infections is greatly reduced, making HIV/AIDS into something similar to a chronic disease. Moreover, the health-related quality of life of patients hugely benefits from antiretroviral therapies. In sum, antiretroviral treatments are bound to rank high when it comes to both priority to the worst-off and ability to benefit.

Moving beyond the interventions addressed at patients who are both extremely badly-off and capable of greatly benefiting from treatment, public reason also requires that the allocation of resources among other interventions should be governed by priority to the worst-off and ability to benefit. However, we have seen many times that clinical care resources are scarce to the point that decision-makers are forced to ration them. Thus,

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[307] For example, Fleck (2009, 208–218) discusses fusion inhibitors (which cost $20000 per year in the U.S.) and protease inhibitors (which cost $35000 per year).

interventions that address the concern for strong complaints will have to be funded by diverting resources from interventions that do not sufficiently address that concern. In other words, deliberative democracy suggests that health services should *abandon the idea that the package of clinical care should be comprehensive*, i.e. aimed at covering all areas of clinical care provision.[308] In what follows, I explore the categories of interventions that should be considered for exclusion.

First, interventions that only yield *small benefits* should certainly be excluded, regardless of how badly-off potential recipients are. The justification for this exclusion is rooted in the response to the bottomless pit problem offered in section 5.1. In brief, I argued that complaints based on how badly-off a patient is do not apply below a threshold of minimal ability to benefit. This is because the willingness to give help to the worst-off is a key part of the motivation behind a principle of priority to the least well-off. Such motivation loses its force when the benefits that can be offered are too small, leading to the conclusion that interventions providing small benefits fail to satisfy not only ability to benefit, but also priority to the worst-off. Therefore, this kind of interventions should be excluded from coverage before decision-makers discuss cuts to interventions that offer greater benefits.[309]

When it comes to interventions offering benefits that are too small to be covered, end-of-life care provides a rich source of examples. Especially in the U.S., numerous ethicists have attacked the "heroic" attitude of many clinical care providers, who are willing to try anything, no matter how trivial the expected benefits, when faced with terminal illness.[310] If elderly,

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[308] As stressed by Weale (1998), the idea that the package of clinical care should be comprehensive is endorsed by many existing health services. For example, the ideal of comprehensiveness is enshrined in the NHS Constitution – see NHS (2013).

[309] At this point, one obvious question is, who gets to choose when a benefit is too small? I provide an answer in section 7.2.

[310] Among others, see Callahan (1987), Dworkin (1994) and Menzel (1990).

the patients towards the end of their lives are often affected by multiple chronic diseases – some of them may even be in a state of advanced dementia or in a persistent vegetative state. If a patient has had her mobility impaired by a stroke, is on dialysis and suffers from dementia, the improvements in quality of life that can be obtained from the treatment of any potential acute problem that may arise are bound to be limited. Still, even when no life extension is possible, physicians are sometimes willing to perform interventions that provide a trivial improvement in quality of life.[311] As for those treatments whose main aim is to extend life, an interesting case study is offered by Janet Shim and colleagues, who focus on the use of cardiac procedures such as bypass surgery or implantable cardiac defibrillators in the U.S. They document that patients in their 9th or even 10th decade have become routine recipients of those procedures, even when surgeons know that the expected benefit will be negligible.[312]

Second, decision-makers should turn to a broad family of diseases that may be called "*moderate conditions*". Funds should be diverted from the treatment of moderate conditions *to the extent necessary* to muster the needed resources to respond to stronger complaints. Roughly speaking, by moderate conditions I mean conditions that do not make patients very badly-off. Clearly, these kinds of conditions do not stand out when it comes to giving priority to the worst-off. Moreover, even if an effective treatment exists, the fact that the condition is moderate prevents patients from displaying the same ability to benefit as some of the patients who are less well-off.

With regard to moderate conditions, many examples are provided by the strategies adopted by Clinical Commissioning Groups and, before the reform that took effect in April 2013, Primary Care Trusts to achieve the

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[311] Fleck (2009, 276–299).
[312] Shim et al. (2006, quoted by Fleck, 2009).

cost-containment objectives set by the NHS for local commissioning authorities. Indeed, numerous local commissioning authorities have restricted access to interventions such as hip and knee replacements, hernia procedures, hysterectomy for heavy menstrual bleeding and cataract operations.[313] Even when effective interventions are available, the fact that the condition in question exacts a relatively light toll and that there is no room for large benefits justifies excluding or otherwise rationing such interventions, if there is the need to muster resources to fund interventions that respond to stronger complaints.

7.2. Towards a decision-support tool

In the foregoing section, I used a number of vague concepts. For example, the reader was left wondering when a condition should be considered to be moderate. The use of vague concepts was instrumental to the aim of the section, which was to capture the spirit of the framework of values constructed in the previous two chapters. This section demonstrates that public reason can overcome vagueness, at least to a large extent. The purpose of this section is to show that the substantive values accepted by public reason lend themselves to be made into a rather formalised decision-support tool for resource allocation agencies.

Before starting, I need to state two caveats. First, I do not mean to argue that public reason can build such a decision-support tool on its own. We will see that there are points where resources from outside public reason are likely to be necessary, even though the use of such resources is only justified within limits dictated by public reason. Second, this section does not complete the construction of the decision-support tool. My aim is to show

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[313] See Klein and Maybin (2012, 21–24) and the results of a survey of 111 Primary Care Trusts carried out by the magazine GP (Moberley, 2011, discussed by Wright, 2011).

that public reason can go a very long way towards building a decision-support tool. However, to complete the construction of such a tool, questions of specification must be answered that I do not have the space to address here.

This section proceeds by considering in turn the four values accepted by public reason, starting with cost. My rejection of cost effectiveness may lead some to think that a decision-support tool governed by public reason is left with no obvious way of taking costs into account. On the contrary, how costs should be factored in becomes immediately clear if we look at my discussion of the twofold reason why decision-makers should take costs into consideration.[314] First, and most importantly, I have claimed that costs should be considered to ensure that covering a certain intervention does not deprive the resource allocation agency of the necessary funds to cover interventions that respond to a stronger complaint. This justification points to a very specific approach to how costs should be factored in by decision-makers, i.e., a *prioritised-list approach*. Through this approach, interventions are ranked according to how much value they create, irrespective of costs – on my conception of deliberative democracy, interventions will therefore be ranked according to the strength of the complaint they respond to. Available funding is allocated starting from the top of the list and moving down until the money runs out.[315]

For example, the prioritised-list approach is adopted by the state of Oregon to allocate Medicaid funds. Oregon has engaged in a transparent process for allocating Medicaid funds since the early 1990s. In the beginning, the commission in charge of prioritisation employed a method with many points of contact with cost-effectiveness analysis. In response to

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[314] See section 6.2.

[315] In their analysis of the idea of need, Hope et al. (2010, 476) refer to an analogous strategy for taking costs into account. This strategy is contrasted with a number of alternatives, which all revolve around the use of a cost-effectiveness threshold.

the storm of criticism following their initial recommendations, the commission changed tack and interventions are now ranked according to 8 values that are weighted by health care category. Given their available funds, Oregon currently funds line 1 through 498 of their list.[316] If the ranking is determined by strength of complaint, the prioritised-list approach perfectly fits with the basic idea that resources should be allocated by means of pairwise comparisons between each potential recipient and everyone else. Indeed, the potential recipients of all interventions excluded from coverage have a weaker complaint than the recipients of any intervention that has been covered.[317]

Second, I have shown that the cost of the treatment of a single patient serves as a *tie-breaker* when decision-makers have to assign relative priority to interventions that, as far as priority to the worst-off and ability to benefit are concerned, have the same value. Again, the implications for the creation of a decision-support tool should be clear: if two interventions respond to complaints that are otherwise of the same strength, the cost of the treatment of a typical patient determines which intervention should be placed higher on the prioritised list.

What do the other values endorsed by public reason tell us about how to formalise the strength of complaints, which is the key to producing any prioritised list within a deliberative democratic system for clinical care resource allocation? Section 5.4 pointed out that the specialness of clinical care dictates which evaluative space should be adopted. Specifically,

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[316] For the current list, see Health Services Commission (2013). For the method employed, see http://www.oregon.gov/oha/herc/Pages/Prioritization-Methodology.aspx (last accessed 14/10/2014). Instead, Bodenheimer (1997) provides a synopsis of the early stages of the Oregon experiment.

[317] At least, this conclusion holds if we accept my argument that, in many circumstances, resource allocation decision-makers are forced to work with simplifications and ignore a certain amount of difference between patients affected by the same condition – see section 6.2.

specialness requires that priority to the worst-off and ability to benefit should be understood in terms of health, not overall well-being. At present, *Quality-Adjusted Life Years* (QALYs) are the most well-developed measure of health available. Thus, the two bases for complaint that I have identified should be measured in terms of QALYs. The number of QALYs that a patient expects to live with treatment minus the number of QALYs that she expects to live without treatment can measure ability to benefit. Depending on the way in which the relationship between time and the notion of the worst-off is spelled out, how well-off a patient is should be measured either by the amount of QALYs she expects to live from now on without treatment or by the amount of QALYs that she will have lived from birth to death if she does not receive the treatment in question.[318]

To say that the bases for complaint should be measured in terms of QALYs does not yet explain how QALY scores measuring how well-off patients are should be combined with the scores measuring ability to benefit to calculate the strength of complaints and, therefore, the position of interventions on the prioritised list. To start with, a whole range of interventions should be placed *at the bottom of the list*, in joint place with each other; these are the interventions that only produce a *small benefit*. In the previous section, we saw that if the expected benefit is too small, both ability to benefit and priority to the worst-off lose their force. Consequently, the complaint of the potential recipients of the intervention at hand is bound to be weak, justifying the conclusion that the stretched resources of clinical care resource allocation agencies should not be used in this context.

At this point, the question for all resource allocation systems that wish to

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[318] Section 5.1 explained that the relationship between time and the notion of the worst-off is one of those definition issues that, in virtue of their complexity, must be placed beyond the scope of my thesis. However, it is important to stress that this issue must be acknowledged, addressed and given an answer before any decision-support tool governed by public reason can be considered to be ready.

follow deliberative democracy is, where exactly should we place the threshold below which benefits count as too small? To answer, the designers of the decision-support tool that I have been discussing have to go beyond public reason. However, this fact hardly distinguishes public reason from any other theoretical approach that might have been adopted. Consider the work of Alena Buyx and colleagues, who advance a proposal that has many points of contact with mine. Indeed, they claim that those interventions producing "minimal" clinical benefits should be excluded from coverage. Buyx and colleagues propose that, to identify minimally effective interventions, the two components of the QALY should be treated separately. Specifically, they suggest that an appropriate threshold of minimum effectiveness could be either increasing one aspect of health-related quality of life by 10% or prolonging life by 3 months. Still, they admit that the choice of the threshold is "ultimately arbitrary" and should be left to the public.[319] I add that, if public reason cannot do much to help set the threshold, a process should be established that complies with the other requirements of deliberative democracy. The threshold chosen through this process should be built into the decision-support tool for resource allocation decision-makers.

Presumably, setting an ability-to-benefit threshold would not eliminate the need to ration interventions above it – unless the threshold is placed so high as to become implausible. This leaves us with a last question concerning the design of a decision-support tool: how should interventions be prioritised above the threshold? Specifically, how should QALY scores measuring how well-off patients are be combined with QALY scores measuring ability to benefit to calculate the strength of complaints above the threshold? Of all the questions that have been asked in this section, this one

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[319] Buyx et al. (2011).

necessitates the greatest amount of work. In fact, I do not mean to provide a complete answer. Instead, I only aim to outline two possible ways ahead and emphasise that a choice among them needs to be made before the decision-support tool that I have been discussing is offered to resource allocation decision-makers.

A first possible way ahead is to adopt *a simple subtractive model*. When two quantifiable substantive values are taken to have the same importance, a simple additive model appears to be the default option for the designers of decision-support tools for resource allocation decision-makers.[320] After an intervention has been assigned scores on each value, the scores are added together to determine a single index for the intervention under consideration - the greater the index, the higher the priority of the intervention.

I need a subtractive model simply because, although the strength of a complaint increases with the QALYs measuring ability to benefit, it diminishes if there is an increase in the QALYs measuring how well-off a patient is. Other things being equal, if I expect to live one more QALY without treatment than another patient, my complaint is weaker than hers, not stronger. Hence, to determine the position of an intervention that falls above the threshold, decision-makers should subtract the amount of QALYs measuring how well-off a patient is from the amount of QALYs measuring her ability to benefit. The greater the resulting index, the higher the position of the intervention on the prioritised list. To put it another way, the strength of a complaint S is given by $S = A - W$, where A is the amount of QALYs measuring the ability to benefit of the patient under consideration and W is the amount of QALYs measuring how well-off she is. The greater S is, the higher the position of the intervention on the list.

The subtractive model has the attractiveness of simplicity. Moreover, a

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[320] Peacock et al. (2007, 900–901).

simple model appears to be suitable for the task at hand. Thanks to the filtering ability of public reason, we only need to determine how *two* substantive values should be combined. Furthermore, we have seen that these two values are amenable to be measured by the *same metric*, i.e., the QALY. In brief, it is not necessary to find a way to combine a large number of very different values, which would certainly require a more complex formula than a simple subtractive model.

Still, I do not consider the simple subtractive model above criticism. Some might ask whether I am sure that being badly-off and being capable of considerable benefits should count as *equally important* bases for complaint. Perhaps, equal concern for each and every individual requires that decision-makers should worry primarily for how badly-off patients are and only secondarily for their ability to benefit. If this was true, a different method for combining priority to the worst-off and ability to benefit would be in order. For example, it could be argued that the QALYs measuring ability to benefit ought to be discounted by a certain percentage to express the greater importance of complaints based on how badly-off patients are - subtractions should be done only after discounting.

I do not have the space here to address the issue of the relative importance of priority to the worst-off and ability to benefit. To be honest, I cannot exclude that public reason might turn out to be unable to solve this issue on its own. At some point, help from outside public reason might be needed, perhaps in the form of an “act of the will”, which is choosing what appears to be the right solution even though no determinate reason can be offered in its support.[321] At any rate, I wish to stress that the question of relative importance is a significant issue that must be addressed by any society interested in subjecting clinical care resource allocation to

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[321] See Andrew Williams (2000, 209–211) on how to fill the gap between reasons and final decisions when public reason cannot provide a determinate answer.

deliberative democracy. Indeed, an answer must be provided to complete the construction of the decision-support tool to be handed to resource allocation decision-makers.

In conclusion, I would like to emphasise that, even though this section terminates with an issue that I need to bracket and may even fall beyond the reach of public reason, our attention should not be distracted from the main point of the section, which is the great extent to which public reason can help build a decision-support tool. Indeed, it is public reason that has dictated a specific approach to the way in which costs should be taken into account, namely through a prioritised list in which the cost of a typical intervention should work as tie-breaker. It is public reason that has pointed to the QALY as a suitable evaluative space for measuring both bases for complaint and, therefore, determining the position of interventions on the list. Moreover, it is public reason that has required an ability-to-benefit threshold below which interventions deserve to be placed at the bottom of the list. Still on the basis of public reason, I have outlined two possible directions of research to determine priorities above the threshold, even though I cannot be sure that public reason will be able to solve all the problems involved.

7.3. A superior alternative to both utilitarianism and intuitionism

The aim of this section is to demonstrate that the substantive recommendations offered by public reason constitute a strength distinguishing my theory of clinical care resource allocation from a range of important alternatives. I intend to show that, thanks to the substantive recommendations offered by public reason, my conception of deliberative democracy achieves a goal that John Rawls sets for any good theory of fairness in the allocation of resources, i.e. to find an alternative to both utilitarian and intuitionistic modes of reasoning. As will soon be clear, the arguments advanced by Rawls are especially compelling for anyone sharing the basic ideas of my conception of deliberative democracy, namely that resource allocation decision-making should implement equal respect for individuals, particularly for their ability to impose decisions on themselves in light of their own reason.

After summarising Rawls's arguments, I explain why they are of great relevance in the field of clinical care resource allocation. Next, I demonstrate that deliberative democracy constitutes an alternative to both utilitarian and intuitionistic modes of thinking. Finally, I show that multi-criteria decision analysis, Norman Daniels's accountability for reasonableness and Leonard Fleck's conception of deliberative democracy all fail to strike a middle way between utilitarianism and intuitionism.

The reason why Rawls rejects utilitarianism and its aggregative logic was explored in full detail in section 6.1. The idea is that, instead of taking care of the interests of each and every member of society, aggregative approaches pursue the interests of social conglomerates as if they were our ultimate units of concern, for which individuals can be sacrificed.[322] Once utilitarianism and other aggregative single-value approaches to resource allocation have been shown to be untenable, it is tempting to turn to *long lists* of substantive values. According to Rawls, the temptation is especially strong when it comes to specific public policy fields such as fair wages, taxation and, we may add, clinical care resource allocation.

Intuitionists yield to this temptation, arguing that a) a plurality of irreducible values applies to political issues and b) no explicit criterion for determining the balance of such values is available. If a plurality of values

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[322] Rawls (1999, 19–30).

applies to political issues, they will often conflict with one another. Given that no criterion is available to balance values in all cases of conflict or, at least, confine intractable value conflicts within narrow limits, intuitions are bound to do a great deal of work in the decision-making process. What is the problem with the work done by intuitions in settling value conflicts? Intuitive judgements are opaque in the sense that one cannot be expected to satisfactorily explain to others why her intuitions have favoured one option over the others. Thus, *vested interests and sheer custom* are free to hide behind intuitive judgements to determine the solutions to value conflicts in a way that is virtually impossible to detect. In sum, the risk is that resource allocation ends up being steered by power and bias, violating the deliberative democratic idea that decision-making should be governed by the members of the public in light of their own reason.[323]

Rawls's argument against intuitionism is of particularly great relevance in the context of clinical care resource allocation. This is because a range of lobbies have both a strong interest in clinical care resource allocation processes and the power to exert huge pressure on them – pharmaceutical industries, patient advocacy groups and the media provide excellent examples of such lobbies, while elected politicians often have strong incentives to yield to their pressure. As claimed by Iestyn Williams and colleagues, it seems fair to say that “the interplay of interest group agendas is nowhere more significant than in health care”.[324] Moreover, resource allocation decision-makers may have conflicts of interest in the allocation process, with deleterious effects on the impartiality of their judgements.

As an example of the sort of pressure that lobbies can exert on clinical care resource allocation, consider the case of Herceptin. In 2005, Herceptin had been used for a few years to treat advanced breast cancer under the

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[323] Rawls (1999, 30–36).

[324] I. Williams et al. (2012, 90). See also Goddard et al. (2006) and R. Robinson (1999).

NHS. Thanks to a smart use of press releases by the pharmaceutical company Genentech, pressure mounted on the NHS after a paper was published showing positive results in the treatment of early-stage breast cancer. Newspapers published a great deal of stories, attacking what was depicted as red tape preventing many women from accessing a wonder treatment. Patient advocacy groups did their part, with one of them marching on Downing Street in September 2005 to submit a petition. It is important to emphasise that, at this stage, the European Medical Agency had not yet received the necessary information to assess the safety of Herceptin in the treatment of early-stage breast cancer in order to issue a licence. Thus, Primary Care Trusts (PCTs, which were the local commissioning authorities at that time) were pressurised into making coverage decisions not only before NICE could appraise value for money, but also before safety could be assessed. Nonetheless, politicians went to great lengths to make sure that as many PCTs as possible would decide to cover Herceptin. In a Department of Health press release, the Secretary of State for Health Patricia Hewitt declared that she wanted to see Herceptin in widespread use. She went as far as obtaining a meeting with the staff of one of the PCTs that had upheld the principle that the licensing process should not be bypassed – unsurprisingly, the decision taken by the PCT was reversed after the meeting.[325]

Turning to the impact of conflicts of interest on the judgement of decision-makers, consider the example of Clinical Commissioning Groups (CCGs), which took over the functions carried out by PCTs in April 2013. General practitioners (GPs) form a much larger proportion of the staff of CCGs than used to be the case with PCTs. However, many GPs hold stakes in private providers of clinical care. Hence, such GPs have a strong incentive to commission as many services as possible from the providers

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[325] Ferner and McDowell (2006) and Syrett (2007, 1–9).

they hold stakes in, regardless of costs and any other value consideration.[326] Moving somewhat beyond the most typical cases of conflict of interest, it is widely known that pharmaceutical industries invest a great deal of money in gifts and other strategies for winning the sympathy of clinicians.[327] Given that these efforts have been shown to have a considerable impact on the clinical judgement of physicians, they are most likely to effectively sway the judgement of GPs when it comes to commissioning pharmaceuticals treatments.

We are now in a position to appreciate the extent of damage that an intuitionistic approach to reasoning about values can make to deliberative democracy in clinical care resource allocation. According to my conception, deliberative democracy is essentially about building decision-making procedures that approximate the state in which every individual can be regarded as imposing decisions on herself. However, we have seen which sort of *pressure* vested interests and the self-interest of decision-makers can put on resource allocation processes. If we accept that a plurality of values apply to resource allocation and only intuitions can settle their conflicts, decision-makers are offered the “easy” option of giving in to that pressure and obfuscating the fact that vested interests and self-interest are effectively governing the decision-making process. Indeed, decision-makers can always appeal to intuitions to justify an ordering of conflicting values that favours themselves or the most powerful lobbies with an interest in the decision at hand. In sum, *confining value conflicts and the use of intuitions within narrow limits* is the only way to block a major route that vested interests and self-interest could otherwise use to steer resource allocation processes without being detected.

Does my model of deliberative democracy constitute an alternative to

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[326] Jackson (2013, 66).

[327] Angell (2005, 115–172) and Kassirer (2005).

both utilitarian and intuitionistic modes of reasoning? As argued at length in section 6.1, public reason rejects cost effectiveness and all other utilitarian-like aggregative values. In what follows, I demonstrate that my conception of deliberative democracy also avoids the trap of intuitionism.

Whereas intuitionists endorse a plurality of values, my conception of deliberative democracy only accepts four values out of the long list discussed in chapters 5 and 6. Moreover, intuitionists believe that intuitions have a major role to play in determining how values ought to interact and be balanced in specific decision-making situations. In contrast, two values accepted by deliberative democracy (cost and specialness) only play a constraining or a framing function. This means that there is *no possibility of conflict* among these two values or between them and any of the other values accepted by deliberative democracy. If conflicts are not possible, there is no need to balance values, ruling out any appeal to intuitions to determine how values should interact with each other in specific situations.

Turning to the other two values accepted by deliberative democracy, I have not been able to specify how exactly priority to the worst-off and ability to benefit should be combined above the ability-to-benefit threshold. Thus, I cannot explore in full detail the role played by intuitions in balancing them. However, the idea that intuitions have a major role to play in settling value conflicts appears to be considerably less appealing in the case of *two* values amenable to be measured *by the same metric*, as opposed to a large number of very different values. Still, I cannot exclude that intuitions might turn out to have a role to play after either of the two ways ahead outlined at the end of section 7.2 has been developed. Even if intuitions turned out to have a role to play, however, the use of intuitions in settling conflicts would be limited to only two values, most likely at the margins of the process. Hence, the use of intuitions would be confined within much narrower limits than in the case of intuitionism, offering limited opportunities for vested interests, self-interest and sheer custom to hijack the resource allocation process by exploiting the opacity of intuitive judgements.

A supporter of intuitionism could object that confining the use of intuitions within narrow limits leads to lack of flexibility in the face of complex practical problems. Choosing which values are relevant and how to balance them on the basis of the context of a decision is necessary to make wise choices. In response to this objection, I reiterate that vested interests and the self-interest of decision-makers exert an extremely strong pressure on clinical care resource allocation. Thus, it will often be the case that intuitions are *not* used to make wise choices – instead, they will be used to reach decisions that favour powerful vested interests or the self-interest of decision-makers. Moreover, my thesis has demonstrated that clinical care resource allocation is a matter for public reason. We have seen that public reason constitutes a duty of restraint from a wide range of considerations that may be appealing to those who look at a certain issue from within their whole comprehensive doctrine. Therefore, adopting the perspective of public reason *decreases the complexity* of practical problems, reducing the need for the sort of flexibility that is granted by intuitions.

The ability to find an alternative to both utilitarian and intuitionistic modes of reasoning constitutes a strength distinguishing my theory of clinical care resource allocation from a range of alternatives. Section 6.1 already emphasised that there is near consensus among theorists that cost effectiveness or similar utilitarian-like aggregative values should play a role in clinical care resource allocation. I now turn to a few prominent theories that are also affected by the problems associated with intuitionism.

The most obvious place to start is multi-criteria decision analysis

(MCDA). By MCDA I mean those approaches proposing a *long list* of often *very different* substantive values deemed suitable to govern clinical care resource allocation.[328] During the past few years, MCDA has gained great momentum. Importantly, its success is not limited to the academic literature – numerous resource allocation agencies all over the world have adopted MCDA methods.[329] In the U.K., NICE relies on multiple values, specifically cost effectiveness plus six equity weightings, to appraise health technologies.[330] Before ceasing to exist in March 2013, the Advisory Group for National Specialised Services had its own MCDA tool.[331] Furthermore, MCDA is in widespread use among CCGs. We already saw in chapter 6 that many CCGs rely on the Portsmouth scorecard to make resource allocation decisions.[332] Another MCDA tool that is common among CCGs is programme budgeting and marginal analysis (PBMA). By focusing on a unit of resources at a time, PBMA allows decision-makers to see whether the budget could have been allocated so as to create greater value than under the current allocation. Widely used worldwide, PBMA is generally coupled with the idea that the potential value of allocative arrangements has multiple dimensions.[333]

MCDA approaches differ in their account of how precise the guidance

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[328] I. Williams et al. (2012, 67).

[329] See Devlin and Sussex (2011, 22–40) for a few examples.

[330] Rawlins et al. (2010). See also NICE's Scottish counterpart, the Scottish Medicine Consortium, at http://www.scottishmedicines.org.uk/About_SMC/Policy_Statements/SMC_Modifiers_used_in_Appraising_New_Medicines (last accessed 14/10/2014).

[331] http://www.webarchive.org.uk/wayback/archive/20130328000654/http://www.specialisedservices.nhs.uk/library/27/Decision_Making_Framework.pdf (last accessed 14/10/2014).

[332] I. Williams et al. (2012, 70–71).

[333] Donaldson et al. (2010). It is worth pausing to take notice of the communitarian interpretation of PBMA offered by Mooney (2009, 199–209), who claims that values protecting the good of the community should be taken into account by decision-makers. More in general, the pluralism of values characterising many communitarian approaches to political philosophy appears to create a close link between communitarianism and the use of MCDA in specific public policy domains, such as clinical care resource allocation – see also Etzioni (2011) on communitarianism and bioethics.

they offer to decision-makers can be. At one end of the spectrum, there are the MCDA approaches that most closely resemble intuitionism as defined by Rawls. Their supporters claim that balancing conflicting values is a complex task and the relative importance of values may vary with the context in which different clinical care resource allocation decisions are made. Hence, intuitions are needed for decision-makers to identify the ordering of values that is most fitting to the specific resource allocation decision at hand.[334] At the other end of the spectrum, there are MCDA approaches suggesting that the responsibilities of resource allocation agencies include deciding once and for all the importance weights that will be assigned to each value in the process of allocating resources. The supporters of this kind of MCDA approach also believe that a function (for example, additive, subtractive or multiplicative) to move from the scores assigned on each value to a composite index for each intervention should be chosen before resources are allocated. At this point, interventions can be scored along each value, so as to derive a composite index for each intervention.[335]

It goes without saying that decision-makers adopting a MCDA approach of the first kind are bound to make large use of intuitions in settling value conflicts. Frequent use of intuitions is also involved in more formalised MCDA approaches, although intuitions do a different job. To start with, intuitions are likely to play a major role when decision-makers are asked to choose the weights and the function capturing the relative importance of the multiple values governing resource allocation. As I pointed out when I was analysing the difference between my model and intuitionism, the appeal of

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334 Orr et al. (2011) and Persad et al. (2009). Drawing on Aristotle, Rhodes (2012) offers a philosophical analysis that may serve as an excellent foundation for this sort of MCDA approach.

335 Baltussen and Niessen (2006), Cunich et al. (2011), Peacock et al. (2007) and Youngkong et al. (2011). Moving towards the middle of the spectrum, we have Goetghebeur et al. (2010) and Golan et al. (2011).

intuitionistic modes of reasoning is at its peak when we are asked to establish an order of priority among a large number of values. More importantly, decision-makers are bound to rely heavily on intuitions when they have to assign *numerical scores* on values that appear to *resist quantification*. Without resorting to intuitions, how can members of CCGs assign an exact score on a scale from 0 to 40 to the ability of each intervention to reduce health inequalities within society?[336] The same holds true for many other values populating MCDA tools, such as innovation, preferences of stakeholders, government priorities and umbrella concepts like "other equity considerations". In sum, MCDA approaches from across the whole spectrum are prone to the risk of having the resource allocation process hijacked by vested interests, self-interest and sheer custom.

The ability of deliberative democracy to find an alternative to both utilitarianism and intuitionism allows me to bring to a conclusion my critique of accountability for reasonableness (AFR), which is Daniels's conception of fair process in resource allocation. In section 1.1, I described AFR and its great success among theorists and decision-makers. Later on in my thesis, I have argued that Daniels's case for fair procedures is unsatisfactory and his conception of fairness does not adequately acknowledge the importance of public involvement.[337] Here I demonstrate that AFR not only assigns a key role to utilitarian-like aggregative values, but also suffers from the problems associated to intuitionism, falling prey to both strands of the criticism originally advanced by Rawls. This conclusion is of great interest because not only does Daniels believe that a close fit exists between his model and Rawls's theory, but AFR is generally considered to be a Rawlsian approach to clinical care resource allocation.[338]

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[336] See the discussion of the Portsmouth scorecard by I. Williams et al. (2012, 70–71).

[337] See sections 2.4 and 3.1, respectively.

[338] Daniels (2008, 29–30).

Starting from utilitarian-like aggregative values, Daniels sees no problem in regarding cost effectiveness as one of the most important value considerations that resource allocation decision-makers should employ.[339] Moreover, AFR has many points of contact with intuitionism. Among the four conditions making up AFR, it is relevance that is meant to constrain the substance of the deliberation leading to resource allocation decisions. However, the relevance condition is rather inclusive in that it only requires that decisions be grounded in rationales that all reasonable persons can find relevant to the pursuit of value for money in allocating scarce resources.[340] In contrast to universal acceptability or similar constraints, relevance works as a *wide umbrella concept* – virtually all sorts of values can be considered to be relevant to the pursuit of some unspecified value for money. This leads to long lists of relevant values and, in turn, to the need to make frequent use of intuitions to solve continual value conflicts.

The intuitionistic character of AFR perfectly fits with the reason why Daniels proposed AFR in the first place. Daniels's case for procedural fairness is grounded in the recognition that philosophical reflection has been unable to find a way to solve the conflicts between cost effectiveness, priority to the worst-off, ability to benefit, fair chances and numerous other substantive values that are commonly proposed as suitable to govern resource allocation.[341] Thus, AFR is meant to suggest which kind of process should be employed to *juggle* those values in a fair manner. This provides a stark contrast to one of the main achievements of my own conception of fair procedures, which is to *filter out* many of the substantive values that pure philosophical reflection cannot handle.

The critique of AFR was needed to distinguish my conception of

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[339] Daniels (2008, 127–128).
[340] Daniels (2008, 123–131).
[341] Daniels (2008, 105–108).

deliberative democracy from an account of fair procedures that has several points of contact with the deliberative paradigm. In addition, the importance of finding an alternative to utilitarianism and intuitionism allows me to complete the critique of a theory that is even closer to my proposal than AFR, i.e., Fleck's conception of deliberative democracy. Fleck advocates a deliberative democratic approach to clinical care resource allocation that assigns a role to public reason. He argues that deliberative democracy imposes constraints on the substance of deliberation. Moreover, he rightly claims that a system in which resource allocation decisions are steered by the rich and the powerful is inconsistent with the basic ideas of deliberative democracy.[342]

Still, Fleck is keen to stress that the constraints imposed on the substance of deliberation leave room for a *pluralistic* account of the substantive values that should govern resource allocation.[343] This commitment to pluralism leaves Fleck open to Rawls's objection to intuitionism, clashing with Fleck's own remarks about the importance of preventing powerful vested interests from steering the decision-making process. This argument adds to the criticism offered in section 3.1, where I argued that Fleck fails to appreciate the changes in the content of public reason following the passage from neutrality-centred to distribution-centred debates.

7.4. Conclusion

This chapter has completed the more abstract part of my analysis of the implications that the due concern for procedural fairness has for the substance of clinical care resource allocation. Public reason has turned out to provide determinate recommendations not only about the substantive

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[342] Fleck (2009).

[343] For example, see Fleck (2009, 124–125).

values that should be employed, but also about the way in which such values should be combined. This ability has been shown to be a strength of my conception of deliberative democracy, which is capable of avoiding the twin traps of utilitarian and intuitionistic modes of reasoning. The next chapter aims to add to the plausibility of the analysis carried out in chapters 5, 6 and 7 by discussing how to implement the use of public reason in dealing with substantive values.

8. IMPLEMENTING PUBLIC REASON

The aim of this chapter is to discuss how to implement the use of public reason in dealing with substantive values. However, this aim comes with an important caveat. I do not intend to point out a set of practical arrangements that can lead our societies *from where we are now* to a state of affairs that *fully* satisfies the recommendations of public reason that I discussed in chapters 5, 6 and 7. To start with, it seems highly questionable to assume that a normative theory can only be justified if there is a feasible route starting from where we are at present and leading to a state that is perfectly in line with that theory.[344] Moreover, my thesis is a work in political philosophy, which means that a complete analysis of implementation falls beyond its scope.

Still, I think it worthwhile to demonstrate that several practices adopted by real-world societies can be interpreted as already contributing to the implementation of the recommendations of public reason. Furthermore, it is worth identifying a number of steps that could be taken to bring our societies considerably closer to my theory without involving any radical change to the way in which societies are organised. These kinds of analysis add to the plausibility of the theoretical proposals that I advanced in chapters 5, 6 and 7. Indeed, the feasibility of implementing a theory *at least*

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[344] My idea of what a normative theory does not need to prove is consistent with a wide array of views of the relationship between normative theorising and feasibility, starting from G. A. Cohen (2008, 229–273), passing through Estlund (2011) and including Rawls (2001, 4–5). If placed against the background of his work on capabilities, also a critic of idealisations such as Sen (2006) turns out to be included.

to some extent appears to be an important desideratum of any normative proposal – any good normative theory should be able to respond to a critic suggesting that nothing can be done to translate that theory into practice.

Before starting my analysis of implementation, I wish to summarise my discussion of what is required by public reason with regard to the substantive values governing clinical care resource allocation – given that my discussion of substantive values occupied several chapters, I need to make sure that the reader did not miss anything important. At the most fundamental level, public reason dictates that resource allocation decisions should be grounded in reasons that all reasonable persons can accept. This commitment to reasons that all can accept entails that the self-interest of decision-makers and powerful vested interests should not provide a basis for decision-making.[345] Furthermore, decisions should rest on well-constructed rationales, as opposed to bias. Public reason also requires that decision-makers should allocate resources so as to minimise the strongest complaint any individual may have. Finally, decision-makers following public reason should be committed to the compartmentalisation of different areas of government activity.[346]

Chapters 5 and 6 demonstrated that public reason is inconsistent with numerous substantive values that are commonly proposed as suitable to govern clinical care resource allocation. Out of a long list of values, public reason was found to uphold only priority to the worst-off and ability to benefit, framed by the idea of specialness of clinical care and constrained by cost considerations. Moreover, chapter 7 showed that public reason can go a long way towards determining how these four substantive values should be combined to provide specific guidance to resource allocation decision-makers.

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[345] See section 3.1.

[346] See section 4.3.

The question for this chapter is, how can we prompt resource allocation decision-makers to employ the substantive values that are upheld by public reason and combine them in a way that is consistent with public reason? Strategies must be devised to steer decision-makers away from forces that risk leading resource allocation processes astray – popular passions and vested interests above all else. Moreover, decision-makers must be steered towards public reason.

In section 8.1, I argue for the insulation of clinical care resource allocation from popular passions and vested interests. Furthermore, I discuss what insulation means for the design of resource allocation agencies. Section 8.2 explores how the design of insulated resource allocation agencies can encourage the use of public reason. Section 8.3 acknowledges that if we wish decision-makers to fully embrace public reason, interventions are needed beyond the design of insulated resource allocation agencies. Thus, I discuss how representative institutions and the media can help to create a culture of public reason.

8.1. Insulating clinical care resource allocation

The insulation of sensitive decisions is advocated in what is sometimes called the "republican" side of deliberative democracy. The main concern of the supporters of insulation is to protect decision-making from the *biases* affecting the popular perception of certain issues. Philip Pettit illustrates the problem by referring to criminal sentencing reform. If a criminal system decides to adopt a "soft" approach to imprisonment and takes community service as sanction of first resort, its fate is likely to be decided by something different from its overall performance. Sooner or later, a convicted offender will commit a heinous crime that she would not have committed if she had been put in prison. Popular passions are easily inflamed by single events of this kind, while they tend to be blind towards the reasons backing the system as a whole. Therefore, the public debate is bound to be swayed by the narrow focus that characterises the popular perception of crime policy.[347]

The biases of popular passions are highly relevant to clinical care resource allocation. While discussing the case of Herceptin in section 7.3, we had a glimpse of how pointing to single instances of treatment denial can effectively stir popular passions. Neither the lack of evidence for the safety and effectiveness of a treatment nor any reference to the merits of the resource allocation system as a whole can have the same impact on the popular perception of the issue at hand. Moreover, section 6.4 demonstrated that the public dread certain conditions (most notably cancer) well beyond their actual impact on length and quality of life. This fact puts pressure on decision-makers to deviate from public reason and prioritise dreadful diseases. In sum, popular passions threaten to push decision-makers away from public reason. Thus, popular passions constitute *the first element that resource allocation agencies should be insulated from*.

The problem is compounded by the fact that numerous *vested interests* have the power to take advantage of popular passions and much to gain from doing so. The public outrage over treatment denial serves well the aims of the pharmaceutical industry, whose huge lobbying power is always at work to loosen the constraints on drug coverage. In turn, the interests of big pharma generally converge with the interests of patient advocacy groups. The media constitute another important actor, which has traditionally been keen to launch campaigns against resource allocation efforts. Treatment denial arouses the passions of the public and, therefore,

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[347] Pettit (2004, 54–55). See also Sunstein (2005a, 109–128).

sells a great deal of copies. If resource allocation agencies are not protected from the pressure exerted by vested interests, decision-makers will be pushed further away from public reason.[348] Hence, vested interests constitute *a second element that resource allocation agencies should be insulated from*.

What does it mean to implement insulation from popular passions and vested interests? Insulation has implications concerning the *status* of resource allocation agencies, the *actors* who should contribute to making decisions and the existence of *appeal procedures*. In discussing these topics, I aim to show that the method of insulation builds upon arrangements that NICE and other real-world resource allocation agencies have already put in place. Furthermore, the reforms that I intend to propose do not involve any radical change in the way in which societies are organised.

Starting from the status of resource allocation agencies, insulation involves depoliticisation. Depoliticisation is needed because elected officials (both in power and in opposition) have strong incentives to yield to the pressure of popular passions and vested interests – for example, politicians who are seen fighting against rationing decisions are likely to gain popular support, improving their chances of being re-elected. By depoliticisation I mean two things. First, the vast majority of clinical care resource allocation decisions should be placed in the hands of *administrative agencies*, not of representative institutions. Second, institutional designers should identify the most sensitive clinical care resource allocation issues and *further distance* should be put between those issues and elected officials, e.g. by using arm's length agencies.

This is not to say that representative institutions should have no role to play in clinical care resource allocation. As with the Health and Social Care

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[348] Ferner and McDowell (2006). For more on the problems posed by vested interests, see section 7.3.

Act recently approved in the U.K., representative institutions should be in charge of the foundations and broad contours of the system for clinical care resource allocation. Should universal access to clinical care be guaranteed? Should competition and private providers of care play any role in the health service? It is natural to think that these sorts of questions should remain in the hands of representative institutions. Indeed, to completely sever an area of political activity from representative institutions seems hardly consistent with a commitment to democracy. However, within the broad contours set by representative institutions, it is administrative agencies that should shoulder resource allocation responsibilities. Although it is difficult to set boundaries in the abstract, the responsibilities of administrative agencies should include the choice of at least a large part of the substantive values governing their deliberations, together with the specification of such values. In this space, the main responsibility of representative institutions should be to periodically review the job of resource allocation agencies as wholes in order to check that they are staying within the contours established by elected officials.

To a large extent, the depoliticisation of clinical care resource allocation has already been put into practice by many real-world societies. In many societies, a large part of clinical care resource allocation decisions are already made by administrative agencies. Throughout my thesis, we have had many opportunities to appreciate how administrative agencies such as the Advisory Group for National Specialised Services, Primary Care Trusts and, starting from April 2013, Clinical Commissioning Groups have played a major role in the allocation of NHS resources. For example, Clinical Commissioning Groups are currently responsible for spending £64.7 billion out of a NHS England total budget of £95.6 billion.[349] Moreover, it is worth

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[349] http://www.england.nhs.uk/allocations-2013-14/ (last accessed 14/10/2014).

stressing that NICE, which discusses drug coverage and other highly sensitive issues, works *at arm's length* from ministerial control.

What does it mean to work at arm's length from ministerial control? Arm's length agencies are placed outside traditional departmental structures. The idea is that the relevant department must not attempt to control the single decisions that fall within their remit.[350] In the case of arm's length agencies, the protection of the tenure of civil servants becomes particularly important. To protect their independence from party politics and elected officials, the key figures in the decision-making hierarchy should fear no dismissal by ministers, except in the case of serious misbehaviour or incompetence.[351] As obtained by NICE with regard to positions such as chair and member of its appraisal committees, arm's length agencies may also need no prior agreement by ministers to appoint new members.[352]

No existing arrangement is perfect. Thus, even where an arm's length agency such as NICE deals with the most sensitive resource allocation issues, a critical analysis should be carried out to identify which reforms of its design can further increase independence from representative institutions. For example, there is room to argue that NICE should change the process for selecting the topics for technology appraisal. Health ministers still have the last word on which technologies are appraised by NICE. Given that Clinical Commissioning Groups are legally bound to fund all health technologies approved by NICE, the present arrangement appears to leave a great deal of power in the hands of ministers.[353]

Now consider the actors who contribute to insulation. To start with, the

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[350] Gash et al. (2010).

[351] For the role of protected tenure in two conceptions of democracy that have points of contact with the project of insulation, see Richardson (2002, 229) and Rosanvallon (2011, 92–94).

[352] House of Commons Health Committee (2002, 52).

[353] The problem with ministerial involvement in topic selection is underlined by the Bristol Royal Infirmary Inquiry (2001, 314–319).

use of *experts* to answer the scientific questions relevant to resource allocation helps to break with some of the biases that are entrenched in popular opinion and exploited by vested interests. The use of an expert tool such as the EQ-5D questionnaire offers an excellent example of how expert involvement can break with entrenched biases – specifically, the dread of cancer. The EQ-5D is employed by NICE and numerous other resource allocation agencies to classify health states. The EQ–5D asks patients to classify their condition along five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Based on severity of impairment, each dimension is given a score from one to three, resulting in 243 possible health states. Crucially, when another survey is conducted to determine the quality of life associated to each health state, respondents are not told the name of the conditions they are rating, nullifying the effects of the biased perception of cancer and other diseases.[354]

Continuing on the topic of actors, members of the public should be involved *in deliberative processes* contributing to resource allocation.[355] One option is to establish co-governance systems where public involvement bodies work alongside more traditional resource allocation agencies. Another option is to reform traditional resource allocation agencies in such a way that a sizeable part of their members are drawn from the general public. When involved in deliberative processes, the members of the public are provided with extensive information, exposed to arguments supporting all sides of the issue and made to participate in sustained deliberation. This fact distinguishes deliberative processes from the venues where popular opinion generally takes form. Indeed, the views of participants systematically

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[354] Cookson and Culyer (2010, 150–159). The classification and rating of health states were discussed in greater detail in section 5.4.

[355] Pettit (2004, 57–58) sees a close link between depoliticisation and deliberative mini-publics.

change as a result of deliberation.[356] Hence, deliberative public involvement provides a space of discourse that has the potential to contrast the logic of unrefined popular opinion and vested interests.

The NHS has been experimenting a good deal with the deliberative involvement of the public in the context of resource allocation.[357] A public involvement arena that has been the object of special attention is NICE's Citizens Council, which is meant to provide the perspective of the public on broad value issues that NICE needs to address. Made up of 30 councillors who are selected so as to be representative of the U.K. population, the Citizens Council meets once or twice a year to deliberate for two days.[358] In many respects, NICE's Citizens Council is a good deliberative experiment. Given that the Council's membership rotates slowly, councillors have the time to fully understand the core elements of the value issues that are discussed meeting after meeting.[359] According to the authors of an independent evaluation, the quality of deliberation and the engagement of councillors have improved over the years.[360]

The main problem with NICE's Citizens Council is that the outputs of its deliberations do not have any clear impact on the decisions made by NICE. NICE states that the Council's recommendations are incorporated into *Social Value Judgements*, which describes the values that NICE is supposed to apply during its work.[361] However, the contribution of the Citizens Council is very diluted. In addition to the Citizens Council reports, the values incorporated into *Social Value Judgements* are also shaped by a survey of the relevant literature, a non-deliberative survey of the public, a

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[356] Abelson et al. (2003) and Dolan et al. (1999).

[357] For example, see Bowie et al. (1995), Dolan et al. (1999), Lenaghan (1999), Lenaghan et al. (1996) and Parkinson (2004).

[358] http://www.nice.org.uk/get-involved/citizens-council (last accessed 14/10/2014).

[359] Pathak-Sen (2009).

[360] Davies et al. (2005, 119–147).

[361] For *Social Value Judgements*, see NICE (2008).

workshop among specialists and a wide range of comments on the first edition of this document, provided by NICE staff, publications and a round table discussion.[362]

Stronger and more explicit links between the Council's recommendations and NICE's decisions should be built. Although I do not have the space to explore this issue in full detail, I mention one possible way ahead. The Citizens Council could meet periodically and review the justifications offered in support of the health technology appraisals issued by NICE in the preceding months. The Citizens Council could be instructed to focus on value judgements, and procedures could be in place to force NICE's appraisal committees to reconsider its recommendations if the Citizens Council advances strong objections.

I add a final note on the issue of actors. Section 10.2 maintains that pharmaceutical industry and patient advocacy groups have a valuable role to play as suppliers of evidence. In that section, I aim to suggest that NICE is right in allowing manufacturers and relevant patient groups to provide evidence about costs, clinical effectiveness and quality of life enjoyed by patients. I now wish to make it clear that the role of pharmaceutical industry and patient groups should stop with the provision of evidence, never extending to the stage in which agencies discuss how evidence and values should be combined to reach a resource allocation decision. This arrangement is necessary to pursue insulation, but it clashes with the design of many real-world resource allocation agencies. For example, WHO evaluators have criticised NICE because manufacturers are represented in the appraisal committees, which are responsible for issuing recommendations.[363] It has also been noted that in France and Germany manufacturers are involved in technology appraisals beyond the provision of

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[362] Littlejohns and Rawlins (2009).

[363] Hill et al. (2003, 28–29).

evidence.[364]

Finally, insulation requires that appeal procedures should be in place for the public to challenge resource allocation decisions. Section 3.2 argued that appeal procedures are needed to express the idea that human reason is fallible. Here I add that appeal procedures help to channel contestation away from street demonstrations, representative institutions and media campaigns. If channelled into an appeal process, contestation is forced to adopt the cold and impartial manners typical of judicial procedures, fostering the objective of insulation.[365]

In the U.K., Clinical Commissioning Groups are already expected to establish appeal procedures.[366] However, NICE stands out among the rest of resource allocation agencies for the work done in developing appeal procedures against health technology appraisals. Appeals can be lodged within 15 days after a decision has been made. NICE strives to hear an appeal and reach a decision about it within 3 months of the appeal being lodged. However, the right to appeal is limited to those organisations that NICE has appointed as consultees at the beginning of the appraisal process.[367] To be of any help in channelling contestation, NICE's appeal procedures should be reformed so as to extend the right of appeal to the general public.

A critic might object that if the right of appeal was extended, a great deal of appeals would be lodged and NICE would risk being paralysed. To respond to this objection, the designers of resource allocation agencies should make sure that the *grounds of appeal* are adequately limited. Incidentally, limiting the grounds of appeal is also necessary to uphold the idea that public reason is a moral, not a legal, duty. Indeed, if we decided

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[364] Sorenson and Chalkidou (2012, 31).

[365] See the reading of Pettit's contestatory practices offered by Urbinati (2010, 79).

[366] National Prescribing Centre (2009, 23).

[367] NICE (2014a).

that a resource allocation decision can be challenged on the ground that it simply violates public reason, the right of whoever was appointed to make the original decision to hold public office would be threatened.[368]

It seems fair to say that even if members of the public were allowed to appeal, NICE's current grounds of appeal would still provide strong safeguards against paralysis. In fact, there is room to argue that NICE's grounds should be somewhat expanded to better facilitate the channelling of contestation. NICE draws on three traditional grounds upon which administrative agencies can be challenged through judicial review: a) NICE has breached its decision-making procedure; b) NICE has exceeded its powers; and c) NICE's decision cannot be reasonably justified in light of the evidence submitted.[369]

My idea is that ground c) should be somewhat expanded. In its current form, this ground appears to require potential appellants to check whether a reasonable justification for NICE's decision exists, regardless of whether that justification has effectively been offered by the appraisal committee. In contrast, this ground should make it clear that the original justification provided by decision-makers is the proper object of appeals. That justification must not contain logical errors or fail on its own terms, i.e., fail to advance the values that it sets for itself. Furthermore, the justification must respect formal fairness; it must treat in a similar way cases that are similar in all relevant respects. Finally, there should be no evidence that the justification rests on the self-interest of decision-makers or a special concern for any vested interests. Unlike a full account of public reasons, the requirements that I have just listed should be considered legal duties.

In concluding this section, I respond to the objection that insulation does not fit within a deliberative democratic approach to resource allocation. It

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[368] See section 4.3.

[369] NICE (2014a, 10–11).

may be argued that removing decisions from representative institutions prevents resource allocation processes from giving effect to what the people want, contradicting the idea of democracy.[370] Alternatively, a critic may claim that insulated decision-making processes are bound to be undemocratic because in the absence of elections there can be no authorisation by the public and no accountability to them.[371]

My answer is twofold. First, representative institutions still have roles to play. They are responsible for the foundations and broad contours of clinical care resource allocation. Moreover, section 8.3 argues that representative institutions at large should serve as the “stage” for public reason. Second, the objection under discussion hinges upon an *overly narrow definition of democracy.* I devoted chapters 2, 3 and 4 to the defence of a conception of deliberative democracy that is made up of a *plurality* of requirements that explain what a deliberative democratic process should look like. To start with, my conception of deliberative democracy places great importance on public reason. Furthermore, it entails a public involvement requirement that can be specified in other ways than electoral participation. Insulation protects public reason and calls for public involvement exercises. Moreover, insulation entails expert involvement and appeal procedures, which are in line with two other requirements of deliberative democratic resource allocation, i.e., accuracy and revisability. In sum, insulation is a fitting pendant to deliberative democracy, not a threat.

8.2. Steering insulated agencies towards public reason

Insulation is meant to steer decision-makers *away* from powerful negative influences. To implement my conception of deliberative democracy, we also

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[370] Urbinati (2010).
[371] Waldron (2006, 1386–1395).

need to find ways to steer decision-makers in a more specific direction, advancing *towards* public reason. At this point, the instructions given to resource allocation decision-makers become crucial. Each resource allocation agency should be provided with a *decision-support tool* that collects the recommendations of public reason about the substantive values that should govern clinical care resource allocation.

To clarify what I mean when I discuss decision-support tools, let me recall some of the tools adopted by real-world resource allocation agencies that we came across in chapters 5, 6 and 7. For example, we saw that the Portsmouth Scorecard is used by many Clinical Commissioning Groups to support resource allocation. The Portsmouth Scorecard identifies a list of substantive values and specifies the range of scores that can be assigned on each value. Once scores are assigned on each value, they are added together and a single index for each intervention is calculated – the higher the index, the greater the priority of the intervention.[372] NICE's *Social Value Judgements* can be interpreted as a decision-support tool for the committees operating within the Institute. *Social Value Judgements* does not limit itself to explaining that a cost-effectiveness threshold of £20000-£30000 per QALY should work as the most important consideration, while other values should only be considered to see whether an intervention whose incremental cost-effectiveness ratio lies above the threshold should be recommended. This document also explores which values beyond cost effectiveness should be employed and which ones should not. For example, severity and potential for innovation are deemed to be suitable, while rarity, personal responsibility for health outcomes and socio-economic status are not.[373]

Section 7.2 demonstrated that public reason can go a long way towards building a decision-support tool for resource allocation agencies.

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[372] I. Williams et al. (2012, 70–71).

[373] NICE (2008).

Furthermore, section 7.2 discussed my own account of what a decision-support tool governed by public reason should look like. On my account, the decision-support tool should explain that decisions must rest on well-constructed rationales. Moreover, self-interest and powerful vested interests should never provide a basis for decision-making. The decision-support tool should state that public reason involves both a commitment to the minimisation of the strongest complaint and a strong presumption for the compartmentalisation of different areas of government activity. The substantive values that are consistent with public reason and those that are not should be discussed: out of a long list of values, chapters 5 and 6 demonstrated that public reason only upholds priority to the worst-off and ability to benefit, framed by the specialness of clinical care and constrained by cost considerations. Furthermore, the decision-support tool should explore how the substantive values upheld by public reason should be combined. For example, the decision-support tool should recommend a prioritised-list approach to costs and the use of an ability-to-benefit threshold below which interventions must not be funded. Finally, the decision-support tool should go as far as providing an answer to those issues that section 7.2 had to bracket for reasons of space. At what level should we place the ability-to-benefit threshold? How exactly should priority to the worst-off and ability to benefit be combined above that threshold?

As explained in section 8.1, public reason is not a legal duty. Hence, courts should not step in simply because decision-makers have decided to deviate from the instructions included in the decision-support tool. Indeed, grounds of appeal should cover only the violations of the most basic commands of public reason. Furthermore, decision-makers may face unusual resource allocation problems, which are not adequately covered by the decision-support tool. Thus, further arrangements are in order to nudge decision-makers into having *a positive attitude towards public reason*. If decision-makers appreciated the importance of reasons that all can accept, the minimisation of the strongest complaint and so forth, deviations from the decision-support tool would be minimised and unusual questions would be tackled in the spirit of public reason.

Building a positive attitude towards public reason is a complex task, which cannot be fully accomplished without intervening at the general level of deliberation at which representative institutions and the media operate. Still, the design of insulated clinical care resource allocation agencies can help. In particular, consider *diverse membership* and arrangements aimed at creating *internal conflict*.

Resource allocation agencies should have a diverse membership. Diverse membership broadens the views of decision-makers by making sure that all are aware of a variety of perspectives on the issue at hand. In this way, biases associated to the narrowness of one's initial perspective are exposed and decisions are likely to be grounded in better arguments.[374] Furthermore, if persons discuss under conditions of diversity, it is pragmatically very difficult to single-mindedly push one's interests and views without considering those of the other participants.[375] Consequently, decision-makers are encouraged to look for decisions that are as widely acceptable as possible.

What does diverse membership mean in practical terms? The members of resource allocation agencies should be selected from *a variety of relevant professions*. As I aim to argue in section 10.1, we have reasons other than the need to spread a positive attitude towards public reason to require that experts in relevant scientific disciplines, such as clinical research and health economics, should not constitute more than a half of any agency. In addition

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[374] Mansbridge (1999b, 643–648).

[375] Elster (1986, 112–120).

to experts, resource allocation agencies could include public servants without expertise in relevant scientific disciplines, persons with experience in clinical care management and ethicists.

Public involvement constitutes another element that can foster diversity. When discussing public involvement in section 8.1, I claimed that one option is to appoint members of the public to the resource allocation agencies that also employ scientific experts, public servants and the other actors listed in the previous paragraph. This option is particularly effective in fostering diversity within resource allocation agencies. However, institutional designers should concern themselves with diverse membership even if they adopted a co-governance model in which there are resource allocation agencies entirely made up of members of the public. Specifically, the members of such agencies should be chosen by stratified sampling. The relevant population should be divided into different subgroups before applying random selection within each subgroup. For example, participants could be stratified by age, social class, gender, ethnicity, geography and disability. Consequently, membership is likely to be more diverse than with simple random sampling or self-selection.[376]

In addition to its other merits, some authors praise diverse membership for being conducive to a crucial precondition of deliberation. This precondition can be described as lack of comfort, which jolts participants out of everyday reasoning habits characterised by heuristics and biases.[377] Others speak of internal conflict, which prompts deliberators to abandon intransigent positions.[378] Given that the value of different views on the issue at hand is acknowledged, participants are willing to find widely acceptable solutions above and beyond the need to make decisions with persons

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[376] For example, stratified sampling is applied in the case of NICE's Citizens Council.

[377] Ryfe (2005, 54–60).

[378] Fleck (2009, 195–201).

occupying different positions.

Diverse membership is not the only way in which the design of resource allocation agencies can contribute to creating lack of comfort and internal conflict. In what follows, I discuss a number of other practical arrangements that could be helpful. Institutional designers should consider adopting them, while at the same time taking into account countervailing factors - for example, a certain arrangement may be incompatible with a given agency because of the tight time constraints that the agency must meet.

To start with, resource allocation agencies could involve a number of clearly-positioned external *witnesses*, each responsible for arguing for one possible decision. Furthermore, decision-makers could be split into *small groups* to focus on the strengths of alternative decisions before discussing about them all together. Finally, a requirement of *devil's advocacy* could be built into the decision-making process: at a certain point, a member of the agency could be asked to challenge the main inclinations displayed by the group that far.

A specific kind of *role-playing* is particularly important in that it helps create the sort of internal conflict that is most closely related to my conception of public reason. In my view, public reason requires that the strongest complaint against resource allocation arrangements be minimised. Now, role-playing can encourage decision-makers to look at resource allocation issues from the perspective of those individuals in a position to raise complaints. Consider Choosing Healthplans All Together (CHAT), developed within the National Institute of Health in the U.S.

CHAT is a method for engaging the public in deliberation about resource allocation. It consists of an iterative process that goes through several rounds. At the beginning of each round, participants allocate a limited amount of resources so as to identify which treatments should be included in their health insurance package and the level of service that should be provided. Next, participants spin a roulette wheel that assigns health events. “For example, an individual might choose the basic level of pharmacy coverage ($15 copay, automatic generic substitution for brand name drugs, and the use of a formulary) and then land on the pharmacy category during the health event roulette wheel spin. Here she learns that the drug prescribed by her doctor for her urinary infection is not on the formulary. She will also see on the card that if she had chosen the medium level of coverage, the drug prescribed by her doctor would cost her a $10 co-pay for the brand name or $5 for a generic prescription“.[379] Health events serve as the basis for a critical discussion of the resource allocation decisions that have previously been made.

The complaints of the patients at the centre of health events are likely to take centre stage in the deliberations of the group. Moreover, changes in resource allocation decisions are likely to be governed by the strength of the complaints of uncovered patients relative to the strength of the complaints of those who are entitled to treatment. Given the close fit between CHAT and public reason, institutional designers should consider whether to adopt analogous role-playing arrangements more widely, both in the case of public involvement bodies and more traditional resource allocation agencies.

In the second part of this section, I have discussed how the design of insulated resource allocation agencies can help transmit to decision-makers a positive attitude towards public reason. However, the attitudes of individuals towards political discussions are also influenced by factors operating at a more general level than any insulated resource allocation agency - these factors are the focus of the next section.

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[379] Goold et al. (2005, 578). See also Danis et al. (2010).

8.3. Building a culture of public reason: representative institutions and the media

While arguing for the depoliticisation of the vast majority of clinical care resource allocation decisions, section 8.1 made it clear that the foundations and broad contours of clinical care resource allocation should remain in the hands of elected officials. Moreover, there is another reason why the proponents of a deliberative democratic approach to clinical care resource allocation should not ignore representative institutions when discussing implementation. In Stefan Rummens's words, representative institutions have the potential to serve as a “stage” for public reason.

For many, representative institutions constitute the first encounter with political discussions. Moreover, the debates involving ministers and MPs are given greater visibility than any other.[380] Finally, the example set by leaders is influential in shaping the attitude of citizens towards politics.[381] If elected officials habitually discussed on the basis of public reasons, public reason would establish itself as the standard mode of political discussion. Hence, the members of the public, civil servants and other actors involved in insulated resource allocation agencies would join the decision-making process from within a culture of public reason. In sum, attention must be paid to representative institutions if we wish to maximise the chances that resource allocation decision-makers will uphold the decision-support tool recommended by public reason and tackle unusual problems in the spirit of public reason.

At this point, it is worth noticing that the recommendations that I intend to make in this section differ in an important respect from the recommendations made so far in this chapter. So far, I have purported to

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[380] Rummens (2012).

[381] Ryfe (2005, 62–65).

show that my theory can be implemented by building upon established practices without necessitating any radical change in the way in which our societies are organised. However, representative institutions and the other actors that I aim to discuss in this section are likely to offer strong resistance to any attempt to subject them to public reason. Political parties exert a strong influence over the behaviour of elected officials, leading to an adversarial system of discussion that is at odds with the search for consensus. Furthermore, the prospect of elections creates strong incentives to pander to the passions of the public.

In sum, the recommendations that I aim to make in this section are likely to be harder to implement and involve greater changes than the recommendations made in the rest of the chapter. This means that the recommendations made in this section are not meant to be feasible in the strong sense of the term employed at the beginning of this chapter, where it indicated something that we can reasonably hope could be achieved starting from where we are now. Indeed, the rest of this section is meant to convey a *vision* of what we must strive to realise in the long run if we wish to fully implement my conception of deliberative democracy.

A first recommendation can be extrapolated from studies which focus on how real-world representative institutions can be made more deliberative: *strong parliamentary committees* should be put in place.[382] This recommendation concerns both the legislative committees responsible for reviewing a bill before plenary discussion and the oversight committees responsible for supervising a certain area of government activity. Committees can be either permanent or ad-hoc, i.e. established for a limited time to address a specific question. However, permanent committees discharge their deliberative responsibilities much more effectively. If a

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[382] Bessette (1994, 147–149) and Uhr (1998).

committee is permanent and its membership does not change until a new parliament is elected, members can gain insight into the public policy areas within the remit of the committee. Given the expertise developed by committee members and the time devoted to each issue, committees subject bills and government activities to a more *thorough and well-supported scrutiny* than could be achieved by the whole parliament. In turn, committee work improves the quality of the following deliberation in the whole chamber; committees also help to inform public debates in the society at large. Moreover, strong committees tend to *limit the power of political parties* by offering an opportunity to overcome rigid distinctions and build cooperative relationships with members of other parties.

Societies should remedy the weaknesses in their system of parliamentary committees. In the U.K., even though "select" oversight committees are said to work rather well, "standing" legislative committees should certainly be strengthened.[383] To start with, legislative committees should be made permanent. Furthermore, the procedures regulating the work of legislative committees should be reformed. Currently, the power of committees to amend a bill is rather limited. However, their ability to change the content of a bill could be extended so as to include the principles governing it. Another option worth considering is that the chair of the committee scrutinising a bill should be allowed to lead the debate when the discussion of that bill reaches the whole chamber.[384]

As important as the behaviour of elected officials may be, working on representative institutions does not suffice to spread a positive attitude towards public reason. For the most part, the public receives information

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[383] On Select Committees, see Benton and Russell (2013).

[384] For the criticisms levelled at Standing Committees and a few reform proposals, see House of Commons Committee on Modernisation of the House of Commons (2006, ev 108-ev 112, quoted by Benton and Russell, 2013). The National Democratic Institute for International Affairs (1996, 5–7) contrasts the British and American systems.

about representative institutions through the media. Furthermore, the media critically analyse the decisions taken by representative institutions, adding their own voice to political debates. Hence, the media could create incentives for representative institutions to uphold public reason by attacking elected officials when they deviate from the standards of good argument and the public interest. Moreover, the media could serve as a stage for public reason in their own right.[385]

For the media to foster a positive attitude towards public reason, media channels should a) pay a great deal of attention to political debates and b) subject themselves to rules of communication that echo at least the most basic standards of public reason. However, there are at least two difficulties with the implementation of the role of the media that I have outlined. Given the current level of interest in politics, media channels lack incentives to produce the reports on political debates that would foster a culture of public reason. Other kinds of content attract bigger audiences at a lower cost.[386] Furthermore, powerful economic and political interests lie behind important media channels. Therefore, the media may have a vested interest in distorting the messages of elected officials or otherwise deviating from the communication rules required by public reason.[387]

How can we tackle these difficulties? Societies should adopt a system of *public licences*, as in the case of the British Broadcasting Corporation. In this way, at least part of the media will be shielded from partisan economic and political interests. Moreover, the mission of the media operating under a public licence should be specified so as to require them to produce a considerable amount of the content that will help to create a culture of public reason, i.e., coverage of political debates that is both impartial and

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[385] Chambers (2009, 341–342).

[386] Claassen (2011, 72–74).

[387] Habermas (2006, 420–423).

attentive to the standards of good argument.[388]

Further interventions are in order to encourage media channels across the board to uphold the communication rules that foster a culture of public reason. Specifically, societies should ensure that a *code of ethics* is adopted as widely as possible. At this point, my argument turns out to be related to several issues recently explored by the Leveson Inquiry, which is a public inquiry into the British press. Following the News International phone-hacking and police-bribing scandal, the Inquiry was appointed in July 2011 and published a first report in November 2012.

My argument provides strong reasons to follow Lord Leveson's recommendation that a regulatory body should be introduced. The regulator should be able to employ effective sanctions and provide strong incentives for media providers to opt in. Importantly, the members in the regulatory scheme are expected to respect the code of ethics imposed by the regulator. To this I add that the code should be drafted with an eye to the role of the media in a deliberative democracy. In their testimonies to the Leveson Inquiry, both Neil Manson and Onora O'Neill offer analyses that go in the right direction.

According to Manson, the media should uphold a code of ethics that includes norms of relevance and balance. In addition, media reports should be committed not to mislead the audience or create sensation at all costs.[389] O'Neill argues that audiences should be enabled to assess the credibility of media reports. This means that media reports should provide evidence and cite sources. Moreover, media providers should be open about their conflicts of interest and disclose whether money has been paid either by media organisations or by the subjects of a story in the process leading to

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[388] Habermas (2006) and Hargreaves Heap (2005, 122–125).

[389] Manson (2012).

publication.[390] The recommendations of both Manson and O'Neill aim to encourage media providers to offer reports that are built on well-constructed arguments, not on the power of vested interests. Hence, the media channels following their recommendations would provide good examples of deliberation, helping to foster a culture of public reason.

8.4. Conclusion

This chapter lies at the intersection of two of the three main themes running through my thesis. Section 1.3 claimed that one theme of my thesis would be to explore the tensions surrounding the use of scientific experts and administrative agencies in resource allocation. Let us focus on administrative agencies: in earlier chapters, I often discussed NICE and numerous other real-world administrative agencies involved in resource allocation. This chapter has shed new light on the link between the arguments proposed throughout my thesis and the role of administrative agencies. By arguing for the insulation and, in turn, the depoliticisation of the vast majority of clinical care resource allocation decisions, this chapter has clarified that all the arguments advanced in my thesis are meant to apply mainly to agencies working at the level of administration.

Another theme of my thesis is to demonstrate that a concern for procedural fairness can be kept together with a commitment to suggesting answers to issues concerning the substantive values governing clinical care resource allocation. This chapter has taken this theme to the level of implementation, adding to the plausibility of the arguments offered in chapters 5, 6 and 7.

By discussing implementation, this chapter has completed the analysis of

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[390] O’Neill (2012).

the ability of deliberative democracy to provide determinate answers to substantive issues. In the next chapter, I intend to turn to another topic that emerged as particularly salient during my discussion of the justification and general requirements of deliberative democracy in clinical care resource allocation - namely, whether expert involvement can be reconciled with deliberative democracy.

9. RECONCILING DELIBERATIVE DEMOCRACY AND EXPERT INVOLVEMENT IN CLINICAL CARE RESOURCE ALLOCATION

This chapter aims to argue that the tensions surrounding the involvement of scientific experts in clinical care resource allocation can be solved. At all levels of the decision-making chain resulting in the allocation of clinical care resources, a great deal of hard questions of science have to be settled. As with many other problems, the funding of new drugs can serve as a model for clinical care resource allocation at large. Should the drugs be funded? If so, what type of patients should receive the drugs, and under which circumstances? To answer these questions, resource allocation agencies need to know how effective the new drugs are compared to available alternatives. To mention two other issues, decision-makers need to explore how well the drugs can fit within routine clinical practice and how the cost of the pharmaceuticals, the personnel needed to administer the treatment and other factors add up to the total cost of intervention.

It is commonly thought that clinical researchers, medical practitioners, health economists and other experts must be involved to answer these types of questions. Moreover, some of the previous chapters suggested that deliberative democrats have strong reasons to believe that experts should play an integral part in clinical care resource allocation. Section 2.2 maintained that the intelligence relevant to clinical effectiveness, costs and other factual matters crucial to resource allocation is concentrated almost exclusively within expert communities. Section 3.2 pointed out that every citizen has an interest in having the most accurate factual information factored in when clinical care resources are allocated. Hence, the involvement of experts is required by the fundamental principle of due respect for the autonomy of individuals.

At the same time, there is strong tension between the involvement of experts and several principles at the heart of deliberative democracy. The involvement of experts appears to be incompatible with public reason because expert opinions are often incomprehensible to laypersons, who cannot be expected to accept what they do not even understand. Furthermore, numerous experts think it best to hide uncertainty and disagreement from the public when they are involved in political decision-making. As a result, they effectively make decisions that should be left for the public to make. The tensions surrounding the involvement of experts can be thought of as an objection to my model of deliberative democracy. Both the considerations for and against the involvement of experts are very weighty. Thus, whether or not experts are involved in clinical care resource allocation, deliberative democracy seems condemned to sacrifice considerations that it holds dear.

The aim of this chapter is to respond to this objection, demonstrating that the tension between deliberative democracy and the involvement of experts can be solved. In other words, this chapter demonstrates that the involvement of experts in resource allocation does not necessarily involve the sacrifice of any principle that is important to deliberative democracy.

Section 9.1 makes a case for the division of epistemic labour within deliberative democracy, providing what the rest of the chapter is supposed to defend as capable of solving the tension between deliberative democracy and expert involvement in resource allocation. Section 9.2 spells out the charge that expert involvement is incompatible with public reason because of the opacity of expert opinions to laypersons. In the same section, I begin my response by arguing that indirect strategies are available for laypersons to assess expert opinions. Next, section 9.3 discusses the methods that lay citizens can adopt to evaluate expert communities. In section 9.4, I respond to the argument that experts have no real choice but to disguise uncertainty and disagreement, usurping decisions that should be left for the general public to make.[391]

9.1. The division of epistemic labour between experts and lay citizens

The purpose of this section is to identify the terms of the division of epistemic labour that the rest of the chapter aims to defend as capable of solving the tension between deliberative democracy and the involvement of experts in clinical care resource allocation. An alternative but faulty way to escape that tension is offered by the notion of *epistemic equality*, which can be specified in two ways. First, experts could be deprived of any special role in clinical care resource allocation. Returning to the evaluation of new drugs, decision-makers with no expertise in clinical research and other relevant disciplines could assess the clinical effectiveness of the drugs, exchanging opinions that all members of the public could understand. This

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[391] A note on the definition of expertise is in order. What differentiates experts from laypersons is a controversial issue – on this, see Hoffman (1998) and Luntley (2009). Roughly speaking, the debate is characterised by a rift between two schools of thought. On the one hand, there is the idea that experts employ the same kind of knowledge and reasoning methods as laypersons, although at a more advanced level. On the other hand, there are those who believe that unique ways of reasoning and powers of judgement are integral to the definition of expertise. Importantly, nothing in my argument hinges upon the acceptance of either view. Indeed, neither my case for the division of epistemic labour nor the analysis of the problems related to the involvement of experts in resource allocation contradicts either school of thought. Consequently, I do not need to take any stand in this debate – for the sake of my argument, it suffices to define experts loosely as those who perform outstandingly in a certain domain.

process would fall well short of the systematic reviews that we expect from experts. Among other things, the rules for an appropriate literature search, analysis of the robustness of available studies and synthesis of data fall beyond the intellectual reach of the general public.

Alternatively, epistemic equality can be specified by drawing on the notion of “extended peer community”. In many areas of scientific research, “facts are uncertain, values in dispute, stakes high and decisions urgent”.[392] It is argued that, in these areas, inputs from laypersons can enrich scientific knowledge. Thus, the production and review of science should be reformed so that laypersons can participate on the same footing as experts. If all relevant scientific communities were extended peer communities, any of their members could be involved in clinical care resource allocation. For example, the methods used to produce and review evidence about clinical effectiveness would be made widely understandable, and any clinical researcher could be called upon to apply them to the evaluation of new drugs.

Neither form of epistemic equality can effectively pursue the interests of all members of society. All citizens, regardless of their worldviews or life plans, have an interest in the advantages that are gained through knowledge. For example, security, health, leisure, food supply and mobility can all benefit enormously from the advancement of knowledge. Now, given that the possibilities offered by single lives are limited, everyone should wish that epistemic labour be divided among communities developing specific areas of knowledge. In this way, the conditions for the creation of a much larger body of all-purpose knowledge are established.[393] It is now clear why the proliferation of extended peer communities is inadmissible: such proliferation is inconsistent with a principle of respect for what everyone

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[392] Funtowicz and Ravetz (1993, 744). See also Callon (1999) and Jasanoff (2003).

[393] Hardwig (1985).

should want if they exercised their autonomy and directed themselves in the light of their intelligence. Within research communities, laypersons cannot be "raised" to the same status as the relevant experts without contradicting the entire point of specialised communities, which is to advance specific domains of knowledge beyond the reach of the general public. If laypersons participated as peers in the production and review of clinical studies, the quality of the inquiry would be lowered, and all of the experts' knowledge acquired from long years of scientific education and practice would be left aside.

Turning to the process for allocating clinical care resources, we have already seen how often decision-makers need to incorporate knowledge from areas in which some expert community specialises. In all these cases, procedures should be in place to consult the relevant experts and have them answer the hard questions of science involved. Assuming that the decision-making process pursues valuable goals, all citizens have an interest in consulting the relevant experts. The involvement of experts makes it most likely that the final decision embeds the best factual knowledge available, furthering the goals of decisions as effectively as possible. For example, to fall short of any systematic comparison of the available studies of new drugs would be a huge loss, highlighting why the first understanding of epistemic equality is also untenable.

In the previous paragraphs, I put forward considerations that were meant to cast doubt on epistemic equality and push towards the division of epistemic labour. However, a critic might object that it is not clear whether those considerations are consistent with the procedural conception of the value of deliberative democracy that I have developed in my thesis. To put the objection in another way, readers might wonder whether my argument implicitly relies on a rigid distinction between facts and values, which would limit the scope of my procedural conception of deliberative democracy to the discussion of values and open the door to epistemic considerations when it comes to deciding how factual matters are to be settled.

To prepare my answer, I wish to reiterate the main point of this section thus far, namely that it is in everyone's interest to foster communities of expertise and to involve experts in political decision-making. This point is grounded in the idea that it is in everyone's interest to further the objectives of political decision-making as much as possible. In what follows, I aim to demonstrate that the interests that I refer to are *specifically* the interests of citizens of a deliberative democracy built on a procedural mode of justification. In other words, these interests are *integral* to a procedural conception of deliberative democracy. Consequently, my argument does not exclude factual matters from the scope of deliberative democracy.

Although not the only topic that must be addressed by a deliberative democracy, values certainly constitute one important issue that must be settled by deliberative democratic procedures. Such values include the objectives that resource allocation and other political decision-making agencies are supposed to pursue when deciding the issues that fall within their purview; among the values discussed in my thesis, consider, for example, priority to the worst-off and the idea that special attention should be paid to the ability to benefit of patients.

Imagine that objectives have been set through a process that satisfies public reason, public involvement and other requirements of deliberative democracy. Consequently, such objectives have been set through a process that is fair because it effectively expresses and implements equal respect for the autonomy of individuals. What is the link between furthering these objectives as much as possible and my procedural conception of deliberative democracy? First, it can be suggested that *as a matter of logic*, the idea that objectives should be furthered as much as possible is one and the same thing as recognising them as legitimate objectives – and the objectives that we are considering are clearly legitimate because they are the product of fair procedures.

Second, all citizens have an interest in furthering as much as possible the objectives chosen through fair procedures because every citizen committed to deliberative democracy has an interest in implementing the equal respect owed to the autonomy of individuals to the greatest extent possible. According to my procedural conception of deliberative democracy, decision-making procedures that are fair because they implement equal respect for the autonomy of individuals *transfer their value* to decisions. If decisions about which objectives should govern resource allocation are made through fair procedures, the chosen objectives gain a value that the citizens of a deliberative democracy are supposed to acknowledge. Therefore, to aim for resource allocation arrangements that further the chosen objectives to the greatest extent possible is necessary to further as much as possible the values of equal respect, autonomy and fairness that are embedded in the procedures used to choose among all possible objectives of resource allocation.

The idea that the objectives of decision-making should be furthered to the greatest extent possible involves a general commitment on the part of decision-makers, i.e., a commitment to providing the most accurate factual information available when exchanging reasons concerning resource allocation decisions. Moreover, my argument also pushes towards a more specific commitment, which concerns the cases in which decision-makers come across *hard factual questions that fall within the remit of an expert community*. For example, decision-makers may need to know how much the members of different patient groups can benefit from a certain drug and whether the drug in question could fit within best clinical practice. In these cases, it is in the interest of every decision-maker to consult the relevant experts about the hard factual questions that are on the table, thereby ensuring the best possibility of accurately answering those questions to further as much as possible ability to benefit and the other objectives of resource allocation.

The idea that a general requirement of accuracy in dealing with factual information falls upon resource allocation decision-makers beyond expert involvement should have dispelled any lingering suspicion that my argument implicitly places factual matters outside the scope of deliberative democracy. Moreover, it is worth noticing that the entire objective of this chapter and the next is to discuss how the process for expert involvement can be made consistent with the principles at the heart of deliberative democracy, reinforcing the conclusion that the discussion of factual matters is integral to deliberative democratic procedures.

Now that I have defended my argument for the division of epistemic labour, it is time to clear the way for the arguments that I develop in the following sections. To do that, I need to distinguish my conception of division of epistemic labour from the *rule of an epistemic elite* and an overly expansive idea of the inability of laypersons to contribute to science.

The fact that the public cannot be competent in all areas of knowledge has led some to argue for the rule of an epistemic elite. Famously, Walter Lippmann argued that deliberations among experts produce better decisions and, therefore, the epistemic elite should be entitled to mould public opinion so that the public would conform to what has been decided.[394] However, a system in which experts *alone* determine the values governing resource

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[394] Lippman (1922).

allocation clashes with the objective to shape decision-making processes so as to show *equal* respect to the ability of individuals to direct themselves. Furthermore, widespread participation in decision-making is needed to identify reasons that are truly acceptable from all perspectives in society, as dictated by public reason.[395] Thus, the values that govern clinical care resource allocation should be determined by the general public, together with decision-making agendas. Although experts should be asked to answer hard questions of science, their special role must end there – experts should contribute to the discussion of values and decision-making agendas on the same footing as anyone else.

My argument for the division of epistemic labour does not mean to deny that laypersons can sometimes participate in the production of scientific evidence and its use in clinical care resource allocation. Indeed, there are contexts in which laypersons can work as collectors of scientific evidence and interpreters of data.[396] Most importantly for the sake of my argument, there are groups of persons that, although lying outside traditional communities of expertise, occupy a privileged viewpoint which gives them precious insights into issues of scientific interest. As pointed out by James Wilsdon, Brian Wynne and Jack Stilgoe with regard to the British Alzheimer's Society, patient and carer representatives can fruitfully dialogue with clinical researchers to check that research methods do not overlook any important aspect of diseases as experienced by those directly affected. Similarly, patient and carer groups can contribute to clinical care resource allocation by checking that the simplifications involved in the methods used to measure ability to benefit and how badly-off patients are do not leave out

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[395] See also Kitcher (2011, 20–25).

[396] Here I am thinking about the so-called "citizen science" projects. See the NASA Clickworkers experiment, in which thousands of laypersons have been contributing to mapping Mars’s craters (http://beamartian.jpl.nasa.gov/welcome - last accessed 14/10/2014). In turn, the idea of the NASA Clickworkers has been brought several stages forward by Zooniverse (https://www.zooniverse.org/ - last accessed 14/10/2014).

any key aspect of diseases.[397]

As I intend to discuss in full detail in section 10.2, I agree that patient and carer groups have a role to play as providers of factual evidence: they should check that the modelling involved in scientific analysis does not end up overlooking important aspects of the actual experience of disease. However, the role of patient and carer representatives with regard to questions of science should not be confused with that of traditional experts. Indeed, the privileged insights of patients and carers into the experience of disease fall far short of enabling them to perform a great number of core functions that clinical researchers, medical practitioners, health economists and other experts are expected to fulfil in clinical care resource allocation.

9.2. Direct and indirect assessment in the face of opacity

My idea of division of epistemic labour and expert involvement in resource allocation faces serious criticism. Two problems stem from the opacity of expert opinions to laypersons, suggesting that public reason and expert involvement are incompatible. The first problem concerns the assessment of the evidence that *individual* experts are supposed to provide in the context of clinical care resource allocation, while the second problem concerns the assessment of the *whole communities* of expertise to which those experts belong. Consider first the contributions that individual experts are supposed to make to resource allocation. Going back to the evaluation of the clinical effectiveness of new drugs, clinical researchers are expected to address such topics as the relative robustness of available trials and the synthesis of data. The opinions that clinical researchers may wish to offer in this context are likely to be incomprehensible to the general public. Now, it seems obvious

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[397] Wilsdon et al. (2005, 30–32). On a similar note, Fischer (2009, 77–104) discusses the activities of gay activists in the early days of AIDS and other examples.

that laypersons cannot accept as reasonable expert evidence that they do not even understand. Thus, all resource allocation decisions based on opaque expert evidence violate the requirement that decisions should be grounded in public reasons. This can be referred to as the “individual claims problem”.

Furthermore, a Foucauldian suspicion is aroused when the project of public reason is applied to the choice of the expert communities whose members ought to participate in clinical care resource allocation. Given the experts’ opacity to laypersons, it seems that the public has no reason to believe that any body of expert knowledge offers any privileged approach to the truth. Why should resource allocation agencies continue to consult, say, clinical researchers and not alternative medicine practitioners? Even more radically, does not the involvement of any expert community equate to the domination of certain elites over society? This can be referred to as the “community assessment problem”.

To overcome these two problems, I need to demonstrate that strategies are available to assess both expert opinions and expert communities using reasons that laypersons can understand and accept. This task distinguishes my argument from the work of James Bohman and Stephen Turner, who have already discussed issues related to the individual claims and community assessment problems. From the perspective of public reason, their arguments are not satisfactory, because they do not engage in any in-depth analysis of the strategies that laypersons could employ to assess expert evidence and expert communities.[398]

The individual claims and community assessment problems are rooted in the fact that laypersons are often unable to *directly* assess expert evidence. This is especially true of the individual claims problem: given that

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[398] Bohman (2001) and Turner (2001).

laypersons are often unable to assess an expert opinion’s premises and the support they lend to the conclusion, most expert opinions incorporated into clinical care resource allocation seem unacceptable to lay citizens.

One way to respond to this problem could be to find a mechanism through which laypersons are enabled to directly assess expert opinions. In this regard, Thomas Christiano's notion of “overlapping understanding” seems to offer a promising route to follow. Overlapping understanding occurs when two individuals share expertise in some areas but not in others. Under these conditions, one individual can translate opinions from a discipline the other does not comprehend into understandable concepts within the area in which they are both experts. Imagine that the two individuals are scientific experts, and one of them wishes to voice an opinion drawing from a discipline in which they are not both experts. The other individual may serve as the starting point for a translation process for expert evidence that can ultimately reach as far as the general public. Administrators with some knowledge of relevant scientific disciplines, mainstream politicians and journalists could be the other links in this translation chain.[399]

Can the translation chain envisioned by Christiano be employed in clinical care resource allocation to communicate expert evidence in a way that laypersons can understand and accept as reasonable? There are at least two reasons why the answer is “no”. First, a number of scientific disciplines are relevant to clinical care resource allocation. Moreover, resource allocation decisions are made by numerous agencies at many different levels. Consequently, large volumes of expert advice are needed, while Christiano's translation chain is a complex process, mobilising multiple actors for each expert contribution. When aimed at bringing the practice of

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[399] Christiano (2012).

expert involvement in line with public reason, Christiano's proposal appears infeasible. Second, Christiano admits that each translation may involve great losses of meaning. By the time expert opinions reach the general public, much information will be lost. In one important sense, scientific opinions as translated for the benefit of laypersons are other than those that were originally offered by experts; however, it is the original meaning that will be used in resource allocation. Thus, whether or not laypersons find translated expert opinions acceptable, the use of the original opinions in decision-making falls short of the requirement that resource allocation decisions should rest upon reasons that all can accept.

At this point, I am ready to concede that only a minority of expert opinions can be directly assessed by laypersons. However, direct assessment is not the only path to assess opinions. Laypersons can justifiably accept expert opinions after *indirectly* assessing them, that is inferring the value of the opinions based upon assessment of the expertise and honesty of the speaker. Indirect assessment is the key to tackling the individual claims problem.

Classically proposed by Alvin Goldman as a response to the expectation that laypersons must evaluate evidence provided by conflicting experts, the idea of indirect justification has obvious relevance to the judicial context.[400] Recently, this approach has been brought to bear on a more general theory of democracy by Elizabeth Anderson. In particular, Anderson claims that laypersons can carry out indirect assessment to identify who should be trusted when general scientific theories clash, as in the case of climate change.[401]

I argue that the use of indirect strategies should be taken to a further level. As exemplified by the evaluation of the clinical effectiveness of new

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[400] A. I. Goldman (2001).

[401] Anderson (2011).

drugs, clinical care resource allocation agencies routinely face *specific* scientific issues that extend well beyond the clash of general theories. Therefore, indirect strategies should also be applied when decision-making agencies need scientific evidence about specific issues. The agencies intending to involve experts should identify the main strategies for indirect assessment. Based on those strategies, agencies should provide justification for the opinions given by each expert contributing to decision-making. These justifications should be made public on the website of the agency in question and also through other channels employed to publicise its processes and conclusions. If the strategies for indirect assessment yield a sufficient amount of evidence supporting the expertise and honesty of a given expert, lay citizens are provided with good public reasons to accept the expert's opinions as reasonable.

In section 9.3, I complement my position with a necessary corollary: the assessment of expert communities should ground the practice of providing indirect justifications for expert opinions. Before that, I sketch several indirect strategies that could be employed to identify the public reasons supporting expert evidence.

The first strategy for indirect assessment aims to identify conflicts of interest. For example, researchers may be funded by or hold stakes in a private corporation. In these cases, serious doubts are cast on any opinion they provide about that particular corporation or its products. Many agencies already dictate that experts involved in clinical care resource allocation must disclose their conflicts of interest. If conflicts of interests are particularly acute, experts may be prohibited from participating in the process.[402] Therefore, my proposal that resource allocation agencies should explore the indirect reasons supporting expert opinions builds upon an established

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[402] For example, see NICE (2014b).

practice. However, other factors besides conflicts of interest may threaten the public acceptability of expert opinions and should also be investigated.

A second strategy is centred on the use of past track records of cognitive success. The value of many scientific statements is esoteric until a certain moment, at which point it becomes exoteric. After the value of a statement has become exoteric, laypersons can see whether the experts who made that statement were correct. For example, after a medical treatment has been repeatedly applied and the treated patients have returned to good health faster than others, laypersons can identify the treatment as a success. Laypersons can also appreciate that there were individuals who believed the statement in question when it was esoteric. Consequently, laypersons have reasons to believe that those individuals really possess expertise in the field.[403]

Credentials are a third strategy for indirect assessment. Academic degrees, positions held in the field of study, professional awards and leadership roles in professional societies are all signs of how scientific communities assess the expertise of a member. As suggested by Anderson, an expert's number of publications should be added to the list, together with a citation count and the impact factor of the journals in which the expert has been published.[404]

A fourth strategy consists of checking whether the rest of the relevant community shares the bases of an expert opinion. There may be reviews of peer-reviewed literature, surveys of experts and consensus statements showing that certain methods or substantive conclusions are dominant.[405] If expert opinions are grounded in such methods and conclusions, the resource allocation agency employing those opinions should make that known when

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[403] Track records are hailed as the best source of indirect evidence by A. I. Goldman (2001, 106–108).

[404] Anderson (2011, 146–147).

[405] Anderson (2011, 149).

advancing the public reasons supporting their final decisions. Famously, Goldman casts doubt on the use of "numbers", highlighting that a small fraction of the scientific community (if its members are more independent and more credible) can provide stronger reasons to trust an opinion than a bigger group.[406] Although Goldman has a point, his arguments do not justify the conclusion that numbers should never count. First, resource allocation agencies could look for agreement among experts who work in geographically distant research institutions, so the concurring experts are most likely to belong to different "schools". Second, numbers are supposed to work as a defeasible reason in favour of expert opinions, to be backed up by other indirect assessment strategies.

Finally, dialectical prowess should be considered. Laypersons can appreciate how promptly and smoothly technical questions are answered. Moreover, laypersons can see whether an expert offers rebuttals that engage with the substance of criticism, as opposed to dodging difficult issues.[407] Nonetheless, dialectical prowess has limited applicability. The employment of dialectical prowess as an indicator of expertise is strongly criticised in the context of criminal trials, where many lawyers choose experts on the sole basis of dialectical talent, regardless of its connection with expertise.[408] To ease this concern, one could respond that the adversarial nature of criminal trials is not common to most of the venues in which clinical care resources are allocated. I accept this response, but we should remember that, outside the judicial context, expert evidence is often submitted in written form. In this case, the resource allocation agency does not have much scope to point out the dialectical prowess of the experts. In brief, dialectical prowess should contribute to building public reasons when evidence is submitted

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406 A. I. Goldman (2001, 97–104).
407 A. I. Goldman (2001, 95–96).
408 Brewer (2006, 139–141).

orally and when the meeting is open to the public or the minutes are publicly available. As for the lingering concern that experts may be selected on the sole basis of dialectical talent, I reiterate that dialectical prowess is one source of evidence among several other types and should be used in conjunction with them.

Indirect strategies have been introduced as an answer to the individual claims problem, i.e. the charge that, given the opacity of expert opinions, lay citizens cannot reasonably accept any decision that relies on expert evidence. However, apart from conflicts of interest and track records, all of the indirect strategies rely heavily on *trust in the relevant expert community*. Laypersons are justified in accepting the opinions provided by a well-credentialed expert whose arguments are shared by her peers only if they have reason to trust the community that issued the credentials and agrees with the arguments. To some extent, the same holds true for dialectical prowess; in addition to constantly re-defining the subject matters to be discussed by their members, expert communities contribute to setting the expectations for a well-conducted discussion. Thus, if the trust placed in the relevant community is not grounded in public reason, indirect assessment does not provide solid reasons to accept expert evidence.

The strategies for assessing expert communities are where the solutions to the individual claims and the community assessment problems meet: not only is the assessment of expert communities meant to dispel the residual worry that expert opinions cannot be acceptable to the public, but this type of assessment can also drive away the suspicion that scientific communities are nothing more than a tangle of bias and vested interests.

9.3. The assessment of whole communities of expertise

There are at least two sources of evidence that lay citizens can employ to evaluate the trust they place in expert communities. Laypersons can a) analyse the *track records* of expert communities, and b) appraise the extent to which *internal arrangements* foster integrity and the accumulation of new knowledge.

Goldman considers track records to be the most promising source of evidence supporting the trustworthiness of *individual experts*. In my view, track records are also a key part of the assessment of expert *communities*. Laypersons can appreciate the success of many of the previsions and interventions that expert communities have put forward. To support the trust placed in expert communities, these successful applications should result from broad projects within the relevant community, involving the joint effort of a number of persons and organisations. Laypersons recognise the achievements in question as the products of expert knowledge: they can appreciate that members of the expert community believed in the broad projects under consideration even when their value was still obscure to lay observers. Obviously, it is important that each expert community can point out numerous successful applications that have answered complex problems.

To provide an example of the use of track records that is relevant to the expert communities being involved in clinical care resource allocation, let us compare conventional medicine and homeopathy. Virtually all members of the public are aware of a number of major successes resulting from broad projects within medicine. Think of the eradication of smallpox and the near eradication of polio, or the success of antiretroviral treatments that made AIDS akin to a chronic disease. Analogously, it is fair to assume that most persons are aware that, during the last forty years, the survival rates for many forms of cancer have dramatically improved.

Beyond a layperson's awareness, what is really important is that lay citizens have the ability to recognise the value of a long list of accomplishments of the medical community. Moreover, laypersons can appreciate the role that the medical community has played in the process leading to those accomplishments. For example, laypersons can see that access to medical services makes a great deal of difference in regard to explaining the decrease in maternal deaths that several countries, but not others, have enjoyed over the last decades.[409] Turning to homeopathy, laypersons can find no list of successes that are comparable with the greatness of medical accomplishments and the incontrovertibility of their genealogy. While a long list of successes demonstrates that lay citizens have reasons to trust the medical community, there appears to be no such track record supporting the homeopathic community.

At this point, a critic might suggest that my discussion of medicine and homeopathy involves several oversimplifications. Notably, depicting medicine as a monolithic block and placing it in binary opposition with homeopathy is inaccurate. Medicine is made up of numerous sub-disciplines with varied track records. Thus, different medical disciplines deserve different levels of trust. Relatedly, every medical discipline has done both good and harm, and the records of their failures should be taken into account. I grant that my argument makes considerable simplifications, but none of them undermines the aim of my discussion of medicine and homeopathy, which is to outline the way in which the applications of expert knowledge may provide public reasons supporting the trust placed in medicine and other expert communities.

First, laypersons have the necessary abilities to make distinctions

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[409] World Health Organization (2005, 1–19).

between the track records of different medical disciplines. For example, laypersons can see that oncology and psychiatry have different histories of successes and failures. Second, a record of failures is hardly ever a fatal blow to the trustworthiness of a medical discipline. Paediatricians, for example, have certainly done harm; the recommendation that infants be placed to sleep in a prone position, standard until some time ago, is a prime example of a harmful practice.[410] However, we all make mistakes, and authentic expert communities are no exception. Moreover, it is plausible to say that laypersons can look at the record of positive effects on childhood mortality and health-related quality of life to recognise that the good that paediatricians have done outweighs the bad.[411] Furthermore, as in the case of the best sleeping position for infants, laypersons can acknowledge that various medical disciplines have been able to identify some of their own practices as harmful and correct their mistakes.

Track records show that there are many more factors than just biases and vested interests involved in disciplines such as medicine. Once a solid track record has been identified, lay citizens can derive further evidence of trustworthiness from the internal arrangements of expert communities. Issues such as entry into the community, progression, funding of research and professional integrity in the face of business should be objects of analysis. The aim should be to check whether those issues have been handled so as to safeguard the ability of the community to pursue new accomplishments with integrity. The more the internal arrangements of an expert community are infected by bias, vested interests and other instances of diminished integrity, the more its trustworthiness is threatened.

The issues concerning internal arrangements are not beyond the intellectual reach of laypersons. Both the problems involved and the merits

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[410] Chalmers (2001).

[411] World Health Organization (2005, 1–19).

of alternative solutions can generally be evaluated by lay citizens. For example, consider medical education and, in particular, continuing education requirements.

Laypersons can see the merits of long years of education, in which prospective members receive theoretical and practical training by senior members of the medical community. Analogously, if members are required to continue their education throughout their careers, lay observers have more reason to infer that those who belong to the medical community are knowledgeable and up-dated. However, the way in which continuing education programmes are organised in countries like the U.S. has come under serious criticism.[412] Now, laypersons can see the problem in a system in which pharmaceutical industries fund a large part of continuing education activities. Such activities are often delivered by for-profit providers that receive the largest part of their income from "big pharma". Sometimes, doctors obtain continuing education credits for attending satellite symposia that are directly organised by pharmaceutical industries. Continuing education spending allows pharmaceutical industries to circumvent the existing regulations on marketing and gifts, which have well-known distorting effects on the judgement of doctors. Furthermore, industries influence the choice of continuing education programmes and speakers.

Lay citizens can engage in conversation about whether a blanket prohibition on pharmaceutical funding of continuing education activities should be adopted, or whether alternative arrangements could keep the pharmaceutical sponsors at arm's length. For example, lay citizens can discuss Jerome Kassirer's proposal that satellite symposia must be eliminated and that only academic centres and medical schools should deliver continuing education programmes, with speakers who have no

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[412] Angell (2005, 135–155) and Kassirer (2005, 1–24).

financial stake in the health technologies that they explore.

Educational requirements are only one example of the issues concerning the internal arrangements of expert communities that lay citizens should explore. Another important example is provided by the lack of publication of negative clinical trials, which shows that, despite all the proofs of the trustworthiness of the medical community, there are still problems. However, I argue that laypersons have the necessary abilities to address these problems and place the trustworthiness of medicine on even firmer ground. In brief, clinical trials showing positive results are much more likely to be published than negative clinical trials. Laypersons can appreciate the distorting effect of this practice on what the expert community considers the best medical practice. Most notably, interventions that have already been proven ineffective may still be considered appropriate. Furthermore, laypersons can discuss why researchers withhold negative results and what should be done to correct this situation. For example, laypersons can identify the problem with the so-called “gagging clauses”, which allow pharmaceutical sponsors to block clinical researchers from publishing. Also, laypersons can discuss the proposals calling for tough sanctions to be imposed by international legislative bodies or professional associations.[413]

In sum, there are strategies for laypersons to assess expert communities. Now, societies should put such strategies to work so that public reasons can be made available in support of the expert communities that deserve to be involved in clinical care resource allocation. Societies should embark in a continuing discussion of the value of alleged communities of expertise, their aims and the internal arrangements that help pursue those aims. This type of discussion is needed to solve the community assessment problem, dispelling the suspicion that expert communities are not selected on reasonable

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[413] Goldacre (2012, 1–99) and Lehman and Loder (2012).

grounds. Moreover, not even the individual claims problem can be solved if expert communities are not subject to scrutiny: the opinions provided by an expert are grounded in much stronger public reasons if indirect assessment strategies rest on arguments supporting the trustworthiness of the community to which the expert belongs.

As in the case of medicine, it is fair to presume that all expert communities, including those whose trustworthiness is grounded in valid public reasons, have flaws in their internal arrangements. To bring expert involvement perfectly in line with public reason, procedures should be in place to reform the arrangements that are found lacking.

9.4. Uncertainty, disagreement and usurpation of authority

At this point, another criticism could be directed at my attempt to defend expert involvement in clinical care resource allocation. The argument would be that my attempt is bound to fail because it cannot cope with a *realistic* account of scientific practice and the inability of laypersons to deal with the real face of science. In contrast with the popular image of science, uncertainty and expert disagreement are intrinsic to good scientific practice. Many research areas are either short of reliable evidence or characterised by evidence that is still ambiguous. Thus, experts either do not know what might happen as a result of a certain course of action, or cannot assign probabilities to outcomes.[414] Regarding clinical care resource allocation, one could mention drugs that are at an early stage of clinical testing, or that cannot undergo proper tests because they are meant to treat patient populations that are too small. On top of this, a minority of experts dissenting with prevailing opinions is to be expected even if issues are not

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[414] Stirling (2010).

new to the expert community and a good deal of evidence is available.[415]

When involved in political decision-making or otherwise communicating with the general public, experts tend to obscure uncertainty and disagreement.[416] To a large extent, this tendency is founded upon the expectations of the public about science. The more a scientific community makes uncertainty and disagreement explicit, the greater the risk that it loses recognition and influence. Moreover, politicians welcome certainty and consensus because policies grounded in uncertainty and disagreement are more likely to be met with scepticism. An excellent case in point is provided by John Beatty, who describes how the most important American geneticists of the mid-50s decided on the maximum acceptable dose of radiation. Fearing that the discipline they represented could lose authority, the appointed committee negotiated an answer that fudged uncertainty and hid the substantial disagreement that divided the experts.[417] As far as the reticence to voice one's dissent is concerned, inner logics of expert deliberation also contribute. If they find themselves in the minority, experts tend to think that they must be mistaken. Moreover, those who voice a dissenting opinion are often perceived (and treated) as if they were disrupting the work of the group.[418]

The practice of obscuring uncertainty and disagreement is unacceptable for manifold reasons. First, deliberative democracy requires that experts be involved in resource allocation because decisions should be grounded in the best evidence available. If scientific inquiry yields uncertainty and disagreement, to hide them amounts to distorting the best evidence available, contradicting the purpose of seeking expert opinions. Second,

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[415] Beatty and Moore (2010).

[416] Bucchi (2008, 61–65).

[417] Beatty (2006).

[418] For expert deliberation and disagreement, see Perron Tollefsen (2006, 39–45) and Sunstein (2006, 195–205).

those experts who hide uncertainty and disagreement are deceiving the public while participating in a deliberative democratic process whose aim should be to show equal respect to everyone. Third, and perhaps most important, the experts who hide uncertainty and disagreement are effectively usurping decisions that, concerning values and not factual matters, should be for the general public to make. Consider Beatty's example of how geneticists negotiated what should be considered a safe dose of radiation. To misrepresent the output of that negotiation as a well-established fact amounted to deciding how safe society should play in the face of a not-yet-quantifiable risk of genetic mutation. Analogously, to downplay the position of those who believed that there was no need for a maximum acceptable dose of radiation effectively privileged the protection of public health at the expense of social security and other values. To compound the problem, the practice of secretly negotiating certainty and agreement is particularly prone to capture by vested interests.[419]

How can the practice of disguising uncertainty and disagreement provide the basis for an objection to my attempt to reconcile deliberative democracy and expert involvement? Experts may justify themselves by saying that laypersons could not possibly orient themselves in the face of uncertainty and expert disagreement. Thus, to hide uncertainty and disagreement is the only way to prevent *arbitrary decisions* and the *wastage of what science can offer*. Deliberative democracy seems caught in a lose-lose situation: either decision-making is non-arbitrary and capable of deriving benefits from scientific evidence, or the public is protected from deception and a degree of usurpation of authority by experts and vested interests.

In the rest of this section, I answer this objection. To do that, I explore why experts may think that laypersons are incapable of orienting themselves

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419 Stirling (2010).

in the face of uncertainty and expert disagreement. Starting from the charge that laypersons cannot make sensible decisions on the basis of expert disagreement, it may be argued that the strategies for indirect assessment described in section 9.2 are of little use. In case of persistent disagreement among experts, those strategies seem unable to provide public reasons that identify which of the conflicting parties should be trusted.

It is plausible to expect that in many cases, different indirect strategies may favour different experts or groups of experts. For example, credentials and numbers may favour one expert, while the absence of conflicts of interest and a good track record may favour another. In this case, the relevant differences between the conflicting experts are in equilibrium, and the indirect strategies do not identify a clear winner. Given that indirect strategies provide the public reasons for assessing expert evidence, public reason appears to be indeterminate. In other words, no choice can be made that is both non-arbitrary and acceptable to laypersons.

I respond that, even when relevant differences are in equilibrium, a non-arbitrary choice can be made on the basis of public reasons. Lay participants in decision-making should build their own *hierarchies* of the indirect strategies for assessing expert opinions. Then, focused deliberation and majority rule should decide which hierarchy should be adopted collectively and, therefore, which of the conflicting expert opinions should be accepted. The outcome of this process is by no means arbitrary or inconsistent with public reason. Such an outcome results from the use of reasonable strategies for indirectly assessing expert evidence. Moreover, participants should be instructed to identify the *most reasonable* hierarchy of indirect strategies, where reasonableness is measured in terms of reasons that all might be expected to accept. Crucially, the fact that different persons are likely to disagree over the most reasonable hierarchy does not make the process any less an instance of public reasoning.[420]

For example, some participants may be more acutely aware of the distorting effects of conflicts of interest. Therefore, they place conflicts of interest at the top level of their assessment strategy hierarchy. On the other hand, someone else may believe that nothing provides greater evidence of expertise than top-notch academic degrees and influential publications from top-ranking journals. Hence, credentials end up at the top of their hierarchy. Even if no agreement is reached through deliberation, both parties are honouring public reason. Indeed, widely accessible and strong rationales support both positions, and both parties may sincerely believe that everyone else should accept their own position as the most reasonable. In this context, a complete hierarchy is so complex an issue that reasonable persons engaged in the search for public reasons are likely to disagree. As we saw in section 2.3, there are many policy contexts in which the hierarchy of agreed-upon principles is an object of disagreement among persons committed to public reason. In line with my argument, it is claimed that the use of whichever hierarchy the majority identifies as the most reasonable satisfies public reason.[421]

What of the charge that laypersons are bound to be overwhelmed by the complexity of expert opinions that state how uncertain science really is? Under conditions of uncertainty, experts can provide neither sure knowledge nor quantifiable risk. To the extent that scientific evidence is uncertain, all resource allocation agencies that wish to make decisions on the basis of the best evidence available must take a leap in the dark. As in Beatty's example, the bulk of the deliberation about how to take that leap will consist in discussing whether resource allocation agencies should play safe in the face of risk and which values should govern decision-making. Now that it is

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[420] See the discussion of reasonable pluralism in sections 2.1 and 2.3.

[421] Among others, see Dryzek and Niemeyer (2006, 638–640).

clear that decisions on the basis of uncertain scientific evidence are essentially a matter of *value judgements*, the argument that laypersons would be unable to orient themselves loses much of its force. Indeed, not only is the general public the legitimate actor to deliberate about values, it is also as capable to do that as any group of scientific experts.

Moreover, there are valuable resource allocation options that are precluded as long as experts are allowed to hide uncertainty from the public. Only if lay decision-makers are aware of uncertainty they have reason to look for *flexible* resource allocation arrangements, i.e., devised in such a way that changes are easy to make if new evidence arises contrasting our previous decisions. Thus, the opposite of the argument from the wastage of what science can offer turns out to be true: if experts are encouraged to voice uncertainty and disagreement, the most can be obtained from expert involvement in clinical care resource allocation.

9.5. Conclusion

This chapter has demonstrated that the tension between deliberative democracy and the involvement of experts in clinical care resource allocation can be eased. This result is very important in the overall economy of my argument. The involvement of experts in resource allocation emerged as both an important topic and a difficult challenge in several of the foregoing chapters. Indeed, section 1.3 described the tensions surrounding the involvement of experts in a deliberative democratic approach to resource allocation as a key part of the third main theme running through my thesis.

To be honest, my defence of the division of epistemic labour and expert involvement in resource allocation is still incomplete. My arguments have stopped at a rather abstract level, providing no more than a rough outline of any implementation strategy. Sections 9.2 and 9.3 outlined a two-tiered model of deliberation to implement my solution to the individual claims and community assessment problems. Analogously, a local and a general level of deliberation must work jointly to give effect to my recommendation that lay citizens should be allowed to make resource allocation decisions on the basis of transparent communication of uncertainty and expert disagreement. On the one hand, the procedures for involving experts in clinical care resource allocation should be designed in such a way that participants are prompted to voice uncertainty and disagreement. On the other hand, venues should be created to build a large-scale discussion of how different scientific practice is from its popular image, focusing on the role of uncertainty and disagreement. Admittedly, these rough sketches of a two-tiered model of deliberation only offer a hint of an answer to the problem of implementation. Thus, it is yet to be demonstrated that steps can be taken to implement the conclusions that I have reached in this chapter. Chapter 10 carries out this task, adding to the plausibility of my account of the division of epistemic labour and expert involvement.

10. IMPLEMENTING EXPERT INVOLVEMENT

This chapter plays a similar function to chapter 8, which discussed how to implement my theoretical analysis of the implications of public reason for the substantive values governing resource allocation. In fact, this chapter aims to discuss how the analysis of expert involvement carried out in chapter 9 can be implemented. The first two sections deal with the design of clinical care resource allocation agencies. More specifically, section 10.1 focuses on how the design of resource allocation agencies can tackle the opacity of expert opinions, while section 10.2 explores how to contrast the tendency of experts to disguise uncertainty and disagreement. Section 10.3 turns to a more general level of deliberation, involving upstream public engagement exercises, representative institutions and the media. Moving beyond the topics covered in the rest of the chapter, section 10.4 brings the argument of the thesis to a conclusion.

10.1. The design of resource allocation agencies in the face of opacity

Chapter 9 argued that resource allocation agencies should provide an indirect justification for all expert opinions used during the decision-making process. Moreover, indirect strategies for assessing expert opinions should be employed to determine which opinion should be adopted in case of disagreement among experts. How can the design of resource allocation agencies help to put into operation the role of indirect assessment?

For a start, the use of indirect strategies should be required by the *methods documents* that resource allocation institutions issue to detail how their decision-making agencies are supposed to work. Section 9.2 identified a number of indirect strategies for assessing expert evidence, namely conflicts of interest, past track records of cognitive success, credentials, numbers and dialectical prowess. My idea is that decision-making agencies should do the same – they should identify a list of reliable indirect strategies for assessing expert opinions. Based on the strategies that they have identified, those agencies should offer justifications for the opinions provided by each expert who has been called upon to contribute to decision-making. These justifications should be made public on the website of the institution in question and also through the other channels employed to publicise its process and decisions. In case of disagreement among the experts involved in the resource allocation process, indirect strategies should be applied to see which of the conflicting opinions should be adopted. Now, all the responsibilities that I have just listed should be enshrined in the methods documents setting out the process to be followed by resource allocation agencies.[422]

This recommendation builds upon a prerequisite adopted by many real-world clinical care resource allocation agencies, specifically that the experts joining the process must disclose their conflicts of interests. If conflicts of interests are particularly serious, experts may be barred from participating in the resource allocation process.[423] However, conflicts of interest are not the only factor that may threaten the justified acceptance of expert opinions on the part of lay citizens. Hence, conflicts of interests should be investigated

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[422] For an example of the methods documents I am referring to, see NICE (2013a).

[423] For example, see NICE (2014b) and the regulations imposed by the Institute for Quality and Efficiency in Health Care in Germany (https://www.iqwig.de/en/participation/conflicts_of_interest.3074.html – last accessed 14/10/2014).

together with the other sources of indirect justification. In turn, the idea of employing a number of indirect strategies for assessing expert opinions builds upon established practices for assessing expert testimony in a court of law.[424]

A second procedural arrangement (although closely related to the recommendation concerning methods documents) has to do with the *grounds of appeal* against resource allocation decisions. Section 3.2 argued that revisability is one of the general requirements of a deliberative democratic approach to clinical care resource allocation. Revisability requires that procedures should be in place for the public to appeal against resource allocation decisions. To prompt resource allocation agencies to take the indirect assessment of expert opinions seriously, the charge that an agency did not comply with its methods document with respect to the indirect assessment of expert opinions should be considered a valid ground of appeal against resource allocation decisions.

My final recommendation specifically concerns the need to shape resource allocation processes so as to encourage decision-makers to choose between conflicting expert opinions on the basis of indirect strategies. In brief, institutional designers should resist the temptation to define *membership criteria* in such a way that experts make up a vast majority of the staff of resource allocation agencies. Good examples of resource allocation agencies that almost exclusively comprise experts are provided by the committees responsible for health technology appraisal within NICE; their members are selected on the basis of their expertise in clinical practice, health economics and additional academic disciplines, pharmaceutical research and other relevant areas of expertise.[425]

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[424] Brewer (2006).

[425] http://www.nice.org.uk/get-involved/meetings-in-public/technology-appraisal-committee (last accessed 14/10/2014).

Imagine that a disagreement concerning the clinical effectiveness of a new drug arises among the external experts who have been called upon to provide evidence. The members of a resource allocation agency that is almost entirely made up of experts may be reluctant to surrender the issue to non-expert ways of reasoning. As experts, decision-makers are unlikely to feel any strong need for a widely-accessible justification. Thus, they may continue to look for an “expert strategy” to solve the disagreement in question, or settle the issue among themselves.[426] In this context, indirect strategies for assessing expert evidence may be included in their reports as nothing more than window dressing.

If membership was reformed so that *at least half* of the members were not scientific experts, a stronger need would be felt to provide widely-accessible justification for preferring one expert opinion over the others. For example, the laypersons serving on a resource allocation agency alongside experts could be a combination of members of the general public, civil servants with no expertise in relevant scientific disciplines and ethicists. Lay members could deliberate about the relative trustworthiness of conflicting experts, and a vote could be taken if they failed to reach an agreement. To give structure to this deliberation, lay participants could be instructed to make reference to the same indirect strategies that the agency must refer to when explaining why experts should be trusted in the first place.

Chapter 9 pointed out that numerous indirect strategies for assessing expert opinions rest on trust in the relevant expert community. Thus, society at large should find a way to assess which communities of expertise are worthy of the public's trust. This conclusion calls for a more general level of deliberation than the one examined in this section. Before addressing that

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[426] For an example of how experts may be baffled by difficult problems without opening the door to lay reasoning, see the analysis of the radiation crisis in Cumbria proposed by Wynne (1996).

level of deliberation, however, I need to examine how resource allocation agencies should be designed to counter the tendency of experts to disguise uncertainty and disagreement.

10.2. Institutional design and the concealment of uncertainty and disagreement

When involved in political decision-making, experts tend to hide uncertainty and disagreement from the public. As explained in section 9.4, this tendency is rooted in the need to keep up with the popular image of science. Furthermore, inner logics of expert deliberation contribute to explaining the reticence to voice disagreement. If their opinions clash with the views of the majority, experts tend to think that they must be mistaken. Furthermore, voicing a dissenting opinion is often perceived (and treated) as an instance of disruptive behaviour. The practice of obfuscating uncertainty and disagreement constitutes a serious problem. Among other concerns, the experts engaging in such practice are effectively usurping decisions about values that should be for the public to make. How can the design of resource allocation processes ease the problem under discussion? I answer this question by examining uncertainty and disagreement in turn.

I start my analysis of uncertainty by drawing attention to the work done by Jacquie Burgess, Andrew Stirling and others on deliberative mapping (DM). DM is a deliberative process that is meant to address policy issues that are contentious because there is no agreement over the relevant values or because facts are uncertain. For example, DM has been used to discuss genetically-modified crops and the disposal of nuclear waste. Both experts and laypersons participate in the process. In what follows, however, I focus on the procedures for expert involvement. According to the creators of DM, the combination of a) an *analytical approach* to the elicitation of expert opinions and b) the *prospect of review by other experts* greatly facilitates the acknowledgement of uncertainty.[427]

DM requires that experts should go through an individual interview and, subsequently, they should all attend a group meeting. During the interview, experts are not simply asked to provide their opinion about the issue under consideration. For example, they are not asked how the kidney gap can be closed or how we can deal with the risks associated with genetically-modified crops. Instead, experts answer separate questions *about each of the logical steps* leading to their final opinion. First, the alternative options for dealing with the problem under discussion are identified. Second, the expert is asked to select the criteria against which to assess the options. Next, each option is assessed on the basis of how it fares with regard to each criterion. Finally, the expert is asked to prioritise the criteria and, consequently, a ranking of the options is produced. During the interview, experts are often asked to justify the answers that they give. The idea is that the analytical character of the interview leaves limited space for manoeuvre for those who might be willing to obfuscate uncertainty.

The analytical approach to opinion elicitation is developed by DM in two further directions. First, interviewees are asked to specify what they mean by *general concepts* such as “sustainability” or “efficiency”. Indeed, ambiguous concepts may serve as a means of masking one's ignorance about the issue at hand. Second, attention is explicitly drawn to the *possibility of uncertainty*. When asked to evaluate the various options, experts are instructed to consider uncertainty and the extent to which external factors could influence the performance of each option.

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[427] DM incorporates multi-criteria mapping, which is a decision-support tool developed earlier by some of the creators of DM - see Burgess et al. (2007), Stirling (1994), Stirling and Mayer (2001).

The group meeting promises to further facilitate the provision of expert opinions that acknowledge uncertainty. Before such a meeting takes place, the opinions provided by each expert are transcribed in a booklet, which is distributed to each participant. Thus, in the case that any interviewee misrepresented their hypotheses as well-established facts, the meeting would provide an opportunity for the other experts to bring that issue to light.

At first glance, DM might seem too complex and resource consuming to be routinely employed by real-world clinical care resource allocation agencies. However, there are clinical care resource allocation agencies that already involve experts through procedures that strongly resemble DM. As we will see with regard to the prospect of review by other experts, real-world agencies might even be able to overcome problems affecting DM.

NICE's health technology appraisal exemplifies the analytical approach to expert opinion elicitation advocated by DM. NICE's appraisal of health technologies is split into three phases. The process starts with the scoping phase, when the specific questions that NICE has to answer are defined. Next, the assessment phase is devoted to the collection of expert evidence about clinical and cost effectiveness. In the appraisal phase, the appraisal committee takes a decision as to whether the health technologies under consideration should be covered under the NHS. In what follows, I focus on the assessment phase, when expert opinions are supplied.

NICE's appraisal committee provides the suppliers of both clinical- and cost-effectiveness evidence with a *template* of the questions to be answered and the perspectives to be adopted in answering them. This template goes into details and covers a wide array of topics. For example, the template makes it clear that only costs to the NHS and, when applicable, personal and social services are relevant to the assessment of cost effectiveness.

Regarding costs, the template goes as far as dictating which drug price lists must be consulted in the case of primary care, secondary care and the like. The template requires that health benefits should be analysed in terms of QALYs and, more specifically, through EQ-5D data. The template also specifies that actual patients must have classified health states while the general public must have rated the quality of life associated with each state. Furthermore, the template discusses issues such as the appropriate comparator interventions in the analysis of clinical effectiveness, the discount rate to be applied to future benefits and the presentation of data.[428] In sum, evidence suppliers are left with limited leeway in preparing expert opinions. Consequently, they are deprived of opportunities not only to obfuscate uncertainty but also to disguise values and vested interests as scientific opinions in order to steer the appraisal process in certain directions.

As we saw earlier in this section, vague concepts put obstacles in the way of the acknowledgement of uncertainty. NICE tackles this problem by providing a *glossary* of key concepts as an appendix in its guide to the methods of health technology appraisals.[429] Furthermore, the template provided by NICE draws explicit attention to the possibility of uncertainty. A distinction is made between uncertainty about modelling assumptions, uncertainty about data sources and all other possible sources of uncertainty. Moreover, the template spells out the strategies that evidence suppliers should employ to overcome as much as possible the deficiencies in the evidence base.[430]

The Federal Joint Committee (FJC) is often described as the German counterpart of NICE. The function of the FJC is to determine which

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[428] NICE (2013a, 28–55).
[429] NICE (2013a, 77–93).
[430] NICE (2013a, 47–49).

interventions must be covered by the benefit package under the statutory sickness funds. Similar to NICE, the FJC is committed to ground its decisions on the best evidence available – to receive assistance in the assessment of evidence, the FJC has also established a distinct agency, which is the Institute for Quality and Efficiency in Health Care. There is one respect in which the FJC takes the analytical approach to expert opinion elicitation further than NICE. Indeed, the FJC is even more committed than NICE to a strict evidence-based approach to the appraisal of the clinical effectiveness of new drugs.

The appraisal of new drugs by the FJC starts with producers submitting evidence of additional health benefits over the comparator drug. Like NICE, the FJC specifies how to deal with such issues as the appropriate comparator and relevant costs and benefits. Furthermore, the FJC requires that producers should submit a meta-analysis of the clinical studies available. Specifically, producers are required to focus on the clinical trials that form the highest level of the hierarchy of evidence endorsed by the proponents of evidence-based practice. Hence, producers should demonstrate the existence of additional benefits by means of "randomised, blinded, and controlled direct comparison studies, whose methods correspond to the international standards of evidence-based medicine and which are carried out on populations or under conditions, which are representative of and relevant for the usual treatment situation and which have been conducted compared to an appropriate comparator".[431] If it is impossible to identify a sufficient amount of studies at the highest level of evidence, a clear justification for that fact must be provided. In sum, it appears that the endorsement of the evidence-based doctrine has led the FJC to implement a radical version of the analytical approach displayed by NICE, further limiting the leeway to

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[431] See the FJC's rules at http://www.english.g-ba.de/downloads/17-98-3042/Chapter5-Rules-of-Procedure-G-BA.pdf (last accessed 14/10/2014).

obfuscate uncertainty.

Turning to the prospect of review by other experts, NICE appears to have perfected the strategy proposed by DM. During the assessment phase of the appraisal of health technologies, different groups of experts either submit evidence or comment on whether the evidence supplied by other groups is valid. Manufacturers and sponsors are asked to submit evidence concerning clinical- and cost-effectiveness. The evidence submitted by manufacturers and sponsors is assessed by an independent group of academics, who may also carry out further research into the relevant literature. In addition, there are patient advocacy groups, carer groups and medical professional bodies that are appointed as "consultees and commentators". Consultees and commentators are asked to submit evidence if they believe that a) standard clinical- and cost-effectiveness tools have missed any important element of the quality of life experienced by patients; or b) a comment is in order about the way in which the technology under consideration would fit within current clinical practice. As for the appraisal phase, the appraisal committee includes numerous experts in relevant disciplines.[432]

The idea that peer pressure facilitates the acknowledgement of uncertainty as advanced by DM is not entirely convincing. As we saw in section 9.4, groups of experts may be as willing as individual experts to hide uncertainty from the general public. However, NICE has added an important element to the equation: different groups of experts should serve distinct, if not conflicting, aims. Indeed, much of the reason for the existence of the independent assessment group lies in the need to check the evidence submitted by sponsors and manufacturers. Patient advocacy groups, carer groups and the medical profession are instructed to check whether the other

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[432] NICE (2013a, 21–27). Also the FJC engages different groups of experts in the assessment of evidence, which is often carried out in conjunction with the Institute for Quality and Efficiency in Health Care - see Institute for Quality and Efficiency in Health Care (2013).

groups have missed anything. Finally, the experts who are members of the appraisal committee are expected to be committed to the mission of NICE. Therefore, they assess the evidence available from a unique perspective. In sum, a system of *checks and balances* is in place to make sure that experts stick to their role as suppliers of the best knowledge available.

In addition to uncertainty, several of the procedural arrangements that have been discussed so far also go some way towards facilitating the acknowledgement of disagreement among experts. Indeed, employing different groups of experts during the same resource allocation process counters the tendency of experts to silence themselves if their opinion clashes with the views of the majority. For one thing, it is likely that, at most, loose ties connect the members of the different groups of experts employed by an agency such as NICE. Thus, different groups can disagree with one another with little fear of loss of recognition and other sanctions that characterise disagreement within the same group.[433] Furthermore, experts are unlikely to believe that voicing their disagreement with the conclusions of other groups equates to disrupting the work of the whole. As in the case of NICE, the task of the various groups should be defined in almost antagonistic terms, so as to depict disagreement as furthering the work of the whole.

The design of a resource allocation agency such as NICE could be perfected to further encourage experts to voice disagreement. The mission statement and methods documents of that agency should propose a *specific understanding of what it is to be a team player* with regard to the experts involved in the decision-making process. Following Cass Sunstein, team players should be defined as those who maximise the likelihood that the group is right, even at the cost of going against the consensus of other

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[433] See Perron Tollefsen (2006) on how to contrast groupthinking in expert deliberation.

experts involved in the process.[434] Moreover, those who hold the *highest positions* (e.g. chairpersons) in the deliberations of expert groups should be instructed to stress the importance of expert disagreement, stimulate dissenting views and refrain from expressing any determinate opinion until the final stages of deliberation.[435] Of course, mission statements, methods documents and chairpersons should be careful to distinguish the sort of disagreement that furthers the work of the agency from instances of disruptive disagreement, e.g. those rooted in the ego of participants.

As helpful as the design of resource allocation agencies may be, the tendency to hide uncertainty and disagreement is rooted in the shared culture of our societies. Indeed, it is widely (although erroneously) believed that uncertainty and disagreement are alien to good scientific practice. The need to address the popular image of science is at the basis of the argument that deliberative democracy must establish a general level of deliberation about science and policy. The aim of the next section is to discuss how to implement the right sort of deliberation at the general level.

10.3. Deliberation at a general level

The focus on the design of clinical care resource allocation agencies must be coupled with the effort to encourage the right sort of deliberation at a more general level. This section explores deliberation at the general level, starting from the opacity of scientific communities before turning to the tendency to hide uncertainty and disagreement.

Society at large should find a way to identify the communities of expertise that are worthy of the public's trust. Specifically, society should provide public reasons in support of the expert communities whose

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[434] Sunstein (2005b, 1012–1013).

[435] Sunstein (2005b, 1020) and Perron Tollefsen (2006, 46).

members participate in clinical care resource allocation and political decision-making more in general. Section 9.3 demonstrated that the analysis of the track records of expert communities constitutes a first source of evidence for lay citizens to evaluate the trust placed in those communities. Moreover, public reasons supporting the trustworthiness of an expert community can be derived from the analysis of the extent to which the internal arrangements of that community foster integrity and the accumulation of new knowledge.

How can we translate into practice the idea that societies should give sufficient public reasons to trust clinical researchers, health economists and any other expert community involved in clinical care resource allocation? My response is that societies should build upon a method of dialogue between science and society that has become increasingly important during the last two decades, namely *upstream public engagement*.

Following a number of high-profile failures in the dialogue between science and the public such as genetically-modified crops, an increasingly large number of scientists and politicians have accepted that the public should be engaged early in the development of new lines of scientific research. The difference with more traditional approaches to public engagement lies in the idea that government agencies and private corporations should not be content to engage the public after a line of research has been pursued a good deal. In other words, discussion should not be limited to the alternative uses of technologies that have already been developed.

The aim of upstream engagement exercises is not simply to educate the general public about scientific practice. For many, the main point of upstream public engagement is to open up deep questions about science.[436]

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[436] Stirling (2008).

My suggestion is that societies should build upon the idea that upstream public engagement is meant to enable the public to *see through science*, as in the title of a publication by James Wilsdon and Rebecca Willis.[437] Upstream engagement exercises should become an opportunity to critically analyse the trustworthiness of the expert communities involved in clinical care resource allocation and political decision-making more in general. When members of the public are engaged in discussion about new research possibilities, part of the deliberative effort should be devoted to the analysis of the scientific communities involved, from their track records to the internal arrangements preserving their integrity and ability to pursue new knowledge.

A whole range of agencies in several countries has been experimenting with upstream public engagement. Such on-going practices constitute an excellent platform for deliberating about the trustworthiness of expert communities. In the U.K., the Department for Business, Innovation and Skills funds the Sciencewise Centre for Public Dialogue in Science and Innovation. The Sciencewise Centre promotes public engagement exercises when policy decisions involve science and technology.[438] Turning to research funding, Research Councils UK are explicitly committed to engaging the public with scientific research.[439] Moreover, there are individual research councils that have been particularly active in promoting public engagement. An excellent case in point is provided by the Medical Research Council, which is very relevant to my analysis of clinical care resource allocation. Until 2007, the Medical Research Council had an Advisory Group for Public Involvement. Formed by members of the public, the Advisory Group for Public involvement was involved in activities

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[437] Wilsdon and Willis (2004).

[438] http://www.sciencewise-erc.org.uk/cms/ (last accessed 14/10/2014).

[439] http://www.rcuk.ac.uk/pe/ (last accessed 14/10/2014).

including board strategy meetings and research reviews. In 2007, the Advisory Group for Public Involvement was substituted by a Public Panel, which provides guidance on broad issues such as biobanks and motor neurone diseases.[440] The Sciencewise Centre, Research Councils UK and the Medical Research Council should continue to involve the public early on in the discussion of research priorities. Moreover, they should redirect part of this deliberative effort to the critical analysis of the trustworthiness of the expert communities involved.

Ideally, upstream engagement activities should be placed in a broader deliberative context. A fully satisfactory analysis of the trustworthiness of expert communities can only be expected if links exist to *representative institutions* and *the media*. Further deliberative arenas, in addition to upstream engagement exercises, would enable societies to put together a much greater number of public reasons supporting the trust placed in the communities of expertise whose members participate in resource allocation.

At this point, it is worth reiterating a comment made in section 8.3, where my analysis of the implementation of public reason was taking a turn analogous to the one that my argument is taking here. So far, the aim of this chapter has been to show that my theory can be implemented by building upon established practices without forcing any radical change in the way in which our societies are organised. However, politicians and the media appear to create problems for the implementation of my conception of deliberative democracy. Politicians are likely to be ambivalent about the prospect of engaging in any in-depth discussion of scientific disciplines. Notoriously, most politicians are keen on science only to the extent that science is capable of providing unambiguous and irrefutable evidence in support of their political goals. However, the image of science entertained

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[440] http://www.mrc.ac.uk/public-engagement/public-involvement/ (last accessed 14/10/2014).

by such politicians would be rejected by any in-depth discussion of what science really is.[441] As for the media, they have a strong interest in creating hype and sensation. Thus, it is often the case that the media have strong incentives to misrepresent scientific research and findings.[442] Therefore, the recommendations that I intend to make with regard to representative institutions and the media are likely to be more difficult to implement and involve greater changes than the other recommendations made in this chapter.

As demonstrated by initiatives such as the Sciencewise Centre, steps have already been taken to implement the idea that the outputs of upstream engagement exercises should be incorporated into the political process. According to the proponents of upstream engagement, however, closer ties with representative institutions should be created. Wilsdon and Willis suggest that the outputs of upstream engagement exercises should be discussed between MPs and their constituents, examined by all ministers and given time for debate in parliament.[443] James Wilsdon, Brian Wynne and Jack Stilgoe propose that a new commission, half of whose members could be drawn from the general public, should be created to advise the government on emerging technologies and society.[444] If implemented, these proposals would create other venues where the trustworthiness of expert communities could be examined. Moreover, close links between upstream public engagement and political actors are important for another reason. If the internal arrangements of a particular expert community were found lacking, strong links to representative institutions would make it easier to introduce changes.

The media have the potential to make a substantial contribution to the

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[441] Henderson (2013, 16–68).

[442] Henderson (2013, 69–98).

[443] Wilsdon and Willis (2004, 58).

[444] Wilsdon et al. (2005, 56–58).

critical analysis of the track records and internal arrangements of expert communities. The media could help arouse the interest of the public in upstream engagement exercises. Moreover, journalists could launch their own investigations into the workings of the communities of expertise that participate in clinical care resource allocation and policy-making more in general. However, the media coverage of science has attracted severe criticism. Among other concerns, numerous media channels serve partisan economic and political interests, which may have vested interests in misrepresenting science.[445] To tell the whole truth, the problems posed by the partisan interests behind the media go well beyond the misrepresentation of science.[446] Thus, there is room to argue that societies should make every effort to disentangle at least part of the media from any close link to political and economic interests. Something akin to the system of *public licenses* employed in the case of the British Broadcasting Corporation could serve as a good starting point. The media operating under the system of public licences should be required to offer a certain amount of the responsible investigative content that contributes to the critical analysis of expert communities as dictated by deliberative democracy.[447]

In the previous paragraphs, I presented the deliberative network comprising upstream engagement exercises, representative institutions and the media as part of the solution to the problem posed by the opacity of expert knowledge to laypersons. However, the deliberative arenas where the trustworthiness of expert communities should be analysed can also be employed to attack the cultural assumptions behind the tendency of experts to hide uncertainty and disagreement.

Before the trend towards upstream engagement started, public

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[445] Anderson (2011, 154–155).

[446] Habermas (2006).

[447] For more on the role of public licences in my account of deliberative democracy, see section 8.3.

engagement exercises tended to focus on the *measurable* risk attached to the *well-defined* alternative uses of a given technology. In contrast, the supporters of upstream engagement are keen to stress that the focus on the earliest stages of research forces participants to acknowledge uncertainty and disagreement as intrinsic to scientific knowledge.[448] If the discussion is about emerging technologies, it is virtually impossible for the scientific establishment to hide how tentative science is at that stage. Thus, upstream engagement activities offer a unique opportunity to challenge entrenched but unrealistic assumptions about the role of certainty and agreement in science.

Upstream engagement exercises should pay explicit attention to the gap between the popular image of science and actual scientific practice. If close links were created between upstream engagement, representative institutions and the media, the message emerging from upstream engagement exercises would be amplified. Moreover, representative institutions and the media could provide further venues for questioning the popular image of the role of uncertainty and disagreement in science. A more realistic understanding of science would spread. Step by step, experts would feel less compelled to hide disagreement and uncertainty when involved in policy-making. At least in the long run, this outcome promises to have a positive impact on the acknowledgement of uncertainty and disagreement by experts involved in clinical care resource allocation and political decision-making more in general.

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[448] Wilsdon and Willis (2004, 15–19).

10.4. Conclusion of the thesis

In this final section, I would like to pull together the most important lines of argument that I proposed in my thesis. The main aims of my work were a) to defend the idea that clinical care resource allocation is a matter for deliberative democratic processes and b) to investigate what is required by deliberative democracy in this context. I started my argument by making a procedural case for deliberative democracy in clinical care resource allocation. I argued that the procedures for clinical care resource allocation should implement equal respect for the autonomy of individuals. Deliberative democracy is uniquely able to implement equal respect and autonomy – but only if it is understood in the right way. Thus, I turned to the analysis of the general requirements of a conception of deliberative democracy that is meant to implement equal respect for the autonomy of individuals. I suggested that such a conception of deliberative democracy calls for public reason, public involvement, transparency, accuracy and revisability.

The general requirements of deliberative democracy helped me to identify the most important criticisms that may be levelled against my idea that clinical care resource allocation is a matter for deliberative democratic procedures. I took issue with the influential idea that a narrow view of scope is required by any conception of deliberative democracy that involves a commitment to public reason. Next, I responded to the critics of transparency in clinical care resource allocation. Finally, I criticised the argument that the importance placed on fair procedures prevents deliberative democracy from providing guidance about the substantive values that should be employed to allocate resources. I argued that public reason imposes severe constraints on the use of substantive values, coming down to 1) a commitment to well-constructed arguments, 2) the minimisation of the strongest complaint and 3) a strong presumption for the compartmentalisation of different areas of governmental activity. These three sources of substantive recommendations served as the basis for the analysis of substantive values carried out in the following chapters.

I devoted the rest of my thesis to two rather specific topics that had emerged as particularly salient during my discussion of the justification and general requirements of deliberative democracy in clinical care resource allocation. I started with the ability of public reason to provide determinate answers to questions concerning the substantive values that should govern clinical care resource allocation. I critically analysed, one by one, a number of values that are commonly proposed as suitable to govern clinical care resource allocation, so as to identify which values are upheld and which ones are rejected by public reason. Out of a long list of values, public reason only upheld priority to the worst-off and ability to benefit, framed by the idea of specialness of clinical care and constrained by cost. Moreover, I demonstrated that the four values upheld by public reason lend themselves to be made into a decision-support tool capable of providing useful guidance to resource allocation decision-makers.

Next, I turned to the implementation of the use of public reason in dealing with substantive values. I put forward a number of interventions on the design of resource allocation agencies. Most notably, I argued for the insulation and, therefore, the depoliticisation of the vast majority of clinical care resource allocation decisions. In this way, I made it clear that the arguments advanced throughout my thesis are meant to apply mainly to administrative agencies. At the same time, I claimed that attention should be paid to how we can make representative institutions and the media more deliberative, so as to spread a positive attitude towards public reason.

The second particularly salient topic concerned the tensions surrounding the involvement of scientific experts in resource allocation decision-making. I argued that the problems posed by the opacity of expert opinions to laypersons can be overcome if resource allocation agencies provide indirect justifications for expert evidence, i.e., justifications based on the expertise and honesty of those who provide expert evidence. This process of indirect justification should be backed by the use of a number of strategies that lay citizens can employ to assess whole communities of expertise. To overcome another source of tension, I demonstrated that laypersons have all the necessary resources to discuss what resource allocation decisions should be made in the face of uncertainty and disagreement about scientific matters.

I concluded my thesis by discussing how to implement the conclusions that I had reached with regard to expert involvement. Similar to my analysis of the implementation of public reason, I suggested that interventions on the design of resource allocation agencies should be complemented by a focus on a more general level of deliberation, involving upstream engagement exercises, representative institutions and the media.

Throughout my thesis, I levelled criticisms at a wide variety of approaches to clinical care resource allocation. However, my main critical reference was certainly Norman Daniels, who is the most important theorist in the field of clinical care resources allocation. When I was discussing the justification of deliberative democracy, I pointed out that Daniels mistakenly thinks of procedural fairness as nothing more than a remedial value. While examining the general requirements of deliberative democracy, I argued that Daniels fails to appreciate the importance of public involvement as an integral part of any account of fair procedures for clinical care resource allocation. Towards the end of my analysis of the substantive implications of deliberative democracy, I claimed that the ability of my theory to find a superior alternative to both utilitarian and intuitionistic approaches to decision-making distinguishes my proposal from Daniels's accountability for reasonableness. Even though it is widely thought that Daniels's model provides a faithful translation of John Rawls's theory into the domain of clinical care resource allocation, I employed a Rawlsian argument to show that Daniels's inability to strike a middle way between utilitarianism and intuitionism constitutes a serious flaw.

In addition to the points that I have just listed, there is room to level a final criticism at Daniels if we take a bird's-eye view of my analysis of the ability of deliberative democracy to provide determinate answers to substantive issues. This criticism is directed against a step playing a pivotal role in Daniels's argument. According to Daniels, available theories of clinical care resource allocation are unable to provide a satisfactory solution to value conflicts between aggregation of benefits and considerations such as priority to the worst-off, individual ability to benefit and fair chances to be treated. Hence, Daniels believes that theorists have no choice but to be agnostic about the substance of clinical care resource allocation decisions – theorists are forced to focus almost exclusively on the fairness of the decision-making process.[449]

However, my thesis argued that public reason filters out numerous substantive values populating the conflicts envisaged by Daniels; most importantly, all aggregative values and the idea of fair chances were shown to be inconsistent with deliberative democracy. Moreover, I demonstrated that there is little room for conflicts that public reason cannot resolve among the four values that are upheld by deliberative democracy, which are priority to the worst-off, ability to benefit, specialness of clinical care and cost considerations. Indeed, specialness and cost only play a framing and a constraining function, respectively. Thus, there is no possibility of conflict

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[449] For a detailed reconstruction of Daniels's argument, see section 1.2.

among those two values or between them and the other values upheld by public reason. Furthermore, I suggested that there is scope to develop a method for combining priority to the worst-off and ability to benefit so as to solve at least most of their conflicts on the basis of public reason. In stark contrast with Daniels, deliberative democracy was found to be able to keep together procedural fairness with a commitment to provide determinate answers to hard questions concerning the substance of clinical care resource allocation.

To fully appreciate the original contributions of my thesis, it is worth looking more closely at two substantive recommendations of deliberative democracy. Such recommendations are particularly important because they clash with two key elements of the so-called "population-level perspective", which dominates the debate on clinical care resource allocation.[450] First, while discussing the idea of specialness, I argued that when it comes to justice and health, clinical care plays a different function from public health and interventions on the social determinants of health. Specifically, clinical care protects health by attending to complaints that a) come from individuals and b) include the strongest complaints that anyone may have in relation to health. Moreover, I demonstrated that the function played by clinical care places it uniquely close to public reason, which involves a commitment to the minimisation of the strongest complaint. In sum, my argument sounded a strong note of caution about the widespread tendency to lament that both scholars and decision-makers have traditionally paid too much attention to clinical care and too little to public health and social determinants.

Second, my thesis argued that the basic principle of equal respect for individuals and the commitment to the minimisation of the strongest

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[450] See section 1.2.

complaint make deliberative democracy inconsistent with the use of any aggregative value. Hence, I rejected the widely-held view that cost effectiveness is an integral part of any sensible framework of substantive values for clinical care resource allocation. In place of cost effectiveness, I put forward a prioritised-list approach to cost. Interventions should be ranked according to the strength of the complaint they respond to. Next, funding should be allocated starting from the top of the list and moving down until all money is depleted.

In conclusion, it seems fair to say that my conception of deliberative democracy provided a fertile approach to the discussion of how clinical care resources should be allocated. Indeed, looking from the perspective of deliberative democracy at the general requirements of resource allocation processes, the substantive values to be employed and expert involvement allowed us to make progress in understanding how those issues should be solved. Given the usefulness of my conception of deliberative democracy, it would be interesting to further develop such conception and bring it to bear on new topics.

One option could be to tackle the specification issues that I had to bracket when I was discussing the substantive values that are consistent with deliberative democracy. How should past, present and future health states be factored in when decision-makers need to calculate how badly-off a patient is? Who should rate the quality of life associated to different health states in the process of determining how badly-off patients are and how much they can gain from treatment? These and similar questions are extremely important because they can really test the limits of the ability of public reason to provide answers to substantive issues.

Another option could be to bring my conception of deliberative democracy to bear on the allocation of public health resources. My discussion of specialness suggested that when we leave clinical care resource allocation and enter the domain of public health ethics, it becomes less problematic to argue that available resources should be allocated with consideration to the way in which social goods other than health are distributed. Furthermore, we saw that a heavy burden of disease and other forms of disadvantage, such as low income or racial discrimination, tend to cluster together. Thus, it seems fair to argue that the strongest complaints against public health resource allocation come from the groups in which a heavy burden of disease combines with other factors to create multiple jeopardy. Given the link between public reason and the minimisation of the strongest complaint, it seems that those groups should be high on the priority list of a deliberative democratic approach to public health resource allocation. A possible research project could explore whether this line of argument is tenable and what its implications are.

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