

© 2011

Sarah Clark and Albert Weale

Social Values in Health Priority Setting<sup>1</sup>

Background paper

January 2011

## **Introduction**

The purpose of this paper is to provide a 'think piece' for participants at the NICE Workshop on 'Social Values and Health Priority Setting' (London, 17-18 February 2011). It assumes that the setting of health priorities requires value judgements and that these judgements are social.

Justifying social value judgements is an important element in any public justification of how priorities are set. The paper reviews a number of such social values and identifies questions that need to be resolved when these values are used in priority setting decisions. Every health care system resolves these questions in one way or another; the issue is how far that is done in the light of justifiable social values.

By definition, to set priorities is to give higher importance to some things over others. Priority setting in health aims to determine what, in the context of limited resources, is most important. Priority setting is undertaken at many different levels of decision making, from the highest levels of health politics and management, where overall resources are allocated, to decisions at the bedside where the value of interventions has to be assessed. Priority setting is not unique to the public sector. Private insurance engages in priority setting when it determines entitlements and exclusions. In the rest of this paper, we focus on decisions at the policy level (whether national or more local) rather than decisions at the level of the individual clinician.

The aim of ethical priority setting must be to produce a distribution of healthcare resources that it is justifiable. As Daniels points out: "when we knowingly and deliberately refrain from meeting

---

<sup>1</sup> This paper is part of the programme of work for the ESRC Professorial Fellowship on 'Social Contract, Deliberative Democracy and Public Policy' (RES-051-27-0264). It is one of a planned series of policy briefings on 'Social Values and Public Policy' offering a normative policy analysis of topical policy issues. It was prepared for the National Institute of Clinical Excellence (NICE) in advance of a workshop on social values and priority setting in health.

some legitimate needs, we had better have justification for the distributive choices we make.”(Daniels, 1996; 317). Determining when and how decisions on priority setting are justifiable involves values relating to *process* (that is, *how* decisions are made) and to the *content* and *reasons* used (that is, *what* decisions are made and *why*).

There are many values that may be involved in priority setting in specific contexts, including legality, faithfulness to constitutional provisions and respect for international obligations. However, this paper focuses on three general process values which can be seen and assessed in any system:

- Transparency
- Accountability
- Participation

In terms of content, there are also a number of values, but here we identify:

- Clinical effectiveness
- Cost effectiveness
- Justice/Equity
- Solidarity
- Autonomy

## **Process Values**

### ***Transparency***

Decisions about priority setting in health are inevitably controversial, because setting priorities means privileging some needs over others – as such, some legitimate needs will invariably go unmet. Hence, there will be disagreement about priority setting, and about the reasons upon which decisions are based. Making decision arrangements as transparent as possible allows all the relevant parties – from patients to politicians to clinicians – to evaluate how decisions have been arrived at.

Where people lose out as a result of priority-setting decisions it may be thought important, as a matter of principle, that they are able to see that both the reasons upon which such a decision is based, and the processes involved in reaching it, are fair. What is thought fair varies according to whether the context is one of a publicly or privately financed health system, but the *value* of transparency remains the same. Judgments about the fairness of decisions cannot be made without access to the relevant information for those who have an interest in the outcome of decisions, whether directly as a patient or indirectly as a citizen or as someone who pays health insurance.

As well as being a principle, transparency also has an *instrumental* value – that is, it is practically useful. It can facilitate trust in decision-makers and can put clinicians, patients and the public in a better position to accept priority-setting decisions as fair – even (and especially) for those who may lose out – if they can see that those decisions are based on appropriate and relevant reasons.

Transparency in decision making is often associated with *explicit* priority setting, where reasons and criteria are openly stated, and where it is clear who makes the decisions and how they do so. Where there is explicit priority setting, priorities are explained and understood so that people know about the principles which underpin their chances of getting the care they require (Butler, 1999; 203-4). If the process of priority setting is transparent, advocates of explicit priority setting suggest, it is more likely to be efficient, equitable and fair, minimizing the possibilities for misuse of resources, for biased political or clinical decisions, for local variation in provision, or for the exercise of partial or uninformed views.

Contrary to this, *implicit* priority setting, where decision-makers, decision protocols and criteria are not openly stated, tends to obscure decision processes from public and patient scrutiny: what is not known cannot be challenged or criticized, and those who do what is not known are themselves not known, and so cannot be held responsible. As such, implicit priority setting is a less publicly visible way to go about dealing with constraints on resources, and by virtue of that may hinder public understanding and acknowledgement of the real limitations that exist with regard to resources in healthcare.

Nonetheless, some suggest that explicit priority setting could jeopardize the stability of the political process of resource allocation, by creating disaffected groups of people denied treatment who then lobby and agitate for different, or simply more generous, resource allocations

(Mechanic, 1995; 310). However, this situation highlights the importance of the transparency not only of *decisions*, but of the *reasoning and criteria* behind decisions: the problem of disaffection and agitation by interest groups could be seen as a symptom of what Daniels terms the ‘legitimacy problem’ which arises when priority setting *decisions* become increasingly explicit, but yet the *reasons and reasoning processes* behind them remain unclear to the public (Daniels, 2000a).

Priority setting has been described as an ‘iterative’ process – that is, one where decisions are revisited and revised in light of new information, to correct errors or to adapt to a changing healthcare environment. To uphold the value of transparency, decisions should be revised openly in order to “offset the perception that they are simply the result of power plays made behind closed doors rather than the material outcome of new knowledge” (Daniels et al, 2000).

Further, whilst the demand for transparency might arise most in the context of publicly funded systems where it is necessary as an element of democratic accountability, it is also relevant in privately funded systems of healthcare: it must be a presupposition of any debate about the distribution of any type of burden or benefit that what one party claims as a benefit really is such. Hence, when private providers claim to be providing a benefit for which they should be fairly recompensed by funders of either a public *or* private nature, that claim should be capable of being substantiated. In practice this means that both clinicians and pharmaceutical manufacturers should be willing to accept procedures designed to test both the clinical and cost effectiveness of what they are supplying (see for example, Bae and Lee, 2009; Mitchell, 2002).

### ***Accountability***

Accountability exists when one party justifies and takes responsibility for its activities to another party. Being accountable in health priority setting means having the obligation to answer questions regarding decisions about which interventions are prioritized and why. It means providing public justification for decisions. We can think of accountability in terms of three questions: who, what, and how? (see Emanuel, 1996). The answers to each of these questions will vary considerably depending on the nature of the health system in question.

In terms of ‘who?’, we can ask both who is held accountable, and who does the holding to account: that is, who *answers* the questions about decisions, and who *asks* the questions about decisions. Those who should answer the questions, quite obviously, will be those who make the decisions, but there are a range of possibilities here: central or local government, civil servants, health professionals, medical institutions, or insurers all may make decisions and be the actors appropriately held to account, depending on the system in question. Additionally, other parties such as pharmaceutical companies may have important roles in influencing decisions and there may be good grounds for holding them to account too (see Bae and Lee, 2009; Mitchell, 2002).

A special issue of accountability arises when a key decision making body is an independent or quasi-independent expert body like NICE. In such cases it can be argued that transparency and accountability are especially closely linked, since the fact of being independent places a special burden on the organisation to justify its reasoning for particular decisions – since making those decisions is its very *raison d’être*. In short, the question of who has the duty of accountability may be closely linked to how stringent the burden of accountability is.

There is a range of possibilities as to who asks accountability questions: in publicly funded systems, accountability may be thought to be owed primarily to patients, the public and health professionals. However, the courts have also become important actors in holding decision makers to account and, in some countries, in enforcing what are considered by some to be basic legal rights to healthcare as aspects of the even more basic human right to life (see Rueda, 2010). In privately financed systems, employers and individual payers will likely be those who ask the questions of insurers, although insurers themselves also hold healthcare providers to account, so in this respect they are both asking questions of accountability as well as answering them.

The ‘what?’ question, we might phrase as ‘accountability for what?’. The main answer to this in publicly funded systems has traditionally been the spending of taxpayer’s money: the government or, where they are separate, the government agencies that set priorities, are responsible for how public funds are allocated and for the standards of service that are provided (Weale, 2003). In privately funded systems, financial accountability is also primary: private and corporate payers will likely want to ensure that their money is being used responsibly, and will also likely want to know why premiums are set at the level they are.

However because, in both publicly and privately funded systems, decisions about priority setting involve value judgements as well as purely economic ones, financial accountability alone does not provide a comprehensive answer to the questions that patients, insurance payers or the public might ask as to why priorities are set as they are. There is growing evidence that accountability for *value* judgements is increasingly sought by the public in many countries in addition to the more conventional forms of financial accountability (see Dolan et al 2005; Dolan and Tsuchiya, 2006 and Schwappach, 2002). Accountability around value judgments can be difficult to assign however, since even where priority setting is explicit in economic terms, it may not be so in respect of social values - not least because those who rely on such social values in their decision making may not recognise or name them as such. These judgements have been referred to as a 'hidden curriculum' in priority setting: although values underlie all priority setting choices to some degree, implicit social value judgements are often hidden in technical or economic criteria (see Hoedemaekers, 2003; Kenny and Joffres, 2008).

With regard to the last 'how?' question, two general *types* of accountability can be identified

The first type is simply about providing information on decisions, and might include the provision of empirical information or narrative descriptions of decisions. This type of accountability characterizes basic monitoring and implies a one way transmission of information from the accountable decision makers to those to whom accountability is thought to be owed. The second type of accountability, however, moves beyond simple reporting of decisions, and is concerned with explanations and justifications: that is, it is not just about what was decided, but why and for what *reasons*. Where explanation and justification is requested and offered, the process of accountability can become more of a two-way dialogue rather than a one-way transmission of information (Schedler 1999). This latter kind of dialogue can build public trust by signalling that decision makers are interested in the views and well-being of patients and the public (see Gilson 2003).

### ***Participation***

As with the value of accountability, we can ask a series of basic questions about participation:

- why is it a value?
- who should participate?
- how is effective participation conducted?

Why, then, is participation a value in decision-making process of healthcare priority setting? As we have already seen, these decisions are fundamentally value judgments – and value judgments will inevitably vary between individuals and groups within society. As such, it has been suggested, the decision making process is more likely to be *legitimate* if it enables different interests to contribute via participation (Saltman and Figueras, 1997). In particular, those who come out of a decision less well than others may feel better able to accept it if they have at least had their voice heard. Greater legitimacy in this respect may also promote trust and confidence in decision makers.

However, there is a further reason for participation within democracies: it is commonly thought that citizens should be able to participate in decision making about issues that affect their vital interests – and access to appropriate health care is clearly one of the most important of such interests. Health priority setting, then, is an obvious candidate for a democratic mandate (Doyal, 1998). This is all the more salient in systems where those who make priority setting decisions are not themselves elected or formally accountable to the public (Mort et al, 1999). However, in many systems, decisions will be substantially affected – directly or indirectly - by those who hold political power and, as such, in a democracy such actors should be able to justify their decisions in open argument.

Inclusivity can be seen as a mechanism for improving the transparency of decision-making, for sharing accountability for priority setting, and for engaging powerful constituencies in a constructive manner - for example, leaders of the medical profession. However, an appropriate balance between inclusiveness and decision-making effectiveness is necessary – too many people can make decision-making cumbersome, too few people can make decision-making insufficiently informed or leave some constituencies feeling excluded (Martin, Abelson and Singer, 2002). There is also the thought that sharing accountability for decisions may in fact be a way of elected representatives or appointed professionals shirking their responsibility (Weale, 2006). Further, significant conflict over values can arise out of participation, leaving the possibility that decision-making becomes paralysed, if there is no established way to negotiate such conflicts.

However, there are also important instrumental reasons for involving the public in making decisions about priority setting: they are users or potential users of services and, as such, are the only people who can truly bring the user point of view and communicate to decision makers how

they will judge the services about which decisions are being made; they can make important contributions to the technical quality of decisions via their direct experience of, for example, pharmaceuticals; and they can also make important contributions in terms of identifying the full range of relevant moral considerations and providing an opportunity for decision makers to elicit the views of the public on questions of moral controversy and to thereby strengthen both analysis of the issues and, ultimately, decisions (Tantivess et al, 2009; Weale, 2006; pp 37-42;). There is also evidence that the public, in some countries at least, want to be involved in priority setting decision processes and especially want to have their views taken into account on the non-technical aspects of priority-setting relating to value judgements (see Ryan et al, 2001; Wiseman et al, 2003).

Who, then, should participate? The most obvious answer is that patients – the people who are directly affected by priority setting decisions - should participate. However, the patient perspective is not the only relevant one: it has been argued that the perspective of the citizen should also be engaged in order to gain a wider and more inclusive view of the issues (see Coote 1997; Weale 2006). Engaging only patient groups can exclude those who are not current users but who may use the services in the future, and ignores the fact that members of the public have a dual relationship with decision makers - they are both service users and citizens, but in each capacity, people have different interests and these can conflict.

The narrow perspective of a patient who has a particular personal interest in the service which she receives may conflict with the broader, longer-term interest of a citizen who is a taxpayer, a voter, and a member of any number of communities: as such, they are interested in not only what happens to themselves but also to their families, neighbours and fellow citizens, both in the present and in the future (Lenaghan, 1999). It has been suggested by some that there is an increasing tension in some healthcare services between the push to increase individual rights and ‘consumer interests’ in healthcare and the need to make collective decisions which are in the interests of the citizen and the wider community – and the two may often conflict (Mort, 1996; Jordan, 1998). As Montgomery has argued “Some aspects of health care decisions, such as resource allocation, are not easily amenable to individual rights of choice, as it is necessary to maintain an overview to assure the just distribution of resources” (Montgomery, 1996).

Whilst these reasons for including the citizen’s perspective as well as the patient’s apply most obviously in circumstances where decisions are being made about publicly funded healthcare



services, the same principle holds for systems dominated by privately funded care: focusing on the narrow perspective of the patient as the immediate user of services will exclude the wider perspective of all payers of insurance premiums who will have a view not only of their own immediate interests, but also of the fairness of the schemes into which they and their co-payers contribute and of the equity of access to healthcare which they and others enjoy now or in the future.

As to the 'how' of participation, the mechanisms by which the public can be engaged in decision making are numerous: for example, public consultations, surveys, citizens juries, community forums and deliberative polls (Weale, 2006). These mechanisms are characterized, variously, by two broad dimensions: information and deliberation (Harrison and Mort, 1999). Deliberation occurs where participants have the opportunity to discuss and interact with others about the questions under consideration – for example, in a focus group. Consultation is non-deliberative where participants respond as individuals with no opportunity for discussion – for example, in an opinion poll or a public consultation. Further, participation can be informed or uninformed: participants are informed when they are provided with some sort of factual information about the topic before being asked to give their opinion, but when an opinion is sought which relies on an instant response, this is uninformed (Harrison and Mort, 1999).

There are some difficulties with both consultative and deliberative methods of participation. In consultative approaches, obtaining a representative view can be difficult, the methodology of asking people to rank lists of treatments and services to be prioritized which is sometimes used, can be crude in relation to the complexity of the decision to be made, opinion polls can reach large numbers of people, but they are superficial and reflect relatively uniformed views, and surveys do not allow enough time or information for the public to consider the consequences of the trade-offs inherent in decisions (Bowling, 1996). In deliberative approaches, there are questions as to how representative the inevitably limited number of people involved can be: meaningful deliberation must at the same time involve enough people to produce statistically significant results which can be inferred to the larger population, but also not be so large as to make genuine deliberation impossible. There are also questions of selection of participants and the need to guard carefully against bias in the sample of those who attend deliberation. However, overall, research has suggested that mechanisms with informed and deliberated components enhance participation and promote the ability to produce substantive recommendations (Jordan, 1998).

Nonetheless, there can be considerable challenges to achieving meaningful deliberation: clear plans must be made for how input is going to be utilized and how its use is going to be communicated to the public; special opportunities may have to be provided for disenfranchised groups to participate; and measures put in place to guard against the danger that professional expertise will be privileged and participants therefore left unable to contribute on an equal footing (see Bowie et al, 1999; Kenny et al, 2008).

## **II Content values**

### *Clinical effectiveness*

Most simply, effectiveness might be taken to mean “the ability of a procedure to accomplish a given end” (Weale, 1988; 49). The value of clinical effectiveness is a fundamental one in priority setting decisions, given that it is clearly undesirable to waste limited resources on procedures that are ineffective or, worse still, that may actually do harm. The positive aim of the principle, then, is to ensure that health benefits are achieved.

One way of measuring effectiveness is in terms of the advantage an intervention has over the relevant alternatives, so the benefit or effect of a treatment is the difference it makes to the health state of patients over and above the benefits provided by alternative treatments (see eg. NICE, 2004). Analysis of clinical effectiveness can be drawn from the results of randomised controlled trials, controlled observational studies, expert opinion or consensus views, and it can measure both relative and absolute effectiveness, as well as uncertainty of effect (ibid).

There are, however, some practical issues around the principle of clinical effectiveness. One of these concerns the different attitudes towards established interventions and innovative ones. Whilst new interventions may be routinely subjected to rigorous assessment, old interventions may not be so tested, even though they may be less effective both in terms of clinical benefits and cost than the new therapies. Another, related issue here is that there may be little existing evidence about the effectiveness of some new treatments, and whilst it seems entirely proper that clinical effectiveness should be assessed according to the highest levels of scientific validity, this

may mean waiting for long periods of time before a treatment is fully proven as either effective or ineffective, if indeed it is ever proven to be one or the other with any acceptable degree of certainty, since even the best randomised controlled trials will not always produce straightforward results. There may be trade-offs here between making an uncertain benefit available to some, or withholding benefit from all for a long time, pending further investigations.

The level of benefit at which interventions are considered to be clinically effective is also an issue. In instances where an intervention provides only very small benefits, or where it provides small benefits to a very limited section of a patient group, for instance because of contra-indications widespread within that group, the question of whether the intervention can be deemed 'clinically effective' may be one which must be answered by means of a value judgement as to *how much* benefit is required for a treatment to be classed as 'clinically effective' rather than by reference to scientific evidence as to whether *any* benefit is provided.

Moreover, clinical effectiveness may not be all that is of concern to patients and their relatives. The simple fact that 'something is being done', even if it only provides a small or uncertain benefit, may be very important to people. For example, diagnostic procedures may be undertaken to reassure patients even when a clinician considers that doing so may not produce any obvious clinical benefits. And as the example of AIDS and AZT treatments to slow the development of the virus showed, people can feel it urgent to have rapid access to a potentially helpful intervention even if its clinical effectiveness is as yet unproven.

### ***Cost-effectiveness***

The aim of the principle of clinical effectiveness is to ensure that health benefits *simpliciter* are produced from healthcare interventions; the aim of the principle of cost effectiveness is to ensure that *the most* health benefits are obtained from the available resources.

Cost-effectiveness seeks to establish whether differences in costs between alternative interventions can be justified in terms of the health benefits they respectively produce. As such, opportunity costs are the central concern: the comparison between health gained and health forgone is at the heart of the rationale for cost-effectiveness analysis, such that the benefits provided by a treatment for one set of patients must be more than the benefits foregone by *not*

providing a treatment to another set of patients (see Claxton and Culyer, 2006). By using estimates of health benefits and economic costs that are equivalent across treatments, cost-effectiveness evaluation can, in principle, compare the relative worth of healthcare interventions even if those interventions are quite different. Quality Adjusted Life Years (QALYs) provide a means of doing this. The cost of an intervention includes time and effort required in association with an intervention, as well, more obviously, as material resources, and the benefit of an intervention, clearly, is improved health.

The QALY starts from the uncontroversial position that to add a year to a person's life is a health benefit. Hence, the number of years added to life expectancy must be part of the benefit we take into account when we compare the benefits that different interventions produce. Further, the value of the years added to life is thought to be of equal value, no matter who is the beneficiary – young or old, rich or poor, male or female etc. The important fact here is that *someone* benefits, and no particular importance is assigned to *who* that beneficiary is (Rawlins and Culyer, 2004). And QALYs measure health gain regardless of whether it results from improvement in, or the prevention of deterioration of, health.

That QALYs enable comparisons to be drawn between very different treatments and their outcomes has been seen as of great importance in healthcare and health economics. It is very difficult to deal with questions such as “should we put more money into hip replacements or kidney dialysis?” unless there is some common unit of value in terms of which to weigh the different options against one another. Whilst ‘lives saved’ or ‘deaths averted’ can be used in some circumstances, such measures are not applicable to instances where we have to compare, say, quality of life-improving treatments with life-saving procedures (see Menzel, 1990, Chap. 5; Williams, 1985). Supporters of QALYs also point to their impartiality as a strength of the approach since a year of life has the same value regardless of whose year of life it is (Williams, 1988).

However, there are a number of controversial issues around QALYs which raise questions about the value judgements they involve. One issue is around the subjectivity of how people value health states. The valuation of health states which inform QALYs can be thought to be problematic because there is no reason to expect that different people, different groups of people, or even the same people at different points in their lives, will value health states in the same way, and so questions arise over how to draw fair conclusions from varying valuations. Choosing the

average value, for instance, will mean that minorities whose preferences deviate markedly from the mainstream will not have those preferences represented fairly in the health related quality of life indices which are used to make quality of life adjustments in QALYs (Weale, 1988; 60).

Further, society influences ideas of what constitutes minimal or optimal well-being, or what constitutes a minimal or severe burden of disease, and this may influence both individual patient judgments and the judgments of those who make decisions on priority setting, given that their assessment of the potential harmful effects of ill-health is influenced by conceptions of what is acceptable or normal with regard to disease burden and quality of life, as well as by social stigmas attached to certain conditions (Nordenfelt, 1995). Some may also think that it is important to consider whose burden or quality of life is judged – just the person with the illness, or that of her family too? Ill-health can have a detrimental effect on family-members, harming their quality of life as well as the sufferer for whom they may be caring, for example in instance of physical or mental disability or patients with degenerative diseases such as Alzheimer's (Hoedemaekers and Dekkers, 2003).

Another issue is of value judgement in relation to QALYs is their reliance on the conception of need as capacity to benefit. This conception values the outcomes of health interventions, rather than the 'inputs' – in this case need – to which they respond, and logically entails that the more one can benefit from a treatment, the more one needs it. However, it has been argued that this fails to distinguish between those whose needs stem from medical misfortune and those whose needs consist simply of a capacity to benefit (Weale, 1988). Many people might say, for example, that they could benefit considerably from cosmetic enhancements of one sort or another, but that hardly seems a need equal to that of the seriously ill, even if many more QALYs could be produced by cosmetic surgery.

### *Justice/Equity*

The term 'justice' is often used by political theorists and philosophers for the value that economists call 'equity'. The difference in terminology is confusing because 'equity' is also used in jurisprudence to refer to the principle that like cases should be treated as like. In what follows we refer to 'justice' but start from the principle that like cases should be treated as like.

One way of thinking about justice is to start with the principle that like cases should be treated as like and unlike as unlike (Weale, 1978; 11). That is, patients who are alike in *relevant* respects should be treated the same, and those who are unlike in *relevant* respects should be treated in appropriately different ways. In decisions about healthcare, the most obvious condition of likeness of patient groups is likeness of their illness: so it is equitable for two people who have cancer to be treated similarly - the *relevant* characteristic here is having cancer. *Irrelevant* characteristics to take into account in this situation might be the gender or ethnicity or sexual orientation of the patients: to base priority setting decisions on these considerations would be unjust (inequitable in the non-economist's sense) because they make distinctions between persons which are *irrelevant* to their health condition. However, it is not always easy to distinguish which characteristics of persons are relevant and which are irrelevant.

According to one argument, the 'merit' of individuals based on judgments about their contribution to society can be taken into account – that is, their socio-economic contribution by means of paid labour, child-rearing or caring for dependents (see Mooney 1987; McIntyre et al, 2000). The sense here is that healthcare is a 'reward' for making a positive contribution to society. However, the question arises here as to whether healthcare is appropriately thought of as a 'reward' in this way, just as any other form of consumer good or service. Research suggests that citizens of many countries reject this 'rewards' based approach (see Culyer et al, 1982; Culyer, 2001) as an irrelevant characteristic and one which represents a view of health care as a service no different from any other to which monetary wealth gives access, thus ignoring the essential nature of the needs which much healthcare meets. Nonetheless it may be that in some cultural contexts, special significance is felt to be justifiably attached to the health care needs of those with dependent children, not in the sense of reward but rather out of a practical concern that the well-being of others may depend on their health, or of those who are particularly vulnerable or stigmatised (see Wikler, 2004; Youngkong et al, 2010;).

This may in turn lead to priority setting decisions which take into account the age of patient groups, giving greater priority to interventions which benefit those of child-rearing age rather than, say, older people. Some have argued however, that it is fair to seek to provide greater benefits to the young or those of middle age rather than to the elderly – that is, that it is *legitimate* to take age into account in priority setting decisions. One suggestion here – the 'fair innings' argument - is that the elderly have simply already enjoyed more years of life than the young and therefore it is just that we give greater consideration (but not absolute priority) in priority setting

decisions to providing care which can ensure that the young gain a similar number of years of life than to the old who have already had those years (Williams, 1997). Another suggestion is that, if people were to prudently allocate themselves a 'fair lifetime share' of healthcare resources over the course of their lives, they would likely allocate more resources to the periods of their life when they had many projects to fulfil, perhaps have dependents or wish to advance a career – all of which may depend on their being in good health – than to their older years, when most of their personal projects will have been completed (Daniels, 1998; pp88-91). There is also some evidence from research that suggests that there is a preference amongst the public in some countries to prioritize younger patients (see Dolan et al, 2005; Nord et al, 1996; Rodrigues and Pinto, 2000).

There is also a negative version of the 'merit' argument, however, which is more widely debated and suggests that it is relevant to take into account the lifestyle choices of people whose ill-health is related to those choices, for example in smoking, drinking or over-eating (see Cappeler and Norheim, 2005) – that is, that it is equitable to treat people whose behaviour has contributed to their ill-health differently from people whose ill-health has no such association. There are a number of problems with taking these kind of personal responsibility considerations into account: firstly, it can be difficult to determine how far personal responsibility extends - that is, to decide how much of an individual's behaviour is their own responsibility and how much is the result of other factors such as social background or genetics (Michaels, 2006; Cappeler and Norheim, 2005). Secondly, there is a danger of moralistic value judgments being applied to people's lifestyle preferences when deciding what constitutes risky behaviour in terms of health: why, it might be asked, should some people who indulge in risky activities – for example, smokers or heavy drinkers - be punished, and others – for example, those who enjoy dangerous sports – not? So it may be difficult to determine within the category of lifestyle choice, which of those choices justify treating people with the same condition differently and which do not.

The issue is complicated, however, when features of persons which might at first be thought irrelevant, emerge as factors which affect their capacity to benefit from interventions. On the one hand, it could seem illogical to insist on providing a treatment to a patient population whose ability to benefit is limited, purely in the interests of justice – here the value of justice might conflict with those of cost and clinical effectiveness. However, on the other hand, those patients may be able to benefit *somewhat* from an intervention, although perhaps not as much as other groups. For example, people who are obese might be less likely to respond well to a certain form

of treatment even though their disease is as severe or more severe than in non-obese groups. Limiting treatment to those most likely to respond well would be likely to improve cost effectiveness, but it would reduce justice. This situation shows the conflict between a utilitarian, health maximising approach and the concept of justice: the desire to maximise total benefit from available resources must be weighed against the wish to provide equitable treatment on the basis of need. Taking into account factors which affect capacity to benefit, such as age, disability, or lifestyle could seem analogous to determining treatment on the basis of deservedness (Michaels, 2006).

Some conceptions of justice can also justify weighting some considerations more heavily than others if they are concerned with redressing inequalities – that is, with minimizing differences in health among population groups. The concern here is often with those who are worst off either in health terms or in terms of social disadvantage: for example, people whose illnesses are especially severe, who suffer multiple conditions, or who are otherwise vulnerable – this can include, for instance, those who are at or near the end of their lives, or those who are disadvantaged in socio-economic terms. A concern with these inequalities may lead, for example, to prioritizing end of life care, or targeting interventions at those with co-morbidity factors, or focusing some resources on preventative rather than curative interventions in order to tackle health inequalities at the outset where they are related to socio-economic background.

The idea of justice also applies to how healthcare is financed – notably, the effect that different systems of financing have on social or health-related inequalities. Three main sources of funding are involved in many systems: tax-based revenues, insurance premiums and out-of-pocket payments (and there are often out-of-pocket payments to be made in both tax-based and insurance-based systems). Tax-based schemes are more equitable if their structure is more progressive, and insurance-based schemes are thought to be more equitable if they are community-rated, rather than risk-rated, since risk-rating shifts the burden to those at higher risk of illness (Daniels, 2000). However, it is out-of-pocket costs that tend to be the least equitable, since they shift burdens to the sick, rather than pooling risks and burdens of payment across whole populations – either taxpayers or insurance premium payers (there are implications here in terms of the value of solidarity - see below).

In general, inequalities in the coverage and quality of care – what has been termed ‘tiering’ (Daniels, 2000) – explicitly reduce the justice of systems in so far as they privilege certain groups



over others, and will likely work to the *health* disadvantage of those who are already amongst the most socially and economically disadvantaged. As Daniels has suggested, some kinds of tiering are worse than others in terms of justice: for example, it may be less serious if a small but wealthy group does better than others, provided the others do relatively well – for example, the private-sector insurance sector in the UK - than if an already disadvantaged group is left worse off than the rest of society – for example, the lack of insurance amongst the working poor in the US, or failing to deliver a minimal benefit package to the vast majority of the population whilst the top 5% enjoys excellent private insurance, as in Colombia (ibid).

### ***Solidarity***

In general terms, the principle of solidarity implies a commitment to the idea that all members of society will stand together and will not exclude or leave anyone behind, no matter how needy or disadvantaged. However, solidarity can take different forms: it can take a contractual form, such as membership of a welfare state or of a basic health care package, where it is primarily expressed through a willingness to share the financial risks of ill-health, or a more generalized humanitarian form which is expressed in decisions which give priority to those who are worst-off in health terms (Hoedemaekers and Dekkers, 2003). As such, the principle can be manifested either in concern about the negative effects of healthcare financing overall or in the process of priority-setting.

The two forms of solidarity converge on the issue of cost-sharing or co-payment, particularly in systems which are mainly publicly financed: the effect of a decision to make a certain intervention the subject of a co-payment is to put that intervention beyond both the bounds of financial solidarity and health solidarity. The relevant intervention may be either so expensive (whether clinically effective or not) as to impose an unjustified burden on the pool of risk-sharers, or its benefits may be either sufficiently uncertain and/or trivial for it to be justified in terms of health solidarity.

However, the two forms of solidarity can also conflict: for example, in the Netherlands, concern about the disproportionate financial effects on lower socio-economic groups of increasing levels of co-payment has led to great reluctance to reduce the publicly provided healthcare package. But this has contributed to a considerable rise in health care costs and long waiting lists, leaving the possibility that those who are worst off in health terms may not be receiving treatment as quickly

as they otherwise might if the funding that would be provided through co-payment were made available (Hoedemaekers and Oortwijn, 2003).

The value of solidarity is also highlighted in responses to the tension between the principles of medical need and cost-effectiveness, and in how those principles are ordered. Where humanitarian solidarity is valued particularly highly, medical need may be prioritized over all other considerations, including cost-effectiveness. This has been the case in Sweden where, although scarce resources have called for cost-effectiveness considerations to be taken into account in priority-setting, such is the social and political commitment to solidarity in the form of meeting medical need – which itself is measured by the severity of medical conditions – that issues of cost-effectiveness are sidelined (in fact they are stated in Swedish law as being secondary to meeting medical need) (Bernfort, 2003). Of course, this can lead to the undesirable situation where ineffective treatments aimed at serious conditions are always given higher priority than treatments for less serious conditions, no matter how effective these are. That is not to say, however, that exclusive attention to considerations of cost-effectiveness would be preferable since it would blind decision makers to issues of solidarity which, certainly in this country context, are highly salient.

### *Autonomy*

In contrast, a system which privileged autonomy rather than solidarity may take a wholly different view on a range of issues, from personal responsibility to cost-sharing to cost-effectiveness. The concept of autonomy has a varied set of meanings (see Feinberg, 1986) but it is often used to refer to the ability of individuals to be self-directing and to make decisions for themselves about important matters. The notion of autonomy goes hand in hand with that of responsibility: if one is to be self-directing and make important choices, those choices will be one's own and thus also one's own responsibility.

Market-based approaches to healthcare tend to value autonomy more highly than other, notably solidarity-based, approaches. This might affect how priorities are set in a number of ways: it might be thought best that individuals are left to decide individually about how they spend their money and what healthcare goods and services they choose to purchase, and so perhaps only the most severe and urgent medical needs will be prioritized for public funding, with the rest being met either by insurance premiums or ad hoc out of pocket expenses. As we have already seen

however, there will likely be negative implications for justice from such an approach. However, some would argue that if health care priorities are set *collectively*, they will necessarily ignore what matters to some individuals with regard to their own medical need and treatment preferences, and that these preferences should carry more weight and individuals should have greater opportunity to express them. It is doubtful whether this argument can carry much weight however, since where a health care budget is limited, giving full scope to individual self-determination will inevitably lead either ultimately back to collective health care choices in order to secure economies of scale or to long waiting-lists – and there is arguably little self-determination to be pursued whilst one sits on a waiting list.

However, it is possible to conceive of ways in which space could be made for greater individual autonomy without necessarily leading to negative effects on justice. For example, priorities could be set such that aspects of care which are not central to the clinical effectiveness of interventions are left to the individual to select and make the appropriate ‘top up’ payment. So, for example, different standards of accommodation or general ‘hotel’ services of hospitals could be offered at different levels of cost: if health and effectiveness of health intervention is the primary concern from a justice point of view, then this might seem unproblematic. As Culyer has commented, “if equity of distribution derives from the ethical importance attached to health, then not all health-affecting care services have equal equity significance and may be irrelevant” (Culyer, 2001; 277). Further, there could be distinctions to be made according to the effectiveness of treatments: those which are highly effective and medically necessary could be prioritized, leaving the less effective or medically ‘unnecessary’ ones to be paid for by individuals. However, this runs into problems of how to define what is medically necessary, and how apparently marginal factors like different standards of hospital accommodation can affect patient’s overall levels of well-being and their recovery from interventions. So, whilst they might be ‘strictly’ irrelevant from the perspective of the values of justice and effectiveness, it is not clear that this can be guaranteed in practice with real human patients.

## **Conclusion**

Important values underlie both the ‘process’ and ‘content’ elements of decision making in health priority setting.

The ‘process’ values of transparency, accountability and participation are closely linked: transparency forces governance to be more careful so as to stand up to public scrutiny – it is, in this way, the instrument of accountability and justifiability: if transparency is lacking, it will be difficult for decision-makers to be held accountable in any meaningful way since those who wish to hold them to account will not have the relevant knowledge with which to do so. One way to advance transparency may be to increase participation, especially in an area like health where citizens (as well as patients) are directly affected by decisions and where they may have much to contribute to governance. In turn, increasing participation may be a pre-condition to increasing transparency.

In terms of ‘content’, value judgments are often hidden in technical criteria such as clinical and cost effectiveness measures. However, there is a complex interplay between the value and technical components of health priority setting decisions as well as between the values themselves – different conceptions of the values of justice and solidarity in particular are significant in how technical judgments are worked out and how the various reasons within decisions are weighted. The degree to which a society values solidarity will have a large impact on how it weighs justice considerations in decisions, and what form those considerations take, particularly in determining which characteristics of persons are relevant - and therefore legitimate - to take into account in priority setting decisions and which are not.

As such, a purely technical approach to quality of life measures that does not acknowledge the values it assumes will likely be lacking in some way – and it will make accountability for, transparency and participation in those value judgments difficult if not impossible. The Oregon priority setting experiment where a ranked list of interventions was produced on the basis of cost-effectiveness alone, produced considerable counter-intuitive effects (Hadorn, 1991), and further, there is evidence to suggest that the public in some countries at least wish for both accountability and participation in relation to value judgments.

The process and content values are closely related for the following reasons. There is no one knock-down argument that will persuade those holding to different positions on questions of content, for example the relevance of age considerations, to agree on an answer. The issues are complicated and often turn on fine judgements. In this situation it is important to have processes that resolve such disagreements in a fair way, and the process values address this concern. Different countries will resolve these issues in different ways, partly depending on their level of

economic development, and therefore the relative urgency of different needs, and partly depending on their culture.

## Bibliography

- Bae, E and Lee, E (2009) Pharmacoeconomic Guidelines and Their Implementation in the Positive List System in South Korea, *Value in Health* 12: 3; pp 36-41
- Bernfort, L (2003) Decisions on Inclusion in the Swedish Basic Health Care Package—Roles of Cost-Effectiveness and Need *Health Care Analysis, Vol. 11, No. 4*
- Bowie C, Richardson A, Sykes W. (1999) Consulting the public about health service priorities. *British Medical Journal* 311, pp115–8.
- Bowling A. (1996) Health care rationing: The public's debate. *British Medical Journal* 312, pp 670–4.
- Brock, D (1995) Justice and the ADA: Does Prioritizing and Rationing in Health Care Discriminate Against the Disabled?, *Social Theory and Practice* 1995 pp159-185
- Brock, D (2007) Healthcare resource prioritisation and rationing: why is it so difficult? *Social Research* 74:1; p143
- Butler, *The Ethics of Healthcare Rationing*, (Sage, 1999)
- Campbell, A (2003) 'NICE or Nasty: Threats to justice from an emphasis on effectiveness', in Oliver, A (ed) (2003) *Health Care Priority Setting* (London: The Nuffield Trust)
- Cappelen, A and Norheim, O (2005) Responsibility in health care: a liberal egalitarian approach. *Journal of Medical Ethics* 31: pp476-480
- Claxton, K and Culyer, AJ (2006); 'Wickedness or folly? The ethics of NICE's decisions', in *Journal of Medical Ethics*, 32 pp373-377
- Coote A. (1997) Direct public and patient involvement in rationing, New B (ed) *Rationing Talk and Action in Health Care*. BMJ, 1997. pp. 158–164.
- Culyer AJ, Maynard AK, Williams AH. (1982) Alternative systems of health care provision: an essay on motes and beams, Olson M (ed.) *A new approach to the economics of health care*. (Washington: American Enterprise Institute)
- Culyer, A (2001) Equity – some theory and its policy implications *Journal of Medical Ethics* 27: pp275-283
- Daniels, N (1988) *Am I My Parents' Keeper?* (Oxford: Oxford University Press)

Daniels, N (2000) Benchmarks of fairness for health care reform: a policy tool for developing countries, *Bulletin of the World Health Organisation* 78: 6

Daniels, N (2000a) Accountability for reasonableness in private and public health insurance in Coulter, A and Ham, C (eds) *The Global Challenge of Health Care Rationing* (Buckingham: Open University Press).

Dolan, P and Tsuchiya, A (2006) The elicitation of distributional judgements in the context of economic evaluation in Jones, A.M (ed) *The Elgar Companion to Health Economics* (Cheltenham: Edward Elgar Publishing)

Dolan, P, Shaw, R, Tsuchiya, A and Williams, A (2005) QALY maximization and people's preferences: a methodological review of the literature, *Health Economics* 14:2, pp197-208

Doyal L. Public participation and the moral quality of healthcare rationing. *Qual Health*  
Emmanuel, E and Emmanuel, L (1996) What is accountability in healthcare? *Annals of Internal Medicine* 124; pp229-239

Care 1998;7:98–102.

Feinberg, J. (1986), *The Moral Limits of the Criminal Law: Harm to Self*, Volume 3, Oxford:Oxford University Press.

Gauri V. 2001. *Are incentives everything? Payment mechanisms for health care providers in developing countries*. Health and Population, Nutrition, Fertility, and HIV/AIDS Working Paper No.2624. (Washington, DC: World Bank)

Gilson L. 2003. Trust and the development of health care as a social institution. *Social Science and Medicine* 56: 1453–68.

Grimshaw, JM and Hutchinson, A (1995) Clinical practice guidelines – do they enhance value for money in healthcare? *British Medical Bulletin* 51: pp927-40

Hadorn, D (1991) Setting healthcare priorities in Oregon. Cost effectiveness meets the rule of rescue, *Journal of the American Medical Association* 265:17, pp2218-25

Hoedemaekers, R and Dekkers, W (2003) Concepts in Health Care Priority Setting, *Health Care Analysis*, 11: 4

Hoedemaekers, R and Oortwijn, W Problematic Notions in Dutch Healthcare Package Decisions *Health Care Analysis*, 11:4

Jordan J, et al. (1998) Health needs assessment. Whose priorities? Listening to users and the public. *B MedJ* 316, pp1668–70.

Kenny, N and Joffres, C (2008) An Ethical Analysis of International Health Priority Setting *Health Care Analysis* 16; pp 145-160

Maceira D. 1998. *Provider payment mechanisms in health care: Incentives, outcomes, and organizational impact in developing countries*. PHR Major Applied Research 2, Working Paper

No.2. (Washington, DC: U.S. Agency for International Development, Partnerships for Health Reform Project.)

Martin, D Abelson, J and Singer, P (2002) Participation in health care priority-setting through the eyes of participants, *Journal of Health Services Research and Policy* 7:4

McIntyre D, Gilson L Redressing Disadvantage: Promoting Vertical Equity within South Africa. *Health Care Analysis* 2000 , 8:235-258

Mechanic, D (1995) Dilemmas in rationing health care services: the case for implicit rationing. *British Medical Journal* 310

Menzel, P (1990) *Strong Medicine* (New York and Oxford: Oxford University Press)

Mitchell, A (2002) Antipodean assessment: activities, actions and achievements, *International Journal of Technology Assessment in Health Care* 18; pp 203-212

Montgomery J. (1996) Patients First: The role of rights, Fulford K, Erssen F, Hope T, editors. *Essential Practice in Primary Care*. (Oxford: Blackwell Science)

Mooney G (1983) Equity in health care: confronting the confusion. *Effective Health Care* 1983;1:179-85.

Mooney, G (1987) What does equity in health mean *World Health Statistics Quarterly* 40:4, pp296-303.

Mort M, Harrison S. Healthcare users, the public and the consultation industry.(1999) In: Ling T (ed) *Reforming Healthcare by Consent: Involving Those Who Matter*. (Oxford: Radcliffe Medical Press)

Nord, E, Street, A, Richardson, J, Kuhse, H and Singer, P (1996) The significance of age and duration of effect in social evaluation of healthcare, *Health Care Analysis* 4:2, pp103-111

Nordenfelt, L (1995) *On the nature of health: an action theoretic approach* (Boston: Kluwer Publishing)

Norheim, O (1999) Healthcare rationing – are additional criteria needed for assessing evidence based clinical practice guidelines? *British Medical Journal* 319: pp1426-9;

Rawlins, M and Culyer, A (2004) NICE and its social value judgements in *British Medical Journal* 329: pp224-227; p226

Rodriguez, E and Pinto, J (2000) the Social value of health programmes: is age a relevant factor? *Health Economics*, 9:7, pp611-621

Royal College of Physicians (2005) Response from the Faculty of Old Age Psychiatry of the Royal College of Psychiatrists to the NICE appraisal consultation document: donepezil, rivastigmine, galantamine and memantine for the treatment of Alzheimer's disease. [www.rcpsych.ac.uk/members/membership/responseNICE\\_March05.pdf](http://www.rcpsych.ac.uk/members/membership/responseNICE_March05.pdf) (accessed 29 Nov 2010).



- Rueda, P (2010) Legal language and social change during Colombia's Economic Crisis, in Javier Couso, J, Huneeus, A, Sieder, R (eds) *Cultures of Legality* (New York: Cambridge University Press)
- Ryan, M, Scott, D, Reeves, C, Bate, A, van Teijlingen, E, Russell, E, Napper, M, Robb, C (2001) Eliciting public preferences for healthcare: a systematic review of techniques, *Health Technology Assessment* 5:5, pp1-186
- Saltman B, Figueras J. (1997) *European Health Care reform: Analysis of current strategies*. (Copenhagen: World Health Organisation)
- Schedler A. (1999) Conceptualizing accountability. In: Schedler A, Diamond L, Plattner MF (eds). *The self-restraining state: power and accountability in new democracies*. (Boulder, CO: Lynne Rienner Publishers)
- Schwappach, D (2002) Resource allocation, social values and the QALY: a review of the debate and empirical evidence, *Health Expectations* 5:3, pp210-222
- Tantivess, S, Teerawatanon, Y, Mills, A (2009) Strengthening cost-effectiveness analysis in Thailand through the Establishment of the Health Interventional and Technology Program, *Pharmacoeconomics* 27:11; pp 931-945
- Wagstaff, A, Van Doorslaer, E (1993) Equity in Health Care: concepts and definitions. In Van Doorslaer E, Wagstaff A, Rutten F (eds) *Equity in the finance and delivery of health care: an international perspective* (Oxford: Oxford University Press)
- Weale, A (1988) *Cost and Choice in Healthcare* (London: King Edward's Hospital Fund)
- Weale, A (1995) The ethics of rationing in Maxwell, R (ed) (1995) *Rationing Health Care* (Edinburgh and London: Churchill Livingstone)
- Wikler, D (ed) (2004) *Fairness and Goodness in Health*. (Geneva: World Health Organization)
- Williams AH (1988). Economics and the rational use of medical technology, Rutten F and Reiser SJ, (eds.) *The economics of medical technology*. (Berlin: Springer)
- Williams, A (1985) Economics of coronary bypass grafting. *British Medical Journal* 291: pp326-329
- Williams, A (1988) Ethics and efficiency in the provision of healthcare, in Bell, J and Mendus, S (eds) (1988) *Philosophy and Medical Welfare* (Cambridge: Cambridge University Press)
- Wiseman, V, Mooney, G, Berry, G, Tang, K (2003) Involving the general public in priority setting: experiences from Australia, *Social Science and Medicine* 56:5, pp1001-1012
- Youngkong, S, Baltussen, R, Tantivess, S, Koolman, X, and Teerawattanon, Y (2010) Criteria for priority setting of HIV/AIDS interventions in Thailand: a discrete choice experiment *BMC Health Services Research* 2010, 10:197 doi:10.1186/1472-6963-10-197