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Anthony J. Culyer
University of Toronto
University of York
The Rimini Centre for Economic Analysis (RCEA)

EVIDENCE, UNCERTAINTY AND THE POLICY PURSUIT OF FAIRNESS

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**EVIDENCE, UNCERTAINTY AND THE POLICY PURSUIT OF
FAIRNESS**

Anthony J Culyer

Ontario Research Chair in Health Policy and System Design

University of Toronto; Professor of Economics University of York (England)

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Abstract

The article considers the interrelationships between ideas of fairness and ideas of evidence, and how progress in the policy pursuit of fairness in health and healthcare has been plagued by problems with vocabulary, vagueness as to values, deplorable absences of relevant empirical knowledge and failure to address appropriate means of making decisions about fairness in health and healthcare. Specific proposals are suggested as possible ways forward.

Introduction

By any yardstick the record of jurisdictions the world over in achieving fairness in health care systems is dismal. Even in countries ostensibly committed to the idea of fairness in health and health care, the commitment has in fact been weak. A common fallacy has been that, having established easy access to health care, the fairness agenda is thereby delivered whereas, at best, the financial barriers have been lowered¹. It was naively assumed that ‘need’ would determine who got what and when they got it and that resources would follow need. Interest in finding out whether this was indeed so was virtually zero. The first appraisal of the famously fairness-committed NHS in the UK, founded in July 1948, occurred in 1970 when the NHS was already 22. Until then nobody had bothered to find out whether resources were any more fairly distributed than before the Second World War (Cooper and Culyer 1970). In fact it was hard to detect any improvement. This is a common finding (Hanratty et al. 2007). Most measures taken ostensibly to address unfairness are actually seriously flawed and few are ever trialled or subjected to any systematic examination of their effectiveness. Most fail when judged by simple criteria like ‘do they benefit the poorest or the most in need?’²

What accounts for this dismal state of affairs? My thesis is that there are several comorbidities: lack of shared vocabulary (meanings of words), lack of an agreed set of values, lack of evidence as to what would be effective means of redressing inequities, and lack of suitable societal instruments of decision-making.

The heart of the problem is the absence of a clear understanding and agreement about what is meant by ‘fairness’. What one may mean by ‘fairness’ has not been resolved in any generally satisfactory way, despite its having been at the centre of philosophical enquiry for centuries and of political debate in the context of health for a century (Culyer and Wagstaff 1993, Culyer 2007). ‘Evidence’ is also important not merely because it is fashionable in policy circles but because without it policy will be less effective, more easily corrupted by self-interested lobbyists, and more likely to do harm than good (Sackett et al. 1996). However, even here lie important problems of

¹ I do not wish to underplay the significance of the lowering or removal of barriers to health care. It is a tragedy, however, when their removal is seen as the be-all and end-all of policy.

² See, for one of countless examples, Castro-Leal et al. (2000).

meaning (what counts as ‘evidence’?), of relevance (policy cannot be based *only* on ‘evidence’), of availability (mostly there isn’t any evidence anyway) (Ezzo et al. 2001) and of role (what are the respective roles of policy advisers and policy makers?). Uncertainty is all-pervasive, not only because we do not always know what we are talking about, and not only because we do not always agree, and not only because there is usually so little evidence, but also because we do not know how to measure and weigh the uncertainties and the ambiguities. Finally, ‘policy’ – given the foregoing, what kinds of policies, if any, does it make sense to pursue?

Assume as a first approximation that the purpose of having publicly financed health care is for its consequences for health rather than, say, for its consequences for the satisfaction of mere preferences (Culyer 2009), or for the employment of health care workers, or for ensuring the existence of profitable and indigenous pharmaceutical or insurance industries. This assumption is made to stop already complicated matters from being even more complicated. Better health, *more fairly distributed*, is what we ought to seek. Better health care, *appropriately distributed* is one means towards that goal³.

Distributive justice in health and health care

Muddle over meanings was the first reason for lack of real progress. Policy makers *must* determine what, for policy purposes, is to be meant by ‘fairness’ and be able to why that meaning is appropriate in our particular jurisdiction, today -- accountable ‘policy makers’ rather than professional thinkers, for the professional thinkers (mostly academics) are mere citizens with no more right to impose their understandings or values than any other. Academics may, however, be able to help those who are accountable to the citizens⁴. I shall try to do this by offering some common ‘meanings’, complaining about most of them, and forcing the issue by suggesting that one far outshines the rest and ought to be a major candidate for being the gold

³ This is plainly to be consequentialist, though not necessarily utilitarian. So I shall assert that ‘only an end can justify the means’. After all, if not an end, what else could possibly justify a means? (Culyer 1992a).

⁴ In effect, I am assuming that we can categorize public decision making in hierarchical terms. See, for an excellent statement Mookherjee (2006). For present purposes, the main point is to establish the greater legitimacy of ‘the minister’ over ‘the analyst’ as a decision maker.

standard. Whatever definition policy makers choose is bound to be controversial. That is inescapable. But a fudge or ill-informed choices are entirely escapable.

It is easy to forget some useful basics when discussing fairness. An important set is Aristotle's (1972) distinction between horizontal and vertical fairness:

There are the two great Aristotelian principles:

- *Horizontal Fairness*: the *equal* treatment of people who are equal in a relevant respect
- *Vertical Fairness*: the *unequal* treatment of people who are unequal in a relevant respect.

It is easy but dangerous to focus only the first, forget the second, and imagine that fairness always concerns equality (of something).

But what should we mean by 'treatment' and what might count as 'relevant respects'?

The following are commonly asserted criteria that might amount to Aristotelian 'relevant respects'. I shall follow each with some comments, mainly on why the criterion in question will not do⁵:

Risk of mortality and morbidity: equally ill or at-risk populations ought to be treated the same; the sickest ought to get more. This is what some people mean by 'need': absolute health or health deficit relative to some normal expectation.

Objection: if we take 'treatment' to be receipt of health care then this takes no account of the good, if any, the health care resources do. Much health care has low productivity and some of similar productivity has higher cost, denying other uses of available resources to achieve even more health, or greater, fairness. Mortality and morbidity may signal a health deficit, even a need for health, but they cannot signal a need for *health care* unless that health care will confer a net health benefit. Even then, the benefit is likely to vary from one population group to another. The sickest might absorb huge resources to little benefit for themselves but reducing what is available for others more able to benefit. Applying this interpretation may thus actually widen health disparities, especially amongst those at neither extreme of the distribution.

⁵ The points that follow are elaborated in greater depth in Culyer and Wagstaff (1993), Culyer (2001) and Culyer (2007).

Capacity to benefit: those with equal ability to benefit from health care ought to get the same; those with high capacities ought to receive more.

Objection: this goes some way towards meeting part of the first objection but not all of it. It neglects opportunity cost. Two groups may have the same capacity to benefit but one need more intensive and costly care to achieve the same health gain thereby reducing the resources of the system to address health disparities or other greater capacities to benefit. Those with the higher capacities to benefit are likely to be those who already have reasonable health and who are not deprived in other dimensions of well-being, so that treating them ‘more’ might well again increase inequality.

Need: equal treatment of people with equal needs; more favourable treatment of people with greater needs.

Objection: if need is not measured in terms of mortality or morbidity, or the size of their deficit relative to some norm, or in terms of their capacity to benefit from health care then *what* is it that is needed and *for what*?

Desert: people of equal deservingness ought to be treated the same; those of greater deservingness ought to get more.

Objection: the idea of ‘deservingness’ is highly ambiguous. What does one need to do (or to think?) to be deserving, and who might judge? Are the rich deserving by virtue of their riches (high productivity)? It also leads to victim blaming – the idea that if ‘lifestyle choices’ have bad consequences for health the chooser deserves to be penalized. A trace of a good argument lies in the claim that people with harmful lifestyles may not respond well to treatment (the claim is sometimes made about smokers) but this is not an argument about fairness but about clinical effectiveness, and belongs elsewhere⁶.

⁶ But see, e.g. Persaud (1995).

Resources themselves: a purely horizontal fairness argument – each ought to have equal access to resources.

Objection: again, regardless of the good the resources do? And, more deeply, why *equal* access? What matters is that needs for health care can be identified and not go undiagnosed for reasons of access barriers, whether financial, geographical, linguistic, ethnic, etc. It is easy rather than equal access that serves the cause of greater health. Barriers that are merely equal are still barriers.

Health: greater equality of health: give priority to those with low health or who are furthest away from the average.

This gets to the heart of the matter and is, of course, the first proposition advanced in this paper: better health, more fairly distributed, is what we ought to seek. Better health *care* appropriately distributed is one means towards that goal. Need, capacity to benefit, and easy access are *means not ends* to this end. Resources that are not necessary to meet a need are not themselves needed.

Greater equality of health

The virtue of greater equality of health is not merely to be asserted but be grounded in reason and with explicit value judgments. One line of reasoning runs like this (Culyer 2001). The ultimate ‘good’ in secular human society is ‘the flourishing human life’. In the usual case, and on any conceivable definition of ‘flourishing’, good health, unlike ‘great wealth’, is a necessary (though not sufficient) condition if one is indeed to ‘flourish’.⁷ I say ‘in the usual case’ because we can all think of remarkable people with the most appalling handicaps who live apparently very full and flourishing lives. But, by definition, they are unusual. That they overcome their disadvantages is what makes them especially admirable. There are no good grounds why the right to flourish ought not be accorded to all and, given that, good health ought, so far as practicable, also to be accorded equally to all.

⁷ I prefer the idea of ‘flourishing’ to explicitly subjective concepts like ‘desire’, ‘happiness’ or ‘utility’ (Brouwer et al. 2008). One reason is that they are normally grounded in a narrow notion of individual ‘tastes and preferences’.

This approach to fairness has important implications of. First, it does *not* imply equality of health care resources; it *does* imply that we must ascertain the impact of health care – and any other health-affecting strategies – on health and its distribution and then dispense the resources accordingly – probably unequally. Second, it does not imply equality of access to health care. Access should be cheap – so that potential health gain can be assessed and acted upon. Third, it implies that health care is not the only significant weapon in the strategy. That almost certainly implies that fairness in health cannot be the property only of ministries of health. Fourth, relatively ineffective health care is not worthy of public subsidy. Fifth, the health care that *is* provided through public subsidy must also be *cost-effective*. The reason is uncomplicated. Effectively, in any period of time, there is a fixed budget for health care. That means that resources devoted to intervention A are not available for *some* other health intervention B. If A is not cost-effective, it is using more resources to achieve a given health outcome than are necessary. Fewer other effective interventions can be provided. That in turn means that less health is being generated than could be and which could be so distributed as to redress further inequities. That in turn means that the ultimate target – flourishing lives as equalised as possible – is being missed. Therefore, not only ought health to be *equitably distributed*, it ought to be *efficiently produced*.⁸

Evidence – establishing effectiveness (and cost-effectiveness)

Decisions ought to be informed by evidence, especially about the ways in which health care and the other determinants of health can have beneficial impacts on the distribution of health in the community. There is a very substantial and quite authoritative literature on the measurement of inequalities in health, health care and health care financing (e.g. Wagstaff and van Doorslaer 2000, O'Donnell et al. 2008). There is a large – but wholly inconclusive – literature on the concept of fairness in health. There is very little at all on the evidence for effectiveness of policies to redress health inequalities (e.g. Gwatkin 2001, Gwatkin et al. 2005, Tugwell et al. 2006).

The general notion of evidence concerns facts in support of a conclusion. It is helpful to think of three types (Lomas et al. 2005, Culyer and Lomas 2006). Most decision

⁸ See Culyer (1992b)

makers view evidence colloquially and define it by its resonance with experience, expert and professional opinion on a matter, political judgment, values, habits and traditions, the interests of lobbyists and pressure groups, and the particular pragmatics and contingencies of a situation. In matters to do with fairness, political prejudgments are a dominant source of this ‘quasi evidence’.

The second and third types of evidence are provided by scientists. Some emphasise context-free universal truths (identified closely with ‘evidence-based medicine’) and others emphasise a context-sensitive role for. Effective action for fairness in health almost certainly involves a range of public health measures as distinct from personal health care but public health, even in the most developed countries, is notoriously short of evidence to support funding decisions⁹. Scientific evidence on context *must* be more than merely medical and can embrace political acceptability and feasibility, attitudes, implementation, organisational capacity, forecasting, social acceptability, economics/finance and ethics. Not all will always be relevant but *some* will always be relevant (given the context). In decisions about fairness in health, all three kinds of evidence are more or less constantly in play – and the evidence about them is largely absent.

Facts never speak for themselves and no evidence is ever complete enough to enable guidance or policies for fairness to be created without further evidence and assessment. Judgment is needed, mere assertion is not - whether professional or amateur. Values need to be made explicit and defended. Each of the following applies, always:

- all evidence needs to be interpreted
- its relevance needs to be assessed
- its quality needs to be assessed
- its applicability in the current context needs to be assessed
- its completeness needs to be assessed
- qualitative evidence needs to be weighed alongside quantitative

⁹ See Abraham et al. (2008) for an unusually proactive and thoughtful approach to behaviour change in the context of public health; more generally see Killoran et al. 2006.

- any technical controversy over its standing needs to be settled
- the precision of estimates of effectiveness needs to be assessed
- the robustness of the results need to be tested by sensitivity analyses
- the evidence, of whatever kind, needs to be infiltrated by values to determine priorities, ‘worthwhileness’ and to specify what ought to be done and by whom.

These characteristics have implications for the *ways* in which policy decisions are made and implemented at all levels.

Deliberative processes

Effective policies for fairness in health require deliberative processes. To be useful a deliberative process must facilitate the combining and interpreting of evidence of many kinds and it should enable them to explain why they decided as they did. It ought to provide a way through which the values of participants can be *transformed* rather than merely aggregated, even allowing participants to change their minds (Lomas et al. 2005, Culyer and Lomas 2006).

When might deliberation be most helpful in achieving a satisfactory outcome? The following often apply in practice and are nearly all present to a greater or lesser extent in matters to do with fairness in health:

- absence of agreement as to what is ‘fair’
- conflict with other values
- some stakeholders’ interests are threatened by evidence
- evidence from more than one expert discipline is involved
- evidence from more than one profession is involved
- there are technical disputes to resolve
- evidence is scientifically controversial
- evidence is incomplete
- evidence is lacking
- evidence gathered in one context (say Europe) is to be applied in another (say BC)
- there are issues of implementability and operational feasibility

- there are political barriers to overcome
- there are issues of short term financial feasibility
- implementation may seriously destabilise other local strategies and priorities
- wide professional ‘ownership’ is desired
- public credibility is desired
- political ‘trust’ is involved (e.g. no unpleasant surprises for ministers; help on how to handle unwelcome or embarrassing evidence).

Uncertainty

There are two broad categories of uncertainty. One relates to things we know, characteristically statistical; the other to things we cannot know in the same way. The most important of these are probably related to ideas. Have we got the right idea about ‘fairness’? Are the right people at the deliberative table? Are we applying the right methodology (the measures of inequality and changes in them, the population covered? How ought we to measure comparative effectiveness of interventions for fairness? How ought we to assess the costs of promoting fairness?).

How ought such uncertainties be handled? Not by any pretence that there is a certainty just waiting to be discovered. Policy matters are not best settled by abstract consideration by an isolated academic (or politician) but collaboratively by involving key partners right from the beginning. The test of appropriateness in handling uncertainty is best seen as a test of the reasonableness of the procedure itself. *Was it reasonable? Was the procedure conducted as it was stated it would be conducted? Did those consulted include all those with a reasonable claim to be consulted? Was the outcome egregiously at odds with the evidence as judged by a reasonable person?* Practically, and in politically controversial decisions, the case becomes easier to make that the decision was not arbitrary even if it was controversial. Its rationale becomes communicable and the end point can be defended as reasonable to reasonable people. In these ways, *both* the process *and* its outcome help to legitimise the decision.

Policy

There are two broad sets of implications for policy: one relating to the objectives; the other to the means of achieving them.

Regarding objectives, there is a powerful ethical argument for embracing both efficiency and fairness as joint objectives of policy: the latter to be judged by the criterion of diminishing health disparities and the former by using only cost-effective means of affecting both health and its distribution. The policy cannot be one owned exclusively by the health ministry but should be one embraced by all ministries whose activities have impact on people's health.

Regarding the means, there is a powerful case for the use of deliberative and participative methods at all levels, not least in order to identify – not necessarily to eradicate – differences in deeply held values. Consensus may be achievable but failure to achieve it ought not to stifle choosing. New decision making arrangements may be needed and the adaptation of those already in existence. In developing and implementing policies for fairness, the need for deliberation is likely to be especially pressing given its strong value content, the uncertainty as to what policies will actually work, and the high probability that policies developed without deep understandings of local conditions, history, cultures, ethnicity, language and politics, and with the active participation of people with such understandings, are policies that will fail.

Any new decision arrangements will generate their own information needs and, in particular, the need for research into the ways in which health care and other determinants of health actually have impact on the people's health. These will inform both decisions at the high provincial levels as well as at the bedside. This is not a researcher's self-serving argument for 'more research' but it is an argument for reappraising the *kind* of research that would be most useful - more on testing external validity, more on fairness itself and the effectiveness of alternative means of achieving it - and for reappraising how research is commissioned and managed.

Conclusions

My aim has been to diagnose the lamentable state of policy in countries aspiring to social justice in health and health care and to identify treatments that might be effective. The aim has been less to persuade than to provoke. So, if the idea here of what fairness ought truly to be about is wrong, let it be exposed and let a better idea

replace it. If it is right – then let us *act* as though it were right. If the claim about the ethics of efficiency is wrong, let that too be exposed and appropriately replaced. Otherwise, let us help ordinary people to comprehend the need for cost-effectiveness in our publicly-funded health care systems. If the suggested character of evidence and how it ought to be used is wrong, let that too be shot down and a better alternative substituted for it. If not, then let us take evidence gathering and dissemination more seriously and much more comprehensively. If the case for deliberation is misguided, let us hear what should replace it and why. If not, then many ministries have a lot of work to do!

I do not ask you to agree with me but, if you do not, your objections are less important than your alternatives. It is time for principles, mine or some others, to be settled so that practical progress can begin.

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