ETHICS
Reconciling conflicting values in health policy

This paper addresses a need that the Policy Futures for UK Health project identified for ethical debate alongside all the complex developments that are usually highlighted in futures analyses of health. Martyn Evans introduces the characteristics of ethical analysis and some of the main approaches to ethics, before examining some of the ethical debates taking place in health today that are likely to influence the future. His paper highlights the competing values that are played out in modern health debates. Chief among them is the tension between individual choice and collectivism or collective welfare, which are to be found in many conflicts and debates - for example, in reproductive technology, debates concerning the end of life, and in tackling inequalities in health. Ethical debates raise more questions than answers but one of the benefits of a futures-orientated project is to question commonly held assumptions. Martyn Evans raises questions for the future about who takes responsibility for health, the moral importance of health policies such as reducing health inequalities, and the preferences for moral values that lie at the heart of health policy.

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POLICY FUTURES FOR UK HEALTH

Edited by Charlotte Dargie

This paper is part of a series written for the Policy Futures for UK Health Project, which examines the future environment for UK health, with a time horizon of 2015. The full series is listed below.

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Reconciling conflicting values in health policy

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Series Editor: Charlotte Dargie

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Charlotte   Dargie

FOREWORD

Since its inception the Nuffield Trust has identified individuals and subjects that would impact on health and health care policy in the United Kingdom, with notable examples being *Screening in Medical Care* [1], Archie Cochrane's *Effectiveness and Efficiency: Random Reflections on Health Services* [2], Thomas McKeown's *The Role of Medicine: Dream, Mirage or Nemesis?* [3], David Weatherall's *The New Genetics and Clinical Practice* [4] and Alain Enthoven's *Reflections on the Management of the National Health Service* [5].

In keeping with tradition and reflecting the more complex issues in health and health care policy today, the Nuffield Trust established a Policy and Evaluation Advisory Group (PEAG), supported by the appointment of a Nuffield Trust Fellow at the Judge Institute of Management Studies at the University of Cambridge, to provide a research and intelligence capability for the Trust.

The Policy Futures for UK Health Project stems from the work of PEAG. It involves examining the future environment for UK health, with a time horizon of 2015. The first environmental scan has resulted in a series of 10 technical papers, which cover the following areas[1]:

1. The Global Context	6. Social Trends
2. The Physical Environment	7. Organisation and Management
3. Demography	8. Workforce
4. Science and Technology	9. Ethics
5. Economy and Finance	10. Public Expectations

Each paper in the series is a stand-alone piece, but has also been used by the project to derive an overview report, which focuses on policy assessment in the light of the environmental scan. Entitled 'Pathfinder Report', the overview report is published separately and will be subject to external consultation[2].

The Policy Futures for UK Health Project and the work of PEAG are ongoing. Further reports and publications will appear in subsequent years. The technical papers will also be revisited and different subjects will be tackled.

The strength of the technical series is in providing a context for analysing health and health care policy for the United Kingdom. Each author has produced an independent piece of work that analyses trends and issues in their subject area, focusing on 2015. The papers enable one to read across the issues, in order to provide a general analysis of health and health care policy, which is lacking in the highly specialised debates that dominate the health world today. They have formed the basis for consultation and discussion as part of the Policy Futures for UK Health Project.

Finally, the Trust is grateful to the members of the PEAG, to Professor Sandra Dawson and Pam Garside of the Judge Institute of Management Studies and to the authors of the 10 technical papers. A particular thanks due to Dr Charlotte Dargie, Nuffield Trust Fellow at the Judge Institute of Management Studies, the author of the Pathfinder report.

John Wyn Owen CB
July 1999

ENDNOTES

1. *Screening in Medical Care: Reviewing the Evidence* A collection of essays with a preface by Lord Cohen of Birkenhead (Oxford: Oxford University Press for the Nuffield Provincial Hospitals Trust, 1968).
2. AL Cochrane *Effectiveness and Efficiency: Random Reflections on Health Services* (London: Nuffield Provisional Hospitals Trust, 1971).
3. T McKeown *The Role of Medicine: Dream, Mirage or Nemesis?* (London: Nuffield Provisional Hospitals Trust, 1976).
4. D Weatherall *The New Genetics and Clinical Practice* (London: Nuffield Provisional Hospitals Trust, 1982).
5. AC Enthoven *Reflections on the Management of the National Health Service: An American Looks at Incentives to Efficiency in Health Services Management in the UK* (London: Nuffield Provincial Hospitals Trust, 1985).
6. S Williams, S Michie and S Pattani *Improving the Health of the NHS Workforce* (London: The Nuffield Trust, 1998).

Each of the papers in the series is available from the Nuffield Trust.

[2] C Dargie *Policy Futures for UK Health: Pathfinder* (London: The Nuffield Trust, 1999). The Pathfinder Report is for wide consultation and invited comment. You can email your comments to policyfutures@jims.cam.ac.uk. You can also send your comments to Dr Charlotte Dargie, Nuffield Fellow in Health Policy, The Judge Institute of Management Studies, Cambridge University, Cambridge, CB2 1AG. You can also find this Pathfinder Report along with other technical papers in the Policy Futures series at the Nuffield Trust website: http://www.nuffieldtrust.org.uk. Please respond with your comments by Friday 19 November 1999.

SUMMARY

- The inherent ethical dimensions of health care are universally acknowledged in both lay and professional/academic discussions. However, the nature and extent of specialist authority on health care ethics matters is controversial.
- Ethical analysis is a valuable means of clarifying ethical claims, judgements and arguments, but it does not constitute moral authority in itself.
- There is a variety of theoretical approaches to ethics, and no single paramount moral value emerges from this variety.
- The development of medical technology represents a quest for scientific certainty, whilst at the same time the growth of individualist consumerism represents a loss of confidence in traditional moral certainties.
- The current predominance of autonomy may be a temporary phenomenon, and on its own it is increasingly recognised as inadequate to problems requiring a more 'communitarian' approach.
- The conflict between individual autonomy and collective welfare characterises many serious ethical challenges in health care (illustrated by, among other things, the challenges prompted by emergent technological interventions at the beginning and the end of life and by advances in genetics).
- However, still more important may be the ethical challenges in establishing the place of health care within the wider social context, especially the problem of reconciling individualistic technological interventions with societal health needs, above all the need to reduce inequalities in health.
- This particular challenge arises in developments in the nature of medical practice and in our concepts of health and disease, in the extended range of problems amenable to technological intervention, in the growing incidence of chronic illnesses in an ageing population, and thus in the ever-increasing problem of scarcity of resources.
- Future health policy needs to rest on the resolution of a number of key questions concerning the nature of health care needs, the location of responsibility for individual health, the priority to be attached to reducing health inequalities, and the choice of core moral values to drive health policy.

INTRODUCTION TO ETHICAL DEBATE IN HEALTH CARE

Some preliminaries

Health care affects everyone, and few things matter more to us than our health, especially when it is under threat. Thus health care provision affects, quite literally, our vital interests. A concern for how our actions affect other people's vital interests, when we see those interests as self-evidently important in themselves, seems nothing if it is not a moral or ethical concern. Not surprisingly, then, health care provision rightly attracts our ethical attention from first to last: it matters, and matters morally, how health care is provided.

This is now universally recognised, and we can find at least two distinguishable, but surely related, kinds of 'conversation' on ethical matters in medical and health care [1]. There is a popular 'conversation' in which the ordinary (and sometimes extraordinary) concerns of patients and professionals are aired and examined in the popular media. Valuable in itself, this is a conversation which anyone should feel able to make sense of and to take part in, at least in the sense of having a point of view on the concrete issues involved. A second, rather different, kind of 'conversation' is that which consists in specialist commentary on and analysis of medical-ethical matters in academic and other journals. This commentary and analysis is inevitably rather less accessible than the first kind of 'conversation', as any academic or scholarly discourse is bound to be. This should not mean it is obscure or irrelevant. But it is carried on amongst specialists who must devote themselves substantially to familiarising themselves with what has by now become a very large body of literature. It is reasonable to suppose, however, that both the popular and the academic forms of ethical 'conversation' should share the aim of helping to improve our understanding of the ethical dimensions of health care provision and health policies. This improved understanding, in turn, is justified if it helps us conceive and deliver health care in ways which more richly benefit people and which take account of their interests more seriously and sensitively.

Having distinguished these two 'conversations', this paper will be concerned more with surveying important recent trends in academic ethical discussion and analysis. Hereafter, we will for convenience use 'ethical analysis' to refer to the academic form with which we are concerned.

Some characteristics of ethical analysis

There is no complete agreement on the nature or scope of ethical analysis, on the kind of expertise which it requires or represents, or on the extent of any authority attaching to pronouncements upon medical ethics questions. Because of this it is important to set out the conception of ethical analysis on which this paper rests.

First of all, the view we shall take here holds that ethical analysis does not carry moral authority in and of itself. Both critics [2] [3] [4] and defenders [5][6][7][8] of 'professionalised' medical ethics unite in agreeing that claims

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to such authority are improper; they differ rather over whether such claims are actually made by those who put forward ethical analysis and commentary. Another important point is that ethical analysis does not in and of itself amount to taking sides on a particular issue. Rather it consists in making clear the moral and, often, *conceptual* assumptions on which a particular point of view rests. By this means, it becomes easier to see exactly where any points of disagreement lie, and whether or not a particular moral position is held consistently. Of course, the result of doing this may well be to make a particular moral position seem more (or indeed less) plausible than before the analysis. Moreover, in choosing what topics to investigate, and what substantive views to analyse (and, especially, to dismantle), the ethical analyst cannot help but influence the way that sides are in fact taken on a particular issue [9]. The point is simply that those whose job it is to take sides need to be aware of the limits to the authority of ethical analysis.

Second, and connectedly, expertise in ethical analysis may be a skill, but is not in itself a moral virtue; the skilled analyst does not enjoy moral wisdom just on account of her skill. Working out, through ethical analysis, what a particular moral position entails and requires does not, for instance, give one the conviction or the courage to maintain that position in practice. Ethical analysis is therefore a resource that people may use in their own moral reflection [5] [10] [11], but is not a substitute for that reflection. Moreover, the ethical analyst cannot *as analyst* tell other people what to do or think [12]. Since, however, the ethical analyst no less than other people may well have her own views on a particular matter, she must either suppress those views or, where this is unrealistic, declare them as her own, to be understood as such by the reader.

Third, it is worth stressing that ethical discussions, in any field, have no independent life of their own; they concern dimensions of other substantive discussions or activities, and do not constitute a further, freestanding activity or discourse. So, for instance, the ethical issues in health policies arise in and with those policies. But this means that ethical analysis is clearly *reactive* rather than proactive, responding to the ethical dimensions of other activities, choices and judgements. Though this is sometimes lamented, it is hard to see how ethical analysis could be 'proactive' in anything other than the most general sense: for instance, in confirming society's determination to embrace - or alternatively to avoid - a utilitarian approach to future policies.

Fourth, ethical analysis does not evolve or develop rapidly. The very general concerns of ethical analysis, such as the nature of good action or intention, or the relative importance of duties, consequences and the virtuous character of the agent, have been debated for literally millennia, as part of philosophy's perennial concern with the study of ethics. Whereas the practical capacities of the physical and the social sciences can develop rapidly by substantial theoretical advances, the concerns and values that are at stake in ethical analysis are relatively unchanging, and their importance is not a matter of the accumulation of knowledge.

This paper proceeds on the basis of this general view of ethical analysis.

The variety of approaches to ethics

It is obviously well beyond the scope of this paper to review the history of ethics or the development of ethical thought. However - partly on account of the gradual evolution of ethics described above - many of the major historical trends in ethical thinking are still current, and can be found in the ways that ethical analysis of health care is conducted.

In a nutshell, these trends typically concern what various thinkers have taken to be the morally decisive element in a situation. Some (the best-known being the utilitarians) have thought that the decisive element was solely the *outcome* or *consequences* of the available courses of action [13]; others, forming a much older tradition, have thought it was an attention to whatever absolute and inviolable *duties, obligations* or *rules* were at stake [14]; a modern variation on this has been an attention to guiding *principles* (whose content usually involves duties, but might also identify certain of those duties in terms of the beneficial outcomes that such duties are usually intended to promote) [15]; still others have thought that morality can be captured by the idea of respecting the *rights* of others [16]; and so forth. All of these approaches tend to focus on the question of action - what one ought to *do* in a given situation - as being the principal concern of moral thought and judgement. An alternative view is that the main question of morality concerns, not what I should do, but how I should *live;* those who favour this approach have taken the decisive element in a moral situation to be whatever *virtues of character* are summoned by that situation, or are needed to sustain the person facing it [17]. These are the main traditional branches of moral thinking (if we discount the appeals to various forms of religious or divine authority); significantly, all have found expression in the modern literature of ethical analysis of health care through, respectively, the work of broadly utilitarian writers such as Singer [18], duty-theorists such as McCormick [19], principle-theorists such as Beauchamp and Childress [20] and those advocating a rights-based approach such as Dworkin [21]. Moreover, the very substantial revival of attention to virtue ethics is perhaps as marked within health care ethics as outside it [22] [23]. To these we may add renewed attention to a number of other approaches, some of which have found perhaps their clearest expression in the field of ethical analysis of health care, including narrative ethics [24][25], interpretive ethics [26], casuistry [27][28], the 'ethics of care', often closely allied to feminist ethics [29][30][31], particularist ethics [32][33], the ethics of community or solidarity [34][35] and - ostensibly minted for the purpose - 'clinical ethics' [36].

We shall not review these in detail, but it is worth our recognising that these varieties of ethical reflection vary in the values that they support or to which they give prominence. This in turn is important because the result of ethical deliberation is strongly influenced by the question of which moral values are taken to be paramount - something that has been subject to significant change alongside the emergence and development of modern, high-technology health care. We shall consider this next.

Competing values

The rapid development of medical science and technology over the last three decades has been accompanied by at least two important developments in the way that human values are applied to the provision of medical and health care. First, the notion that ethical values were integral to medical practice and provision has become orthodox and, moreover, institutionalised with 'medical ethics'. Indeed medical ethics has by now become an acknowledged subject of study (both professional and academic) as well as of professional discipline [3 7] [9]. Second, and at the same time, patients have been permitted and/or encouraged to become 'consumers' of health care provision, with commentators dividing sharply between those who applaud this development [38] and those who lament it [23]. In the process, a concern to promote individual, autonomous *choice* has appeared to replace a concern for *welfare* as the new dominant value in the practical discourses of clinical medicine. We might well find this particularly striking within the context of the United Kingdom (UK) national health service (NHS), amongst whose founding values individual and collective welfare were so prominent.

The current situation is therefore one in which these competing values must somehow be reconciled within health policy. It is an uncomfortable one for both those fashioning policy and those attempting to implement it in the clinical context. Whilst ever-greater certainty is being sought in scientific and technical terms, in ethical terms patients and practitioners alike appear to be subject to considerable uncertainty [39][40][41][42][43].

The emergence of a respect for individual *autonomy* as, perhaps temporarily, the dominant single value in the ethical analysis of health care means that health care choices and decisions are required to be made more transparently with regard to patients' own conceptions of their desired health care outcomes - indeed, that such outcomes need to be as it were 'negotiated' between clinicians and patients within a policy framework that allows for and facilitates such negotiations. This 'negotiation' is important - but also tricky - for two reasons. First, as we recognised earlier, there are no genuine experts on the moral preferability of specific outcomes over others, if by 'expert' is meant the kind of authority whose accumulated special knowledge entitles her to demand the agreement of other people. If anyone is an expert on the practical *individual* preferability of specific health care outcomes, it would in most cases appear to be the patient [44]. All well and good, but the second difficulty is that it's not obvious that the patient's special knowledge about what is best for him in practical terms can in any sense entitle him to *require* specific provisions at society's expense. After all, patients essentially compete for limited health care resources [45], and clinicians also legitimately exercise a measure of personal autonomy within the clinical encounter - they will resist being required to act against their own moral convictions simply in order to satisfy the 'consumer' preferences of patients.

Autonomy's emergence as a dominant value in ethical analysis of health policy and clinical health care may to some extent be an artefact of the way that the discipline of 'medical ethics' has itself developed [46][47][48]. This dominance has in recent years given rise to a sharp, even fierce, dispute

among medical ethics commentators concerning not only whether autonomy should be the overriding moral value but also even whether its dominance is itself morally pernicious [40] [49] [50] [48]. Some commentators urge the examination of personal notions of responsibility as a counterweight to individualistic patterns of demand [51][52][53]; others anticipate the decline of what we might call 'autonomism' (and indeed individualism as such), to be replaced by more a communitarian sense of responsibility [54][55][56][57][58], particularly in the face of inequalities in health status and health care access and the problem of poverty [59] [60] [61].

Some of the recent trends in ethical analysis of health care (summarised above) arguably grow from a sense of dissatisfaction, both with the dominance of autonomy as a value, and with the widespread adherence to an essentially 'principles'-based approach to analysis as such, an approach that has hitherto been highly influential [20] [3 7]. It is difficult to predict which, if any, of these newer (or revived) approaches is capable of providing a credible and sustainable alternative to autonomism as a guide to practical policy or clinical decision-making. However, we can make the more cautious suggestion that considerations of autonomy, whilst in the past providing a valuable response to paternalism on the part of the physician [62], must henceforward be substantially qualified by considerations of the needs of the community [45][63][49][57].

ETHICAL DEBATES IN ACTION

The influence of different values and approaches - particularly the tension between a focus on individual autonomous choice and a focus on collective welfare - is best illustrated by concrete examples. Issues at the beginning and end of life provide us with vivid instances of typical debates involving these conflicting value assumptions. It may be helpful to look synoptically at these two broad areas of debate, as a means of illustrating what is at stake when values themselves are in conflict. But in paying attention to these particular areas, we should remember that they are no more than particularly vivid arenas for moral conflict prompted by specific biotechnologies. The 'small change' of health care ethics perhaps lies elsewhere, typically in the realm of how a resource-limited service responds to a burden of health care needs and demands, which - as presently conceived - seem considerably greater than it can hope to meet. Such debates are less glamorous or vivid, but are arguably of greater importance to health policy in the long run. We shall encounter them later on (and we shall see that they too embody a competition for pride of place among conflicting moral values, including those of individual choice and maximal collective welfare).

Conflicting values at the beginning of life

Reproductive medicine has been the focus of extraordinary and rapid technological development and, not surprisingly, of corresponding ethical concerns. These concerns include a regard for the effects of assisted reproduction techniques through stimulating new patterns of demand for health care resources [64], demands that plainly pit the collective interest in conserving those resources for meeting clinical need against the individual's wish to exercise newly available choices in the area of begetting children.

Thus a related concern is whether such techniques meet a genuine clinical need [65][66] or instead simply respond to a claimed 'right' to a child as an expression of a social wish or desire [67]. An important aspect of this is the charge that reproduction is an essentially social matter that has been medicalised, a charge characteristically lodged [68] but also scrutinised sceptically [69] from within feminist ethical perspectives. Variations on the charge that reproductive technologies involve a form of 'playing God' come from both traditional perspectives [70] and broader feminist perspectives, within which they are lodged and also rebutted [71] [72]. Commentators broadly agree on the *relevance* of the interests of the child that is the product of using such technologies, but not necessarily on whether those interests should be thought paramount [73][74][75].

A still more controversial extension of reproductive technology concerns the potential ability to intervene, via genetic screening and selection, in the characteristics of the child that is the intended product of such technology. By such means, it might appear, intending parents are enabled not only to obtain but also to *specify* the child of their choosing. At present the available interventions are generally confined to the prevention of undesired characteristics arising from genetic abnormality, so the correspondingly available 'specification' of the child is broadly a negative one. Even here, however, the attempted justifications for such a startling extension of parental choice seem to rest squarely in the commitment to such 'commissioning' parents' individual autonomy.

Objections to such practices seem predominantly to be grounded in different moral commitments from that to autonomy. For instance, in seeking to reduce the incidence of genetic abnormalities, it has been argued that there is a danger that the moral standing of those currently living with such conditions is impugned, and in the case of pre-natal genetic screening accompanied by so-called 'therapeutic abortion', the implicit message is broadcast that it would have been better had existing sufferers not been born [76]. This objection seems to confront the value of choice with the countervailing value of life as such - a confrontation familiar from all modern debates over the morality of abortion.

A quite different objection is that a programme of negative eugenics (screening for and preventing births with genetic defects) might threaten to evolve into a programme of positive eugenics, in which pre-natal screening will prevent the birth of children lacking a specific, *positively valued,* genetic endowment [77][78]. Such an objection might appeal to the balance of beneficial and harmful outcomes, to the violation of principles or duties, to the loss of key virtues, and so forth - and only implausibly to an infringement of the autonomy of those who, in such a programme, would never be born to enjoy it.

Furthermore, whilst one might claim that at any rate negative eugenics could lead to a reduction in suffering, this seems quite implausible in the case of positive eugenics [79][80] (unless we reckon on the presumed 'suffering' of those parents whose wishes for designer babies are frustrated). Indeed, even in

the case of negative eugenics, it is evident that suffering can afflict both those enjoying and those lacking intelligence or beauty, for instance, and that not all those born with a presumed genetic defect (for instance Down's syndrome) will inevitably suffer. It can even be argued that there is something of value in the sheer diversity of human life, even where this does involve suffering [79]. Whatever the strengths and weaknesses of this argument, it seems clearly to appeal to collectively-held, rather than individual, interests.

Conflicting values at the end of life

A similar diversity of value assumptions can be found in debates concerning the end of life. For example, those who promote the supposed 'right' to die in circumstances of one's own choosing generally presume that the value of individual autonomy should be decisive in debates about euthanasia, or physician-assisted suicide; their opponents typically point to the corrosive effect, which such individualistic 'rights' would supposedly produce, upon our collective expectations of trust and responsibility regarding the medical profession and the institutions of health care provision and upon the solidarities that ought to bind together patients, their families and their carers [81]. Related debates concern whether appeals to autonomy as such are paradoxical insofar as they impose upon the individual patient a particular view about how we distinguish between moral goods and harms [82]; whether the duties attaching to the role of the physician are violated in physician-assisted suicide [83]; and whether the relevant moral principles justifying (indeed, obligating) the relief of suffering extend to physician-assisted suicide [84].

The ability of modern biotechnology to prolong the lives of critically or terminally ill patients inherently raises ethical questions concerning whether scarce health care resources may legitimately be diverted in substantial quantity to the relatively small numbers of patients involved; in turn this raises conceptual as well as ethical questions concerning the balance and identity of the benefits and harms of such prolongation, and in particular the question of whether it is living or dying that is thus prolonged. The medical conditions involved vary considerably, but most attention has been given to the persistent vegetative state (which came to the public notice in the UK through the case of accident victim Anthony Bland) although this condition involves chronically extensive rather than technically intensive care. It has raised several ethical issues, all of them troublesome. Whether or not continued treatment is in the patient's best interests cannot be settled in any ordinary way; nonetheless commentators generally proceed as though it is *not* in such a patient's interests [85][86][87][88]. Some commentators proceed on the presumption that either ordinary dignity or actual 'personhood' has been lost to the patient [85][87] [88] and even some dissenters on this point concede that withdrawal of life-sustaining treatment may eventually be sanctioned, possibly though not necessarily in response to an 'advance directive' [89]. Other commentators argue robustly that such lives ought not to be prioritised at the cost of resources either to society [85][90] or to informal carers and families - the latter even leading to a suggestion of a 'duty to die' on the part of the chronically debilitated patients [91]. The striking result is that in different contexts the death of the patient may be seen as a good thing that the patient is

himself entitled to demand, or as a good thing that society is entitled to require. (This suggests that divergent moral perspectives can occasionally lead people to superficially similar conclusions, but acting upon those conclusions will rarely satisfy the divergent perspectives for very long.)

Among the larger questions raised here is that of the supposed *futility* of continued treatment, particularly in the context of withdrawal of life-sustaining treatment (whether or not this be technically invasive). Commentators disagree over where such 'futility' is properly located. The key problem lies in avoiding the temptation to confuse what we may call the *existential* futility of a life no longer worth living (normally a value-judgement we should expect to be made by the person in question, and crucially dependent on her autonomous choice) from the *medical* futility of a biological intervention that cannot achieve its physiological goals (and, as such, a scientific statement of fact, albeit one that here underwrites a collective imperative neither to squander resources nor to impose needless burdens upon the sufferer). Whilst medicine is clearly more than the biological, it becomes dangerous to impute to it specific moral goals such as the ending of a *particular* life deemed no longer worth living. At any rate, such decisions involving evaluative or normative rather than solely factual components must either be made transparent [92][93][94][95] or abandoned [96].

The continued development of organ transplantation technologies sustains established ethical and conceptual debates such as those concerning brain-centred definitions of human death [97][98][99][100][101][102]. In addition, a number of emergent issues have been identified. One concerns the ethical acceptability of xenografting - transplant organs from other species - as a specific alternative to human organ sources. Here commentators generally regard the onus to rest upon those who wish to justify the further exploitation of non-human species and the production of animal suffering [103][104]. Not surprisingly, such views tend to be cast in terms of welfare, rather than of autonomous choice. Not all these commentators agree, however, that this exhausts the moral concerns, pointing also to the risks of trans-species gene insertion as well as the moral burden of continued human suffering in the absence of suitable human organs for transplant [105].

Perhaps the most striking of the emergent issues concerns the proposal to introduce 'elective ventilation' whereby suitable patients, currently dying on general medical wards, would be transferred to intensive care units to die there under controlled circumstances enabling them to be maintained as organ donors [106]; scrutiny of these proposals (which were actively discouraged by the Department of Health soon after their limited introduction) has focused on the claim that they represent an unacceptable departure from the tradition that individual patients be treated in their own interests rather than in the interests of others - particularly where the treatment in question is of a kind that is typically *withdrawn* from dying patients on the grounds of its burdensome nature [107] [108].

In general, whereas these emergent issues arise because of the shortfall in human donor organs, it has been suggested that some contributions to the

debate on the established issues in part entrench that shortfall [109 p958], a striking instance - if the suggestion be true - of ethical debate producing rather than merely inspecting moral problems.

The broad areas of debate outlined in the two main sections above, concerning the ethical implications of modern biotechnologies, illustrate the scope for bringing to bear the variety of moral perspectives we earlier considered. In particular, the moral perspective one adopts seems liable strongly to influence not only one's style of reasoning but also the actual conclusions one reaches.

As we have already suggested, however, the ethical challenges for health policies stem from more than just specific technological advances, and we shall explore this next.

HEALTH, HEALTH CARE AND SOCIETY

Perhaps the most important divergence among the moral perspectives we have identified is between an emphasis on the value of individual autonomous choice and an emphasis on the value of collective welfare. We can see this divergence reflected strongly in the two main competing influences upon both the past and future directions of health policy - influences that are largely irreconcilable. In particular, it is hard to reconcile the generally individualistic direction of medical technology with a health policy that addresses a conception of health needs at the societal level or, more especially, a health policy aimed at reducing inequality [110][111].

It seems difficult to resist the suggestion that the reduction of inequalities in health and in health care is the most important single ethical challenge for future health policy [59][61]. Of course, health and health care are not the same thing. Health itself is far more difficult to define than is health care, and definitions of the nature of 'health' range from a state of almost Elysian wellbeing at one extreme to a spiritual acceptance, at the other, of whatever infirmities it may be one's vocation to suffer. If we take only the modest notion of health as the absence of specific diseases and infirmities, it is plain that many inequalities in health status can be found among individuals with equally good access to health care and *vice versa.* However, once we admit the impact of social, economic and environmental influences upon both physical and psychological health, it becomes easier to see how, in conditions of relative socioeconomic deprivation, a greater incidence of ill health plausibly coincides with a lower standard and extent of health care provision - the so-called 'inverse square' law [112].

Admittedly, both of the major competing influences that we have just identified regarding health policy can lay claim to ethical support. Medical technology's focus upon individual biological function and pathology aims directly to confront important and immediate sources of individual human suffering, an objective that self-evidently commends itself in ethical terms. At the same time, however, (and in virtue of the same ethical imperative) it is necessary to take account of the psychological, social and environmental causes of ill health, i.e. those causes that ultimately lie beyond the individual

and whose remedy is achieved primarily through changes in social practices, rather than through individual biotechnical interventions [59][60][61].

Moreover, the task of reducing inequalities in health (consisting in inequalities in characteristic health status, in lifelong liabilities to ill health, and in access to health care provision) carries with it a readily recognised ethical claim grounded in considerations of justice. Inequalities in health are arguably widened by the individualistic focus of biotechnological medicine: this focus competes for attention with a focus on social and environmental causes of ill health, the impacts of which are unequally distributed within society [113][114][115][116][111]. In addition, the effects of the inflationary pressure of technology on overall demand for health care resources are disproportionately felt by those whose access to health care is already relatively disadvantaged.

Thus, whilst there is a balance to be struck in health policy between a preferential emphasis on societal needs and factors and a preferential emphasis on individual/biological needs and factors, this is not a choice between the ethical and the non-ethical; rather, it is a choice between two kinds of ethical claim that cannot fully be reconciled. This is not to say that a choice cannot be made or defended, simply that any health policy must do just that. For example, anyone who regards the principal ethical challenge as lying in the reduction of inequalities in health and health care has in fact chosen a societal emphasis in preference over an individualist one.

We have already suggested that this preference has much to commend it; for that very reason it is important to acknowledge the constraints it faces. The most significant of these is perhaps the fact that the core conception of medicine as a practice - what we may call the medical *paradigm* - is only slowly evolving away from a deep-rooted basis in biological individualism.

Changes in the medical paradigm

The current medical paradigm is a mixture of variants of a modified biomedical understanding, variants that are themselves liable to change to some extent in the next fifteen years, depending on how successfully the paradigm's basic assumptions can be challenged. Those assumptions may be summarised as:

- the claim to objectivity
- the location of disease in the individual human organism
- a preference for reductionist accounts of health and disease
- a view of science and technology as separable from the humanistic and the social
- the division of the mental from, and rejection in favour of, the physical. [117][118][119]

Although it is fair to regard medicine as evolving slowly away from these assumptions, the influence of genetics as the basis for human health and illness continues to grow and implicitly to oppose this direction of change. We have already summarised some of the ethical issues most closely arising from

genetic advances in the previous section. It is worth observing also that genetic explanations tend to promote the 'medicalisation' of an increasing range of socially-identified conditions, such as alcoholism or aggressive behaviour, via the examination of genetic endowment [120][121].

Changes in our concepts of health and disease

Concepts of health, of disease, of normality and thence of the effectiveness of medical interventions are also liable to change along with changes in the medical paradigm. Medicine's corrective, restorative, augmentative and forensic roles all carry ethical implications, and all these are liable to be revised with the paradigm itself. (It has even been argued that the 'postmodern' idea, that no choices are possible among the competing values to be found within as well as between societies, will present challenges to the idea of medicine's presumed inherent duty to *act* in response to encountered need [122].)

The conception of what counts as evidence for clinical effectiveness will reflect these revisions. An understanding of illness that reunites the physiological with the *experiential* will, it has been suggested, require a far richer and more varied conception of evidence than that primarily at stake in 'evidence-based' medicine, taking more seriously patients' conceptions of their own values and goals alongside the more easily-measured physical parameters such as blood pressure [123]. To complicate the picture further, our conceptions of what is normal and desirable are themselves influenced by the new situations that emergent medical technology can make available, and these developments in turn are liable to influence the level and nature of expressed demand for health care [124][125][126].

Greater links between health and social care

There is an increasing interpenetration of health and social issues, coupled to policies encouraging the integration of health and social care provision (including the education/training of health and social carers). On its own this would tend to loosen the grip of the biological paradigm of medicine and encourage the recognition of a wider relation between the biological and biographical conceptions of illness, disease and disability, as well as an appreciation of the environmental influences on health as such and on health and social care [127][128]. At the same time this interpenetration complicates the question of who has specific responsibility for individual patients' care, and so potentially enlarges the 'mesh' of the net through which patients can fall.

Future directions for primary care and general practice medicine
The role of primary care and its relation to the scale and range of specialist secondary care services continues to evolve, and the implications of this evolution are perhaps among the most substantial in both policy and ethical terms [129][130]. These implications include:

- the possibility of a significant transfer of roles from doctors to nurse practitioners
- an extension of the public health focus in primary care

- the perceived loss of the family practitioner
- role tensions facing GPs who are required somehow to provide a service on a personal scale as well as on a population scale.

Public expectations of the NHS are intensely focused on the nature and scale of attention they can expect from primary care, an attention that is personified in the traditional (though increasingly mythical [131] family practitioner).

The combined biological and biographical nature of much non-acute illness is transparently obvious in general practice medicine. Elsewhere in medicine this combination may seem less obvious; the 'biopsychosocial' conception of disease has had only a limited effect on medicine outside primary care and psychiatry, perhaps because of still-unacknowledged cultural barriers to communication in medicine [132]. The emergent 'specialist' medical practitioner within primary care (that is, a doctor with distinct medical or surgical specialisms who is located for convenience in the primary care setting) threatens the loss both of traditional attention and of that richer conception of illness in which biological and biographical aspects are fused. The danger is that, by comparison with the traditional general medical practice, this specialist perspective will encourage both an ethical and a conceptual reductionism towards the patient [133]. Hence the claim that an essentially biological, and thus reductionist, understanding of medicine is rarely fully adequate to the 'lived body' experience of patients and their suffering - and the allied claim that better, experiential, understandings are available [134][115][135].

Nowhere are these understandings more important than in general practice. Primary care medicine offers the medical practitioner, almost uniquely, the encounter with the *undiagnosed* human being, rather than simply with the patient.

Chronic illness

Finally (owing in large part to demographic changes, which are described in detail by Dargie in paper no. 3 in this series), the objects of medicine's attention seem increasingly to concern chronic illness conditions for which, by definition, fewer effective curative interventions are possible. This seems to make medicine's palliative role more apparent, albeit one requiring a wider understanding of palliation [135]. Again, chronic illnesses have a more obviously integral biographical dimension; they tend towards the multiplication of intercurrent illnesses; they are more likely to be associated with persistent disabilities, leading to impacts on self-perception and identity, and to social exclusions and other implications [136]. The increasing burden of chronic illness intensifies the challenges of providing combined health and social care. Some commentators detect in this a further challenge to twentieth-century medicine's emphasis of diagnosis over prognosis, and to a modern imperative towards the prolongation of life [137].

The scarcity of health care resources

Roughly at the same time as the rise of biotechnology-based medicine and health care there has also arisen a growing recognition of the resource

constraints upon health care provision [138]. Health economics aims to provide tools for rational decision-making in health care resource expenditure, usually conceived as attempting to maximise one's chosen benefits at minimum cost. To do this, some means are required to measure and trade off costs and benefits in the same scale, which should have fixed points (a 'cardinal' scale) and also, ideally, fixed proportional intervals between those points (a 'ratio' scale [139]; the most famous attempt is the Quality Adjusted Life Year (QALY), which seeks to measure a universal quality-of-life variable on a ratio scale [140][141]. However, such decision-making tools cannot in themselves determine which inputs or outputs to measure; this has to be decided beforehand, and is a matter for judgements involving practical, social and ethical dimensions to them. Moreover, the mere existence of decision-making tools such as the QALY doesn't guarantee that any particular output or input is in fact meaningfully measurable, and whether or not health care outcomes or health status constitute such measurable outputs is controversial.

The rise of health economics as a determinant of policy is consistent with recognising the importance of public accountability for how resources are spent. Because of this, health economics has its defenders in the ethical analysis literature [142] as well as a natural partner in 'evidence-based' medicine. However, it faces challenges, for instance from pressure groups (such as those representing the sufferers of various disabilities), to show how it can accommodate the fullest range of perspectives, including minority perspectives, in either its results or its methods [143] [144]. Moreover, in the application of *market* economics to health care, the patient is seen (and sometimes lamented) as a consumer engaged in essentially self-serving behaviour (i.e. choosing to maximise his or her personal benefits from the health care system) - whilst nevertheless implausibly conforming to an impoverished range of values and value choices in order to be captured on a scale of measurement [145].

The modern preoccupation with resource constraints reflects a number of structural changes in society, all of which tend to inflate demand for health care (documented elsewhere in this series by Barnes [paper no. 10: 'Public expectations'], Ferlie [paper no. 7: 'Organisation and management'], Lee [paper no. 1: 'Global context'] and Pahl [paper no. 6: 'Social trends']). These changes include at least the following four factors:

- the increasing proportion of older people in society, and hence of the chronic illnesses and disabilities primarily associated with ageing
- changes in patterns of employment and of traditional perceptions of role and worth, with an increase in the presentation of psychological illnesses
- the inflation of demand for new or improved health care interventions stimulated by biotechnological and pharmaceutical advance
- the voicing of the perspectives of minority groups with associated specific illnesses or disabilities [76].

In response, a debate has emerged concerning who is responsible for the care of specific groups, and what priorities certain groups of patients or potential patients ought to attract. For example, it has been objected that older people

ought not to be disadvantaged by prioritisation mechanisms such as QALYs, which count the accumulation of benefits over time on the grounds that individuals' abilities to value the life remaining to them should be weighed equally, regardless of the length of life - or the health care resources - they have already enjoyed [51]; some commentators take the opposite view arguing in effect, albeit in more delicate terms, that the old should make way for the young [45].

Taken together, these various changes indicate the ways in which our ideas of health, health care and indeed social arrangements should combine to influence the *general* future directions of an ethical health policy. Such a policy must also reckon with specific ethical challenges arising in modern health care (and we have earlier discussed some of the more vivid of these, arising in biotechnological interventions at the boundaries of life).

KEY QUESTIONS FOR FURTHER ETHICAL DEBATE

In this final section we shall raise and briefly review a number of key questions, for the future development of health policy, all involving what seem especially important ethical implications.

What conception of the nature of health care needs should most appropriately drive health care and health policy?

The limitations of a biological conception of health care needs are plain enough. Biomedical technology embodies and promotes a focus on the biological individual, and consequently tends to promote a similar focus in clinical medicine [113][114][115][116][111]. The likely upshot of this focus is both that those causes of ill health that lie beyond the individual will tend to be correspondingly neglected in the scientific picture of the patient, and that the biological conception of clinical need will be emphasised at the expense of the biographical, psychological, interpersonal and social dimensions [146][147][148][149].

The ethical implications of these tendencies are at least threefold (and all are likely to be felt more keenly by an ageing population encountering an increasing predominance of chronic over acute illnesses):

- The patient may suffer clinically because of an incomplete conception of his or her needs and their causes [145][147][148], whether or not these needs are remediable.
- Public health measures may receive relatively little scientific or technological attention, and as a result attract correspondingly low political and economic support [111]. By reinforcing the individualistic focus of medicine, biomedical technology reinforces this particular source of inequality in health.
- Inequalities in health will be exacerbated both by the neglect of social causes of illness and by the individualistic focus of medical technology.

Where does the responsibility for individuals' health finally rest?

The locus and extent of responsibility for health are controversial. Causal responsibility and moral responsibility are not the same thing, even though they often coincide in the actions of a fully competent, autonomous adult. So while it is right to encourage individuals to make responsible use of health care resources, the moral responsibility for individuals' own health states may not necessarily be confined to those individuals - even when their illness, incapacity or disease are in part caused by their own actions or behaviour. The wider socioeconomic context in which they are located must also be acknowledged as strongly constraining the lifestyles and choices, as well as the health status, of the less well-off.

Moreover, the extent to which people's lifestyles are or ought to be the business of health policy planners is also controversial. Whilst health policy must respond to the consequences of lifestyle choices, no automatic justification follows from this for seeking to influence lifestyles in accordance with a preconception of what lifestyles are suitable or acceptable to health. Individual freedom of choice and individual responsibility for the effects of one's choices are importantly linked, but the linkage is limited to the degree of control that individuals can genuinely exert in their own lives.

Is any aspect of future health policy morally more important than reducing inequalities in health and health care?

We have encountered the view that inequalities in health and health care constitute the single most important challenge confronting health policy. Adverse socio-environmental factors do not affect all sections of society equally, inequalities in health are widened by the individualistic focus of biotechnological medicine, and the inflationary pressure of technology on overall demand for health care resources impacts most greatly on those whose access to health care is already disadvantaged.

The special moral importance of health and health care is exhibited in our society's continued willingness to fund health care, predominantly free at the point of use, and predominantly at the expense of the public purse. This special importance is converted into the special moral urgency of inequalities in health status and in access to health care, when those inequalities are beyond the control or responsibility of the individuals affected by them.

What core moral values should drive health policy?

The views that one takes on all these questions are heavily influenced by one's preference among the moral values we have encountered in the course of this review - individual autonomy and freedom of choice, individual or collective welfare, the special importance of care, trust and accountability, adherence to central virtues, the adherence to central duties, the upholding of principles and so on - all of them typically liable to conflict with one another in any given situation. Future health policies ought to be driven by a clear and openly-defended choice of its core moral values.

Autonomy is perhaps the best-known and most oft-cited moral value in contemporary health care, but it is not the only important moral value. Whilst attention to individual autonomy has in the past provided a valuable response to inappropriate paternalism on the part of physicians and other health care professionals, autonomy as an isolated value is incapable of underpinning any shared, societal responsibility for the health care of all its members, including the least advantaged. As health inequalities widen (both within and between societies), the moral claims of alternative communitarian values become more urgent.

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