Our Certain Fate: Rationing in Health Care

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1. Introduction: is health care rationing inevitable?

Benjamin Franklin remarked in 1789 that ‘in this world nothing can be said to be certain, except death and taxes’. To these two certainties the economist would add that of the scarcity of resources, as ‘the central economic problem for society is how to reconcile the conflict between people's virtually limitless desires for goods and services and the scarcity of resources (labour, machinery and raw materials) with which these goods and services can be produced’. This conflict is resolved by various methods of prioritisation, and textbooks often define economics as the study of the processes by which scarce resources are allocated between competing ends. Economic efficiency consists of maximising the outcomes from limited resources, and also of optimising the distribution of these outcomes according to society's value systems.

In the case of health care, the innocuous process of resource allocation becomes a controversial and suspicious process of ‘rationing’, as scarce resources are allocated between the many and rapidly increasing number of health care interventions from which, hopefully, patients can benefit in terms of improved health status. The inevitability of some form of rationing in all health care systems shows economics living up to its reputation as the ‘dismal science’ as allocation decisions determine who is treated and who is left untreated, to live in pain or discomfort, or to die.

Alan Williams defines rationing in health care as occurring ‘when someone is denied (or simply not offered) an intervention that everyone agrees would do them some good and which they would like to have’. This process has existed throughout the life of the UK National Health Service (NHS). In the early decades of the service, rationing was undertaken quietly by doctors. In more recent decades, as public and professional realisation of scarcity in the NHS increased, the rationing debate has become more explicit. Scarcity of resources means that decisions to undertake a health care intervention incur an opportunity cost – the value that those resources would have provided had they been allocated in another way, to another patient.

Thus the policy issue is not whether resources have to be rationed, that is unavoidable and ubiquitous, but how: what principles should determine patient access to health care and how should they be applied? This harsh reality can be mitigated, but never removed, by increased spending on health care and by improving the efficiency of use of these resources. New Labour’s ‘£21 billion’ spending increase announced in the summer of 1998 (in reality less than £9 billion in England) will not eliminate waiting lists in the UK
NHS and meet all other capital and service needs: it will merely ease the suffering of some and leave others to wait for better services. Similarly persuading doctors to reduce marked practice variations and ineffective treatments will release some resources but still leave decision makers rationing care locally throughout the NHS.

There are advantages and disadvantages of moving from the present implicit system of rationing, with local discretion (rationing by post code) to explicit rationing. Doyal\(^4\) has argued that explicit criteria are essential for ‘the moral management of health care’. Keeping rationing criteria from patients may make clinicians’ lives easier, but it is not in the best interests of patients or taxpayers. Those opposing explicit rationing emphasise the difficulties of implementing any system, and the conflict created by denying care to patients. Implicit rationing, and its associated equivocation, may enhance satisfaction more than harsh explicitness. Coast\(^5\) argues for evaluation of these issues before ‘jumping on the bandwagon of explicit rationing.’ Despite such arguments, the assumption made in this paper is that the benefits of explicitness, in terms of public rights and provider accountability, outweigh the costs. This judgement needs continued testing as rationing criteria develop.

Some would argue that the best way to address rationing problems is to leave it to doctors to determine treatment priorities. Unfortunately this approach may be inequitable (doctors offer very different treatments to similar patients) and inefficient (doctors may provide inappropriate and cost ineffective treatments to patients). Doctors, and other decision makers, need to work to explicit criteria and be managed in relation to them so that performance is judged systematically.

This paper considers the principles which could be used to determine rationing in health care, and examines critically the practice of rationing in various countries. This discussion demonstrates clearly both the need to have explicit principles which determine patient access to care and to have an evidence base to inform rationing decisions in all health care systems. Perhaps only when rationing is explicit will patients be empowered to question practice, and will practitioners be managed scientifically and enabled to give evidence based answers to the issue of who gets what treatments and why in the NHS.
2. The principles of rationing health care

2.1. Rationing by ability to pay

With the inevitable problem of scarcity of health care resources, however generously the health care system is funded, the question is not whether to ration care but how to do so. In markets for most goods and services the price mechanism is used, and individuals who are willing and able to pay get access, for example, to apples and computer games. In the case of health care, inherent uncertainty about if and when health care will be needed, creates a demand for an insurance market if allocation is left to the market mechanism. However, no health care systems rely solely on the market due to market failure and equity problems. Health insurance markets fail due to two major problems. ‘Moral hazard’ means that as a third party (insurer or government) pays for care, neither patient nor provider has any financial incentive to restrict the amount of health care interventions which are used. This leads to the over consumption of health care, particularly when providers of health care (e.g. doctors) are paid on a fee-for-service basis, as they may encourage more interventions to increase their own income. The second major market failure is known as ‘adverse selection’. This occurs because people choosing an insurance package know more about their own health status than do insurers, and therefore know more about their expected health expenditure. This means that people who are likely to be higher risk choose more comprehensive insurance packages. As expenditure on these patients increases, premiums must also increase, so people who know their risk is low may opt out of these schemes into either less comprehensive schemes or even a decision to self insure. As this process continues, higher risks drive out lower risks and insurance markets are unable to function as risk is not adequately spread. Given that ill health and wealth are inversely related, this also compounds the problem of distributional equity.

Distributing health care by income and ability to pay results in unequal access to health care and offers few incentives for providers to use scarce resources efficiently. As a result most societies appear willing to subsidise access to health care depending on individuals’ need for care – people view health care in an altruistic way, often as a ‘right’, in contrast to other goods and services. Even in the US, ‘the last major holdout against national health insurance’,6 federal and state government fund over 40 per cent of health care expenditure, and health care is not solely rationed by ability to pay for health insurance.

It is important to acknowledge that the consequence of a market mechanism, rationing by price, is to exclude the poorest and discourage the rest
of the population from using health care they cannot afford. Its success in this role is well documented, for example around 40 million US citizens are uninsured and many millions more have inadequate coverage. Some 10 million children have no health insurance, and over three million of them would be eligible for Medicaid (health care for the poor) but are not registered within the scheme. Unregulated markets reduce access to care for those with limited means to insure or purchase care directly. Regulated markets can mitigate these effects, by subsidy, risk pooling and income based premiums, but the costs of managing this regulation are high.

### 2.2. Rationing by ‘need’ or ability to benefit

In the UK NHS, and in many other health care systems, the price mechanism has been explicitly rejected as a method of allocating care, eliminating (at least in theory) rationing by ability to pay. The 1946 Act stated that the NHS ‘imposes no limits on availability, e.g. limitation based on financial means, age, sex, employment or vocation, area of residence or insurance qualification’.7 This principle has been reiterated frequently since, for example by Margaret Thatcher in 1983: ‘the principle that adequate health care should be provided for all, regardless of their ability to pay, must be the foundation of any arrangements for financing health care’;8 and by Tony Blair in 1997: ‘the NHS will get better every year so that it once again delivers dependable, high quality care – based on need, not ability to pay’.9

In the UK NHS and other health care systems world-wide, rejection of the price mechanism means that other systems of allocation must be found. One way in which the UK NHS rations care is by ‘that familiar British phenomenon, the queue’.10 Waiting lists, with the implicit and explicit rationing they involve, are to some extent inevitable in a system where willingness and ability to pay is rejected as a rationing system. Some forms of rationing, not mutually exclusive, are illustrated in Figure 1. This ‘continuum of government involvement’ illustrates how rationing decisions can be made at different levels, from the discretion of individual physicians to a nationally controlled State health care system, and in different ways, by ability to pay, queues and private or public insurance schemes.11

Ideally, in a public health care system, care should be allocated on the basis of ‘need’. This is a difficult concept to define and put into action. Williams,12 in an ‘economic exegesis of need’, quoted Matthew (1971):13

> The ‘need’ for medical care must be distinguished from the ‘demand’ for care and from the use of services or ‘utilization’. A need for medical care exists when there is an effective and acceptable treatment or cure. It can be defined either in terms of the type of illness or disability causing the
### Figure 1: Forms of rationing: a continuum of government involvement

<table>
<thead>
<tr>
<th>Form</th>
<th>Criteria used</th>
<th>Effects on health care</th>
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<tbody>
<tr>
<td>Physician's discretion</td>
<td>Medical benefit to patient</td>
<td>Reinforces technological imperative</td>
</tr>
<tr>
<td></td>
<td>Medical risk to patient</td>
<td>Increases costs with no constraint on major access points</td>
</tr>
<tr>
<td></td>
<td>Social class or mental capacity</td>
<td>Reinforces differential access</td>
</tr>
<tr>
<td>Competitive marketplace</td>
<td>Ability to pay</td>
<td>Creates tiered access system</td>
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<tr>
<td>Insurance marketplace</td>
<td>Ability to pay for insurance</td>
<td>Encourages use of resources</td>
</tr>
<tr>
<td></td>
<td>Group membership</td>
<td>Escalates demand and costs of health care</td>
</tr>
<tr>
<td></td>
<td>Employment</td>
<td>Spreads risk and thus expands access</td>
</tr>
<tr>
<td>Socialised entitlement</td>
<td>Entitlement</td>
<td>Covers people lacking adequate private insurance</td>
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<td></td>
<td></td>
<td>Increases role of government in medical decision making</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Increases costs to public</td>
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<tr>
<td></td>
<td></td>
<td>Creates new tiered system of public v. private sector patients</td>
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<tr>
<td>Implicit rationing</td>
<td>The queue</td>
<td>Imposes shortage of some health care</td>
</tr>
<tr>
<td></td>
<td>Limited staffing and facilities</td>
<td>Increases role of government in regulation and budgeting</td>
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<td></td>
<td>Medical benefits to patient with consideration of social costs</td>
<td>Limits access to specialists</td>
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<td>Reinforces tiered system</td>
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<td></td>
<td></td>
<td>Shifts emphasis toward social benefits and costs</td>
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<tr>
<td>Explicit rationing</td>
<td>Triage</td>
<td>Limits high cost care with dubious benefits</td>
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<td></td>
<td>Medical benefit to patient with emphasis on social costs and benefits</td>
<td>Makes peer review mandatory</td>
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<td></td>
<td>Imposes cost containment measures</td>
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<td></td>
<td></td>
<td>Imposes regulation of private as well as public sector</td>
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<td></td>
<td></td>
<td>Bureaucratises rationing</td>
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<tr>
<td>Controlled rationing</td>
<td>Equity in access to primary care</td>
<td>Eliminates private health care sector</td>
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<td></td>
<td>Social benefit over specific patient benefit</td>
<td>Fully bureaucratises medical decision making</td>
</tr>
<tr>
<td></td>
<td>Cost to society</td>
<td>Limits discretion of patient, physician and other health providers</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Imposes strict regulation and control on all facets of medicine</td>
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<td></td>
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<td>Eliminates tiered system</td>
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Source: Blank 1988
need or of the treatment or facilities for treatment required to meet it. A
demand for care exists when an individual considers that he has a need
and wishes to receive care. Utilization occurs when an individual actu-
ally receives care. Need is not necessarily expressed as demand, and
demand is not necessarily followed by utilization, while, on the other
hand, there can be demand and utilization without a real underlying
need for the particular service used.

Williams views need as a quasi-supply concept, existing only as long as
the marginal productivity of a treatment input in terms of improving health
status is positive. This means that there is only a ‘need’ for health care if an
individual is able to benefit from an intervention. Clear evaluation of the
effectiveness of procedures is therefore required to allocate on the basis of
need. In a situation of scarcity, the concept also implies that one principle
which should guide resource allocation in the NHS is the patient’s capacity
to benefit per unit of cost. Resources should be targeted at those patients for
whom medical intervention is cost effective. Those for whom the costs of
treatment are high and the benefits (in terms of enhancement of length and
quality of life) are low will be accorded less priority and may be denied treat-
ment.\textsuperscript{14}

The concepts of relative costs and effects (health benefits to patients) as
the determinants of access to health care in a needs based health care system
should be distinguished from recently advocated concepts of ‘evidence based
medicine’ (EBM). This appealing concept has been advocated vigorously by
Professor David Sackett and colleagues, who argued:

Doctors practising evidence based medicine will identify and apply the
most efficacious interventions to maximise the quality and quantity of
life for individual patients; this may raise rather than lower the cost of
their care. (Sackett et al. 1996)\textsuperscript{15}

This view is incomplete as a basis for determining patient access or
rationing, although it has the merit of eradicating ineffective care. The word
‘apply’ suggests little patient choice, and EBM as defined here may cause
cost inflation by ignoring the issue of opportunity cost, suggesting that clini-
cal effectiveness is the only criterion to be used in resource allocation. Such
arguments are familiar. For example, an American physician, Dr Erich
Loewy, wrote to the New England Journal in 1980 and argued that the eco-
nomic dimension in clinical choice was unnecessary and clinical practice
based on economic measures was no better than that exercised by German
doctors on the victims of the Nazi era:\textsuperscript{16}

\textit{To the Editor:} Of late an increasing number of papers in this and other
journals have been concerned with ‘cost effectiveness’ of diagnostic and
therapeutic procedures. Inherent in these articles is the view that choices will be predicated not only on the basis of strictly clinical considerations but also on the basis of economic considerations as they may affect the patient, the hospital, and society. It is my contention that such considerations are not germane to ethical medical practice, that they occupy space in journals that would be better occupied by substantive matter, and that they serve to orient physicians toward consideration of economics, which is not their legitimate problem. It is dangerous to introduce extraneous factors into medical decisions, since consideration of such factors may eventually lead to consideration of age, social usefulness, and other matters irrelevant to ethical practice. The example of medicine in Nazi Germany is too close to need further elucidation.

It is incumbent on the physician (especially in a critical situation) to practice not ‘cost-effective’ medicine but medicine that is as safe as possible for that patient under the particular circumstances. Optimisation of survival and not optimisation of cost effectiveness is the only ethical imperative. To select diagnostic tests on the basis of cost effectiveness is a deliberate statistical gamble; to use diagnostic tests in an unthinking medical fashion is poor medicine, not because of cost but because unthinking medicine is dangerous for the patient. Ethical physicians do not base their practices on the patient’s ability to pay or choose diagnostic and therapeutic procedures on the basis of their cost. It may be argued that the welfare of society is threatened by escalating medical costs; indeed, that argument at first appears to introduce a dilemma. Yet a large proportion of our ills are due to smoking, heavy drinking, and overeating, and the consequences of these indulgences consume a large proportion of medical-care dollars. It is unfair to deprive those who have not been overindulgent of the best medical care while allowing the overindulgence of others to consume the available money. Furthermore, our society clearly has money to spend on luxuries and baubles. A physician who changes his or her way of practicing medicine because of cost rather than purely medical considerations has indeed embarked on the ‘slippery slope’ of compromised ethics and waffled priorities. (Loewy 1980)

Both Loewy and Sackett ignored the ubiquitous problem of scarcity and its consequence, opportunity cost. Because of scarcity, regardless of overall funding levels, any choice to provide some care involves a decision not to provide other types of care (to forego some other ‘opportunity’). A decision based on clinical effectiveness may be consistent with the individual ethic of the physician, as stated in the Hippocratic Oath:
I will follow that system of regimen which, according to my ability and judgement, I consider for the benefit of my patients, and abstain from whatever is deleterious and mischievous…

This, however, is likely to be inconsistent with spending health care budgets in such a way as to maximise improvements in population health status.

The economist and the public health physician argue from the social rather than the individual perspective. This clash of cultures is demonstrated in a simple example, assuming a tight budget constraint and no concern about the distribution of outcomes between different groups of patients:

- if a doctor can treat a patient with disease x with two therapies, which should be used if intervention A is likely to produce five additional healthy years of life and intervention B is likely to produce ten additional healthy years of life? Using the principle of EBM and using clinical effectiveness only, therapy B would be chosen;

- what if therapy A costs £1,000 and therapy B costs £5,000? The average cost of producing a healthy year with therapy A is £200 and therapy B is £500. Another way of interpreting these data is to argue that therapy B produces five additional healthy years relative to therapy A at an additional cost of £4,000, so the incremental cost of a healthy year is £800;

- at a population level, five times as many patients could be treated for condition x if therapy A was used in each case. A is clinically less effective, but is cost effective relative to therapy B. A doctor using the principle of the efficient use of scarce resources might use therapy A.17

An economist might also argue that any failure to use the efficient option wastes resources and, as a consequence, patients waiting for treatment are deprived of care from which they could benefit. This inefficient behaviour, as produced by health care provision based only on evidence of clinical effectiveness, is unethical. Instead of solely EBM principles, resource allocation should be based on the costs and benefits (efficiency) of competing interventions – evidence based purchasing.

If the target of public policy is to deploy the limited NHS budget to maximise improvements in population health, it is inappropriate to follow those advocates of EBM who focus solely on clinical effectiveness rather than cost effectiveness. It is necessary to identify interventions which are both effective and cost effective, and target resources at those interventions which have the highest health benefits per unit of cost. Evaluation is likely to demonstrate that individual therapies are cost effective only for sub categories of patients and, as a consequence, rationing will have to be specific so that it benefits particular rather than general groups. Whilst the energy of
EBM zealots in advancing the evidence base and altering practice is to be welcomed, their approach is a necessary but insufficient criterion for achieving an efficient allocation of resources.

2.3. Rationing by social values

This economic or efficiency approach to rationing health care is based on maximising the quantity of ‘health’ outcomes from scarce health care budgets, and thus allocating resources according to a utilitarian ‘cost per unit outcome’ approach. For example, using a quality adjusted life year (QALY) approach, length of life and quality of life are combined into a single measure of ‘health’ outcome (a QALY), and linked with opportunity costs to determine resource allocation decisions. This has been strongly criticised as not adequately incorporating other value systems important to society. Maximising health alone, whilst an efficient approach to rationing health care, will not necessarily achieve equity goals.

One example of this criticism is the potential impact of the application of rationing by cost per QALY approaches on the treatment of elderly people. QALYs have been described as ‘inherently discriminatory because counting extra years as part of the benefit of medical procedures risks shifting resources away from older to younger age groups. Similarly, those judged to have a low quality of life - predominantly older people – will be disadvantaged’.18

A number of cases of rationing health care on the basis of age have drawn media attention,19 primarily regarding treatment of acute myocardial infarction and other forms of heart disease. Such ‘ageism’ has been criticised as unethical, exploiting the weak, and reflecting professional ignorance and prejudice.20 Recommendations on equity and quality of care for elderly people have been published by the Royal College of Physicians (RCP), which includes the recommendation that commissioning bodies should ensure that access for elderly patients to specialist facilities is as good as that for young individuals, and that age is not used as an exclusion criterion in admissions policies.21 Such advocacy may be efficient, if elderly people gain health at least cost. The RCP is, in effect, arguing that equity issues should dominate efficiency, but they are reluctant to define, rank and outline the opportunity costs of their equity arguments, let alone be explicit about the trade offs between equity and efficiency.

Some have argued that age is an appropriate criterion for rationing health care. Callahan22,23 has argued that in order to ‘curb our insatiable appetite for longer life regardless of expense’ it is necessary to ration fairly in a way which sets limits to care. He proposed that care should be focused on enhancing the quality of life, not necessarily extending life, with long term,
low technology care. He argued that rationing should be determined by a flat age limit in the late 70s or early 80s, after which care to elderly people should be rationed. However, this approach has considerable difficulties, similar to those for all allocation principles. In particular:

- what age should be adopted for the cut-off and how should it be selected?
- is there to be the same age cut-off for men and women?
- people do not ‘depreciate’ in a uniform manner in relation to age and thus the capacity to benefit from care is unequal;
- capacity to benefit will be related to the skills and techniques of surgeons and anaesthetists.

Williams has also argued against the ‘vain pursuit of immortality’, and the notion of ‘cure’ as the only criterion of benefit, in favour of effectiveness measures based on health related quality of life – mobility, self care, ability to pursue usual activities, and freedom from pain, discomfort, anxiety and depression. Williams does not argue for the usual economists’ objective of an efficiency allocation but suggests a ‘fair innings’ approach to rationing health care, where the objectives of the health care system should be to reduce inequalities in the quality of people’s lifetime experience of health. With this equity weighted efficiency criterion for rationing, those who allocate access to care would do more to enable young people to survive than to enable old people to survive. Young people would not take absolute priority over old people, but would have more weight in resource allocation decisions. Thus a person in their 20s and chronically ill may be given access to care, even if this care was relatively inefficient, at the expense of an older person who has had a ‘fair innings’ but would benefit relatively more from care. Some, for example Grimley Evans, find this argument unacceptably discriminatory. The translation of such a principle into practice would be a complex process, as the weights would have to be carefully determined by society, to guide how much resource should be transferred from which elderly groups to which young groups.

The ‘fair innings’ argument does not necessarily apply just to age, as other social values can be incorporated into a system of ‘equity weighted QALYs’. For example, it may be appropriate to treat the poor more, relative to the rich. To determine appropriate weights for this and other equity weighted efficiency rationing principles it would be necessary for society (perhaps through its elected representatives) to define and agree a national value system, focusing on equity in health care. While this has been attempted in some countries, society’s views on rationing health care in the UK have yet to be well documented in surveys. Carefully focused questions
elicit evidence that both the elderly and the young support using age as a rationing criterion.26 However, more generally worded opinion polls reject this principle.27 Research to resolve these apparent conflicts, and to consider weights other than age, is a priority.

2.4. Overview: explicit rationing criteria

The explicit rationing of health care requires clarity in the definition of the principles by which access to care will be determined. There needs to be a public debate about such principles so that they reflect social values about efficiency (the patient’s ability to benefit from care per unit of cost) and equity (e.g. a ‘fair innings’ approach). Politicians in the UK are reluctant to admit the need for such a debate, let alone lead it. A problem with the definition of explicit rationing criteria based on efficiency and/or equity is that managers and politicians would be more accountable for their choices!
3. The practice of rationing health care

3.1. Rationing options

The focus of the rationing debate world-wide is prioritisation by relative cost effectiveness or, when data and politics insist, some approximation to this. Sometimes the use of economic principles (cost effectiveness) produces harsh decisions which are politically unacceptable. If we regard politicians as representative of the values of the electorate, these decisions, e.g. the non-treatment of infants with severely low birth weight, might be viewed as unacceptable to society. Thus political resistance of this efficiency concept may reflect equity considerations such as the fair innings. Sometimes data about the relative cost effectiveness of competing interventions is absent and ‘expert’ judgements or ‘consensus statements’ are used as proxies. Experts are often inexpert as the US physician Alvin Feinstein has remarked:

The agreement of experts has been the traditional source of all the errors through medical history.

Consensus processes may help identify factors causing a lack of agreement, but resulting statements are often frail, as the former Israeli Foreign Minister Abba Eban has remarked:

Consensus means that lots of people say collectively what nobody believes individually.

However, despite the problems, groups in many nations have sought to prioritise both in principle and practice in a manner which is explicit, but usually bears only an approximation to cost effectiveness.

The use of such mechanisms can be ‘top down’ from central experts or ‘bottom up’ from care providers. De facto the rationing agent at the local level tends to be the health care professional, often the doctor, sometimes the nurse, and usually in a team context. Rationing by clinical teams needs not only explicit criteria and evidence based practice guidelines but also a resource constraint. Thus a preferred system of organising rationing might be that budgets are devolved to clinical teams, be they in the hospital or in primary care. This obliges rationers to confront the issue of opportunity cost explicitly and debate both the clinical benefits and resource costs of particular decisions. Patients must be informed about and involved in such choices. Interventions may be cost effective to the health service, but involve unpleasant processes which make patients decline them.

Ideally, explicit attempts to ration care might include:

● clear articulation of the rationing principle (based on cost effectiveness,
with appropriate consideration of equity issues such as age, social class and lifestyle);

● robust attempts to prioritise in relation to this principle;

● systematic reviews of the evidence base and investment in the enlargement of that base by appropriate and well designed trials and modelling;

● devolved budgets to clinical teams which carry out rationing (using national rules until the local budget is exhausted) and may, as a consequence of financing in this way (and perhaps linking success in this role to rewards), encourage the allocation of resources on the basis of cost, health benefit for patients (effectiveness) and equity weights as articulated by the public.

### 3.2. The Oregon experiment

In the US there is no national policy of universal coverage for health care. The majority of health care is financed and provided privately, through an insurance market system which is subsidised extensively and expensively by tax offsets. This system of health care creates considerable and harsh inequities, with around 40 million people in the US uninsured. Several government financed health care programmes exist: Medicare, Medicaid, and the Veterans’ programme; and these public expenditures, together with tax offsets, represent around 40 per cent of overall health care expenditure. Medicare is a federally administered programme for those aged over 65, and for certain categories of chronically sick or disabled people. Medicaid is a State administered programme that provides all ‘medically necessary’ services to certain categories of poor people. The US welfare system therefore rations by exclusion, with access to health care determined by being part of a category.

Cost inflation in the US health care system has stimulated increased regulation of the ‘free market’ in health care, in particular by the use of ‘managed care’. There is no agreed, simple definition of managed care: at its simplest ‘managed’ means controlled. Traditionally, the market for health care in the US has been characterised by private insurance, with free choice of practitioners and fee per item of service reimbursement. In this environment, care is ‘managed’ by the choices of patients and doctors, with little control by the third party payers (the insurers). Managed care restricts some of these choices, by using carefully costed, integrated packages of care and utilisation review. This shifts some control to insurers or other funders. Under managed care, insurers contract selectively with providers and give consumers incentives to use providers preferred by and contracted to insurers. These techniques are increasingly used by insurance companies, and by the Medicare and Medicaid programmes.
In 1987 in Oregon, State legislators were faced by cost inflation and incomplete health care coverage for the poor. A seven year old boy, Coby Howard, contracted acute lymphocytic leukaemia, needing a bone marrow transplant for which Medicaid coverage had been discontinued by the Oregon legislature earlier that year. Coby Howard’s death highlighted the problem of denial of expensive life saving treatments despite coverage of less effective therapies for less serious conditions in the Medicaid programme. The other problem in Oregon and other States was the lack of insurance among low-income employed people. These two problems were addressed in 1989 by the ‘Oregon Health Plan’, led by John Kitzhaber, an emergency physician and president of the Oregon senate. This plan included the following features:\footnote{\textsuperscript{30}}

- all people with incomes below the federal poverty level would be eligible for Medicaid;
- the Medicaid package would consist of a prioritised list of diagnoses and treatments;
- the legislature would draw a line on the list below which treatments would not be covered;
- the legislature would not be allowed to reduce reimbursement rates to Medicaid providers;
- Medicaid services would be provided through managed care plans (which are capitated plans administered by vigorous purchasers);
- employers would be required to insure their employees, with the prioritised list as the basic benefit package.

The ‘Oregon experiment’ attempted to develop an explicit system of limiting the number of medical treatments that are paid for under the Medicaid scheme and thus increase the coverage of the programme: seeking to ‘change the debate from who is covered to what is covered’.\footnote{\textsuperscript{31}} Figure \textsuperscript{232} illustrates rationing before and after the implementation of the Oregon Health Plan – essentially the aim was to increase the number of people covered by reducing the benefits package available.

To answer the question of what should be covered in Oregon, a Health Services Commission was created in 1989. It consisted of five primary care physicians, a public health nurse, a social worker and four consumers.\footnote{\textsuperscript{33}} The commission was initially charged with ranking health care interventions, devising a list of health services in order of priority, costing them and using clinical and epidemiological data to advise the legislature where alternative budget allocations would produce ‘cut-offs’ for interventions. The prioritising process included judgements of clinical effectiveness and social values.
To consider clinical effectiveness, around one thousand ‘condition-treatment pairs’ were used, with clinical information being provided by ‘expert’ panels of local physicians. The commission was required to “actively solicit public involvement in a community meeting process to build a consensus on the values to be used to guide health resources allocation decisions” and hold a series of public hearings. The commission contacted interest groups, organised an extensive meeting process in town halls and conducted telephone surveys to elicit respondents’ valuations of different health states.

The result of this extensive process was a series of ‘league tables’ produced from 1990 onwards. The 1990 list consisted of 1,692 condition / treatment pairs. The Commission developed a cost effectiveness formula and collected the data that they needed for that formula. However, this formula was progressively watered down. The ‘cost’ part of the formula was simply based on ‘usual, customary and reasonable’ charges. These prices do not
reflect those costs avoided due to treatment, are not marginal (they do not reflect the additional cost of treating one extra patient) and are not measured from the perspective of society or even Medicaid.\textsuperscript{32} The definition of effectiveness was initially ‘quality adjusted duration’, with duration being the

\textit{Table 1} Summary of data and algorithms used to order Oregon’s four prioritised lists

<table>
<thead>
<tr>
<th>Feature</th>
<th>1990 list</th>
<th>1991 list</th>
<th>1992 list</th>
<th>1993 list</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cost definition</td>
<td>Gross charges</td>
<td>Gross charges</td>
<td>Gross charges</td>
<td>Gross charges</td>
</tr>
<tr>
<td>Effectiveness definition</td>
<td>Quality adjusted duration</td>
<td>Category; quality adjusted duration</td>
<td>Net five year probabilities of death, symptomatic, asymptomatic</td>
<td>Net five year probability of death</td>
</tr>
<tr>
<td>No. of condition/ treatment pairs</td>
<td>1,692</td>
<td>709</td>
<td>688</td>
<td>696</td>
</tr>
<tr>
<td>Proposed no. of pairs covered</td>
<td>Not determined</td>
<td>587</td>
<td>568</td>
<td>565</td>
</tr>
<tr>
<td>Ranking algorithm type</td>
<td>Simple</td>
<td>Lexicographic\textsuperscript{1}</td>
<td>Lexicographic\textsuperscript{1}</td>
<td>Lexicographic\textsuperscript{1}</td>
</tr>
<tr>
<td>Algorithm step 1</td>
<td>Cost effectiveness</td>
<td>Category</td>
<td>Improvement in five year survival</td>
<td>Improvement in five year survival</td>
</tr>
<tr>
<td>Algorithm step 2</td>
<td>Alphabetical by diagnosis</td>
<td>Net benefit</td>
<td>Improvement in symptoms after saving life</td>
<td>Cost</td>
</tr>
<tr>
<td>Algorithm step 3</td>
<td>Hand adjustment</td>
<td>Improvement in symptoms</td>
<td>Alphabetical by diagnosis</td>
<td></td>
</tr>
<tr>
<td>Algorithm step 4</td>
<td>Cost</td>
<td>Hand adjustment</td>
<td>Alphabetical by diagnosis</td>
<td></td>
</tr>
<tr>
<td>Algorithm step 5</td>
<td>Alphabetical by diagnosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Algorithm step 6</td>
<td>Hand adjustment</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\textsuperscript{1} Where condition / treatment pairs are tied after the initial ranking, one or more additional steps are introduced to break the ties.

Source: Tengs 1996\textsuperscript{32}
The number of years over which the treatment benefited the patient, adjusted by quality of life associated with health states gathered by a rating scale method used on a telephone survey of Oregonians. This definition was also simplified over time (see Table 1). The 1990 list was withdrawn due to widespread criticism, and was never submitted for the waiver from Federal Medicaid legislation which would have been required to implement the pol-

### Table 2 The Oregon Health Plan’s prioritised list of health services, 1995

<table>
<thead>
<tr>
<th>The five top items</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Diagnosis: severe or moderate head injury, haematoma or oedema with loss of consciousness. Treatment: medical and surgical treatment.</td>
<td></td>
</tr>
<tr>
<td>2. Diagnosis: insulin dependent diabetes mellitus. Treatment: medical therapy.</td>
<td></td>
</tr>
<tr>
<td>4. Diagnosis: acute glomerulonephritis, with lesion of rapidly progressive glomerulonephritis. Treatment: medical therapy, including dialysis.</td>
<td></td>
</tr>
<tr>
<td>5. Diagnosis: pneumothorax and haemothorax. Treatment: tube thoracostomy or thoracotomy, medical therapy.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>The five bottom items</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>741. Diagnosis: mental disorders with no effective treatments. Treatment: evaluation.</td>
<td></td>
</tr>
<tr>
<td>742. Diagnosis: tubal dysfunction and other causes of infertility. Treatment: in vitro fertilisation, gamete intrafallopian transfer.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Six items near the 1997 cut-off line</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>576. Diagnosis: internal derangement of the knee and ligamentous disruption of the knee, grade III or IV. Treatment: repair, medical therapy.</td>
<td></td>
</tr>
<tr>
<td>578. Diagnosis: noncervical warts, including condyloma acuminatum and venereal warts. Treatment: medical therapy.</td>
<td></td>
</tr>
<tr>
<td>581. Diagnosis: dental conditions (e.g. broken appliances). Treatment: repairs.</td>
<td></td>
</tr>
</tbody>
</table>

Source: Bodenheimer 1997, adapted from Oregon Health Plan Administrative Rules.
The ordering of the 1990 list was intuitively flawed, for example treatment for thumb sucking and acute headaches received higher rankings than treatment for AIDS and cystic fibrosis.\textsuperscript{32}

In 1991 a second list consisted of 709 condition-treatment pairs, reduced by grouping disease codes, and the ranking algorithm was changed (Table 2). Some of the unacceptable rankings were removed, and the Commission abandoned their attempt to rank by cost effectiveness, using a completely different method (Table 1).\textsuperscript{32} The Oregon legislature defined ‘basic care’ by funding 587 of the 709 interventions on this list. Box 1 shows high ranking priorities, and Box 2 gives the Oregonian consensus definition of basic care.

\textbf{Box 1} \textit{Oregon's high ranking priorities}

- Acute, fatal conditions where treatment prevents death and leads to full recovery
- Maternity care
- Acute, fatal conditions where treatment prevents death but does not lead to full recovery
- Preventive care for children
- Chronic, fatal conditions where treatment prolongs life and improves its quality
- Comfort care

\textit{Source: Kitzhaber 1993}\textsuperscript{33}

\textbf{Box 2} \textit{Oregon's consensus definition of basic care}

- Initial evaluation and diagnosis
- All preventive and screening services
- Dental services
- Hospice care
- Prescription drugs
- Routine physical examinations
- Mammography
- Most transplants
- Physical and occupational therapy
- Virtually all Medicaid mandates

\textit{Source: Kitzhaber 1993}\textsuperscript{33}
In order to implement this scheme, Oregon required a Federal waiver. This was refused by the Bush administration in 1991. The rejection was based on complaints by interest groups representing disabled people, on the grounds that it undervalued the quality of life of people with disabilities and violated the Americans with Disabilities Act which required equal treatment of able and disabled people. It has been suggested that rationing was too ‘hot’ a political issue to tackle at the beginning of the 1991 election campaign.30

After the refusal to waive Federal legislation, the Health Services Commission produced another version of the list, combining all conditions with some reduction in quality of life into a single state, ‘symptomatic’. This list was also submitted for a Federal waiver, which was granted by the Clinton administration subject to further changes regarding the ‘symptomatic’ state, which was still thought to disadvantage disabled people. In the 1993 list the only data used by the Commission were five year survival rates, with and without treatment, and cost. This list was finally implemented in 1994.32

Table 2 shows three parts of the 1995 list, the top, the bottom and those near the current line (578) below which services will be denied.30

The Oregon health plan achieved one of its primary goals: that of expanding coverage of Medicaid. All Oregonians with an income under the Federal poverty level (in 1997 $13,000 for a family of three) are eligible for Medicaid, whereas before the plan only 57 per cent of these people were eligible.30 The proportion of uninsured people in the State fell by between two and seven percentage points from 1991 to 1995, whereas in the US overall this rose by one percentage point.30 However, the plan has not achieved an efficient rationing system, due to its move away from cost effectiveness criteria:32

Oregon’s effort to change the way in which care is rationed to Medicaid recipients has resulted in a pattern of resource allocation that is probably better than the situation it replaced, but still suboptimal ….. Although Oregon had the right idea in 1990 when they attempted to use cost-effectiveness to ration care, they unfortunately abandoned this approach when ranking lists between 1991 and 1993. Ranking by cost-effectiveness, rigorously defined and measured, is the only algorithm that has any hope of achieving efficiency.

The Oregon experiment created a great deal of controversy and debate within the State, in the rest of the US and world-wide. One of its main weaknesses is the lack of good clinical evidence of effectiveness, with a reliance instead on consensus views of local physicians. This created a barrier to defining rigorously cost effectiveness, and other less appropriate algorithms were used. It may be possible however to incorporate better information on outcomes as it becomes available, as a new priority list is generated with each budget cycle. However, another defect in the Oregon
process was the failure to consider explicitly and systematically the separate issues of efficiency and equity. Thus the initial cost effectiveness focus was criticised and abandoned because the equity issue of low birth weight babies (fair innings) was treated, in what was deemed by Commissioners and the public, in an inadequate fashion. This blurring of the efficiency and equity distinction, and its effects, has sharp lessons for future public rationing exercises.

The Oregon experiment highlighted the need for clear evidence on costs and outcomes in order to prioritise health care interventions, and demonstrates that efforts to use cost effectiveness as a criterion for prioritisation can be easily eroded by political and social concerns about equity.

3.3. The Netherlands: the Dunning Report

In 1988 the Dutch government accepted the principles of the Dekker Committee report,34 which proposed a purchaser-provider split in health care with a compulsory national health insurance scheme to cover all ‘basic’ benefits. This represented a move from a segmented market of social insurance foundations (‘sickness funds’) and private health insurers. To introduce competition into purchasing, the scheme consisted of competing, prospectively budgeted, health care insurers, with regulated competition for policyholders. Provision of health care remained highly regulated: most physicians and most hospitals are independent but operate in a market in which pricing and entry are completely determined by direct government regulation or by government-condoned self-regulation.

In order to define a ‘basic package’ of health care services the Dutch government instituted the Dunning Committee in 1990. This was to “examine how to put limits on new technologies, deal with scarcity and ration care, and to propose strategies to improve choices in health care on different levels”.35 The Dunning report in 199236 developed a strategy for making choices in health care, suggesting ‘a funnel with four sieves’: is the therapy necessary? is it effective? is it efficient? and should it be left to individual responsibility? (see Figure 3).35

The report highlighted the need to acquire communal valuations of different treatments, to determine what is ‘necessary’ care and what care should be ‘left to individual responsibility’, and also the need to invest in evaluation to determine the effectiveness and efficiency (cost effectiveness) of treatments. Decisions have been controversial, for example the contraceptive pill was thought to be part of the ‘individual responsibility’ sphere, but it was politically impossible to exclude it from the sickness fund benefits package. But some rationing decisions have been made, for example reductions in entitlements to physiotherapy, and exclusion of coverage of dental care for adults, except a periodic control visit.37
Figure 3 The Dunning Report’s ‘funnel with four sieves’

Necessary care
Effectiveness
Efficiency
Individual responsibility

1st criterion
2nd criterion
3rd criterion
4th criterion

Limits to rights
Basic package

Source: Scheerder 1993

35
The Dutch, through the work of the Dunning Committee, have defined clearly a set of rationing principles focused on efficiency and social benefit. The Committee decided not to limit ‘broad solidarity within the basic insurance’ or in relation to ‘age, lifestyle, individual choice or reciprocity’. However they concluded that such issues might be used in situations where costs were high or benefits low.36 Whilst the report of the Dunning Committee precipitated much public debate in the Netherlands and elsewhere, its effect on policy making and choice has been limited. Prioritisation of health technology investments has been undertaken in an ad hoc manner and health care provision has been largely unaffected by the Committee’s review of the rationing issue.

3.4. New Zealand: the Core Services Committee

In New Zealand the health care system was restructured in 1992, with a ‘purchaser-provider split’ reform. The aim was to achieve greater levels of assessment and accountability in the publicly funded health sector.38 The government, in an effort to reduce public expenditure on health care, sought to define the ‘core’ of services that should be publicly provided. This task was allocated to the Core Services Committee in 1992. At first it was thought that the health and disability support services which people were entitled to (or excluded from) could be identified by using a simple list. By mid-1994 this approach had been rejected:39

In the two and half years we have been working to define core services, the Committee has found that on clinical grounds alone, without any consideration of fairness or equity, explicitly identifying core services is not as straightforward as might first have been thought possible. A ‘yes/no’ or ‘in/out’ list approach is just too simplistic. It would either have to be so broad and lacking in definition as to be meaningless, much the situation the Committee inherited, or its explicitness would make it too arbitrary and inflexible resulting in people being unfairly excluded from services. Either way it would fail.

The members of the Core Services Committee have emphasised, as their Dutch and Oregonian colleagues had before them, the need to determine the effectiveness and cost effectiveness of competing interventions. Four fundamental principles underpinned the Committee’s specification of the health and disability services which should be publicly funded:39

- benefit – does the service do more good than harm (effectiveness)?
- value for money – the circumstances which provide most benefit and are most cost effective, that is when compared to other possible approaches, is
it value for money (cost effectiveness)?

● **fair use of public money** – are the people who will benefit most from the service receiving it first? Questions of fairness centre on considerations of social and geographical equity of access to services (giving up some cost effectiveness to achieve equity);

● **communities’ values** – are we spending public money on the services that communities consider to be the most effective and important in a situation of choice (more equity weighting by the political process)?

The resolution of these questions requires consensus via a political process and highlights the need to invest further in the production of clinical and economic evaluation, to provide an evidence base for rationing care, and for community valuation of the definition of ‘core’ services.

Following the election of a coalition government in New Zealand in 1996 further reforms have been introduced, including a move away from ‘competition’ to ‘co-operation’ but with the retention of a purchaser-provider split. Crown Health Enterprises (the equivalent of provider Trusts in the UK) have been radically renamed ‘hospitals’(!) and their theoretical profit motive has been removed. Four regional health authority purchasers have been merged to form one national Health Funding Agency.

Despite the move away from a simple ‘list’ for rationing, other projects have been undertaken to set priorities in New Zealand. For example, a national project has developed standardised priority assessment criteria (essentially a points system) for prioritising waiting lists for elective surgery, covering cataract extraction, coronary artery bypass graft surgery, hip and knee replacement and tympanostomy tubes (grommets) for otitis media with effusion (glue ear). These criteria are used to ration surgical interventions and to prioritise patients on the list using a consistent and transparent approach. They have been developed by professional advisory groups, following a literature review and two stage Delphi process (a process of consultation designed to elicit consensus) open to all relevant specialists and surgeons in New Zealand. Numerical scores were assigned to each of multiple levels of severity on different clinical criteria, and these were added to form a total score. For example, for cataract surgery the overall score is dependent on a number of scales of severity of disability, including visual acuity, glare and comorbidities. Ability to work, the extent of visual impairment and other disabilities are also considered. Social factors were also discussed in the project and partially incorporated within the priority criteria. Those discussed included age, work status, whether patients were caring for dependants or threatened with the loss of their own independence, and time spent on the waiting list. In May 1996 the New Zealand Minister of
Health announced a new fund (of around £57 million) to reduce waiting times, and access to these funds is contingent on the use of priority criteria such as those developed in the national project.\textsuperscript{38}

The priority criteria ‘points system’ has been extremely contentious, with sensational media stories about the death of a young farmer with insufficient points to access heart surgery.\textsuperscript{40} However, response to the initiative has been described as ‘generally positive’,\textsuperscript{38} largely due to the increase in funds to reduce pressure on waiting lists. As in Oregon, it may be that the explicitness of prioritisation criteria has resulted in increased funding for health care, or that explicit prioritisation is more acceptable if introduced at the same time as substantial funding increases. Either way the experience of Oregon and New Zealand is that prioritisation systems are associated with increased health care expenditure.

The priority criteria project represents a start in terms of rationing health care explicitly, but it is limited. It covers only five elective surgical procedures, and ranks within these interventions and not between them. The authors of this process assume that the current allocation between specialties is correct, but do not provide evidence that this is so. It also, like the Oregon experiment before it, relies primarily on consensus views of physicians rather than using explicit cost effectiveness evidence, thus limiting the possibility of maximising improvements in population health outcomes by systematic resource allocation.

Whist the points system was potentially useful as a method of prioritising within intervention categories, their basis was somewhat ad hoc and there was no system to rank interventions and facilitate choices between therapeutic categories. The New Zealand government has recently sought to overcome this problem by commissioning the calculation of a cost-QALY league table covering both the health and social care sectors. The purpose of this is to rank the interventions by relative cost effectiveness and to use these data to inform choices. Such calculations are dependent on the availability and quality of data, and particularly on the valuation system used to determine QALYs.\textsuperscript{41}

3.5. Norway

In 1985, the Norwegian Government, confronted by an oil boom, nevertheless became concerned about future rationing of health care after that period of affluence. It established the first national prioritisation committee in the world. The Lonning Committee report\textsuperscript{42} has not been translated into English, but the thrust of their argument was that severity of disease was the primary criterion for prioritisation, although this notion did incorporate notions of effectiveness and cost effectiveness. The Committee rejected the
use of QALYs in prioritisation and defended the primacy of clinical judgement in resource allocation at the patient level. The Committee advocated ‘equal access for equal need’ when discussing equity but appeared to be unclear in its definition of need. ‘Justice’ and ‘autonomy’ were also discussed but were not well defined, ranked or costed. In 1996 the Government asked the Lonning Committee to reconvene, and a second report was published in 1997. Again severity, effectiveness and cost effectiveness were put forward as the rationing criteria. They proposed that medical committees be established to use these criteria. To facilitate prioritisation, the Committee proposed the establishment of a National Priority Board and investment in health technology assessment to inform resource allocation choices.

### 3.6. Sweden

In 1992 the Swedish Health Care and Medical Priorities Commission was established to examine prioritisation processes in health care, and, in large part, emulated the Norwegian initiative. In 1993 a consultation document was published, proposing three basic principles of prioritisation: human dignity, need or solidarity and efficiency. Together these imply that all individuals are equally valuable, resources should be concentrated where needs are greatest and ‘one should opt, other things being equal, for that which is most cost-efficient’. The Commission rejected rationing by age, low birth weight, self inflicted injuries and economic and social status. They also rejected the idea that a basic minimum health care package should be devised. On the basis of the three ethical principles, the Commission proposed that priority setting should be guided by the following priority categories, with the condition that access to assessment was a pre-requisite:

- **I** treatment of life-threatening acute diseases and diseases which, unless treated, will lead to disablement or death. Treatment of severe chronic diseases; palliative terminal care and treatment of diseases which have entailed a reduction of autonomy (i.e. acute conditions);

- **II** population based prevention and health screening of documented efficiency; individualised prevention and habilitation / rehabilitation, together with the provision of technical aids not forming an integral part of care (i.e. prevention and rehabilitation);

- **III** treatment of less severe acute and chronic diseases (e.g. varicose veins and gastritis);

- **IV** borderline cases;

- **V** care for reasons other than disease or injury.
The final report of the Commission in 1995\textsuperscript{46} followed consultation on the first report, showing general public and professional support for the principles proposed in the 1993 report. However, age was thought by public and professional surveys to be a factor in prioritising, but the Committee's recommendations were not changed. The priority categories were reformulated slightly but basic criteria remained unchanged. The Committee recommended that principles of human dignity, need and solidarity should be given legal status, but not the cost efficiency principle.\textsuperscript{44} Its members recognised that interpretation of these categories might vary and that doctors would be guided by the individual (patient) ethic and managers by the social (population health) ethic.

The legal status of principles excepting efficiency suggests that, once again, the cost effectiveness criterion, while accepted in principle, was apparently undermined by ‘dignity’, ‘need’ and ‘solidarity’ criteria, often ill defined concepts which do not necessarily conflict with efficiency. Again it can be seen that the efficiency criterion is not absolute but has to be weighted by equity criteria which are often ill defined. The need for more careful definition and ranking of equity weights and the exploration of the opportunity cost of their pursuit at the expense of efficiency, is considerable and clear.

Williams\textsuperscript{47} criticised the Commission for defining health imprecisely (the WHO definition of ‘a state of complete physical, mental and social well being’) and lacking clarity in their definition of ‘need’ and ‘cost’. ‘Need’, Williams argues, is best defined in terms of ‘capacity to benefit’. ‘Cost’ was not defined by the Commission and is, of course, the value of alternatives foregone (opportunity cost). Williams points out that the Commission’s definition of solidarity as ‘effort to equalise the outcome of care as much as possible’ implies the use of the health care system to reduce inequalities in people’s lifetime experience of health.

In 1998 the Swedish government created a new Committee with three functions: to promote the implementation of prioritisation; to monitor prioritisation efforts in the County Councils (whose role is to fund and provide health care); and to monitor international developments. Local prioritisation models have emerged, e.g. one County Council is using a modified Oregon system, another is using local guidelines and another has established seven levels of workload and queues ranked according to priorities.

3.7. Finland

The collapse of the Soviet Union, with its sharp effects on Finnish gross domestic product, led to expenditure reductions and market experiments which threatened both the volume and distribution of health care in
Finland. As a consequence, the National Board of Welfare and Health commissioned a review of the prioritisation literature in 1992 and subsequently, in 1993, a working group was created, which reported in 1995.48 The group, like all its other national counterparts, emphasised justice and equality in relation to age, lifestyle, disability and other personal characteristics. It argued that ‘the first priority should be given to cases where intervention is needed to preserve or return the age specific functional capacity’. However, even at this level, they argued that the decision to treat ‘is affected by the individual health benefit and the risk involved in the intervention’. Another argument in the report is that the State ‘guarantees the same level of publicly funded services for everyone’.

Such grand statements, implying a guarantee regardless of ability to benefit, are useful ingredients in public debate but fail to identify and rank rationing options (with detailed quantification and debate of trade-offs). The authors, recognising the limits of knowledge, advocated increased investment in research and development and the creation of a Health Technology Assessment centre. They also emphasised the need for prioritisation to take account of the effects of economic recession and market mechanisms on equity in the health care system.

3.8. UK experience

The approach of national politicians in the UK to systematic rationing of health care is perhaps summarised by the story of a health minister in the 1980s who, when asked by an academic if the UK government would encourage an explicit debate about health care rationing, was alleged to have responded with the words ‘bugger off – I want to be re-elected!’. The political problems associated with rationing health care are presumably related to political perceptions of society’s wish to pursue valued but ill defined equity objectives (and not mere efficiency). This has discouraged explicitness about rationing in the UK at national level, certainly amongst our elected representatives in Parliament. Throughout the 1980s, politicians denied that ‘rationing’ existed, replacing the term with the apparently less sensitive ‘priority setting’. However, rationing has always existed in the NHS, despite the tendency to ignore it, and it is regularly rediscovered in periodic NHS ‘crises’.14

Despite the reluctance of national politicians to engage in debate, rationing issues have been approached at local level and by other groups. There is evidence that the public can accept the inevitability of rationing health care resources, and can express opinions on difficult decisions about who should receive scarce health care resources. An interview survey based on a random sample of adults in Great Britain to elicit views on priorities
Table 3  Priority rating of health services (GB): mean rank

1. Treatments for children with life threatening illnesses
2. Special care and pain relief for people who are dying
3. Preventive screening services and immunisations
4. Surgery, such as hip replacement, to help people carry out everyday tasks
5. District nursing and community services / care at home
6. Psychiatric services for people with mental illness
7. High technology surgery, organ transplants and procedures which treat life threatening conditions
8. Health promotion / education services to help people lead healthy lives
9. Intensive care for premature babies who weigh less than 680g with only a slight chance of survival
10. Long stay hospital care for elderly people
11. Treatment for infertility
12. Treatment for people aged 75 and over with life threatening illness

Source: Bowling 1996

for health services generated a 75 per cent response rate, and most thought that surveys like this should be used in the planning of health services. Using a priority ranking exercise of 12 health services, the public were found to prioritise treatments specifically for younger rather than older people, and there was some public support for lower priority being given to care for people with self-inflicted conditions, for example through tobacco smoking. Table 3 illustrates the mean ranking of various health services by the sample surveyed, and Table 4 shows some stated attitudes about rationing.

The self appointed Rationing Agenda Group (RAG), consisting of NHS managers, clinicians, nurses, media representatives and academics, was created ‘to deepen the British debate on rationing health care’. This group of individuals ‘believes that rationing in health care is inevitable and that the public must be involved in the debate about issues relating to rationing’. Initially, the group prepared a document presenting all the issues relating to rationing in the UK NHS, while developing ways to involve the public in the debate and evaluate the whole process. The group outlined possible objectives for the NHS, including:

- maximising health gain (e.g. maximising QALYs);
- minimising health inequalities, for geographic areas, groups or individuals;
- improving the position of the worst off for geographic areas, groups or individuals;
Table 4  Attitudes about health priorities (GB): percentages (numbers)

<table>
<thead>
<tr>
<th>Possible answers</th>
<th>Strongly disagree</th>
<th>Disagree</th>
<th>Neither agree nor disagree</th>
<th>Agree</th>
<th>Strongly agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>High cost technology (for example transplantation and kidney machines) should be available to all regardless of age</td>
<td>2 (32)</td>
<td>11 (216)</td>
<td>7 (133)</td>
<td>55 (1,092)</td>
<td>25 (505)</td>
</tr>
<tr>
<td>People who contribute to their own illness – for example, through smoking, obesity, or excessive drinking – should have lower priority for their health care than others</td>
<td>10 (188)</td>
<td>33 (656)</td>
<td>15 (289)</td>
<td>33 (656)</td>
<td>9 (186)</td>
</tr>
<tr>
<td>The responsibility to ration health care spending should rest with the doctor rather than a hospital manager, health authority, politician or government minister</td>
<td>1 (30)</td>
<td>14 (271)</td>
<td>10 (196)</td>
<td>48 (946)</td>
<td>27 (524)</td>
</tr>
<tr>
<td>The government should issue guidelines to doctors about when not to use lifesaving medical treatment / technology</td>
<td>28 (548)</td>
<td>49 (962)</td>
<td>8 (165)</td>
<td>12 (245)</td>
<td>2 (47)</td>
</tr>
<tr>
<td>If resources must be rationed, higher priority should be given to treating the young rather than the elderly</td>
<td>5 (94)</td>
<td>24 (476)</td>
<td>21 (422)</td>
<td>40 (776)</td>
<td>10 (203)</td>
</tr>
<tr>
<td>The patient’s quality of life should be considered in determining whether or not to use lifesaving treatment / technology</td>
<td>2 (52)</td>
<td>12 (237)</td>
<td>12 (227)</td>
<td>51 (1,004)</td>
<td>23 (451)</td>
</tr>
</tbody>
</table>

Source: Bowling 1996^9

- social reassurance, stability, cohesion;
- assistance for certain disadvantaged groups;
- control of national public health expenditure;
regulation of the delivery of care to avoid unnecessary or inappropriate care.

They also suggested a list of individuals and organisations whose views might be taken into account when rationing health care, including the general public, patients, patients’ families and friends, interest and user groups, clinicians, managers, central government politicians, local government representatives, ‘experts’, the media, industry, the judiciary and groups with ‘moral authority’ such as the clergy. A combination of some or all of these should perhaps have responsibility for making rationing decisions, with appropriate accountability mechanisms.

Various attempts have been made by health authorities to obtain public preferences, and encourage ‘the public’ to participate in priority setting. However, decisions about who is consulted, when, how and about what have all ‘been neglected in the rush to implement the somewhat vacuous policy outlined by the government since the late 1980s’. The reluctance of government nationally to ration by explicit criteria has meant that district level health authorities have been responsible for this, which can lead to variations in care, often sensationalised. Cambridge and Huntingdon Health Authority chose not to finance the experimental care of Jaymee Bowen (‘Child B’) in 1995 on the basis of lack of evidence of clinical effectiveness of a second bone marrow transplant for her acute myeloid leukaemia, but other purchasers indicated that they would have treated her. This case attracted a great deal of media attention, some of which was selective in its coverage of the case. Many newspaper journalists viewed this as a case illustrating the general issues of health care rationing, and some suggested examples of less worthy uses of NHS funds, for example ‘bureaucracy’, managers’ cars, abortions, cosmetic surgery, sex change operations etc. This poor quality media coverage, which re-emerged after Jaymee’s death in May 1996 suggests that if public participation in the rationing debate is to be encouraged, other means of informing the public will be necessary. It is striking however to note the media and public debate stimulated by this case, particularly given the parallels between the original decision not to fund Jaymee Bowen’s bone marrow transplant for leukaemia and the decision not to fund Coby Howard’s bone marrow transplant for leukaemia which stimulated the Oregon health care debate and rationing experiment.

Citizens’ juries are one attempt which has been made to involve members of the public in health care prioritisation. This has been attempted firstly in Cambridge and Huntingdon Health Authority following the ‘trial by tabloid’ to which the health authority was subjected after its decision not to fund the experimental treatment of Jaymee Bowen. Sixteen ‘jurors’ sat for four days, hearing advice from expert witnesses including a director of pub-
lic health, a representative of the RCP and a health economist. The jurors were asked to consider how priorities for health care should be set, according to what criteria and to what extent the public should be involved. Most thought that there should be an element of public involvement in developing rationing guidelines, but only alongside other interests. Nobody voted for the involvement of politicians in a national council for priority setting. The jury illustrated that 'given enough time and information, the public is willing and able to contribute to the debate about priority setting in health care'.

3.9. Current UK initiatives

The current situation with regard to the definition and use of explicit rationing rules is that politicians in the UK deny the existence of the problem whilst reforming NHS structures which facilitate the practice of prioritisation and denying cost ineffective care to patients. This situation has been questioned by a number of groups, including the RAG and delegates of a conference on rationing, who in 1997 sent an open letter to the Secretary of State for Health. This letter stated that rationing has always existed in health services but is becoming more severe because of an apparently increasing gap between what could be offered (including new expensive therapies with relatively small benefit for Alzheimer’s disease, motor neurone disease and multiple sclerosis) and what can be afforded. The delegates called on the Secretary of State to develop a framework for rationing decisions to ‘bring about a more equitable and responsive NHS’.

The 1997 White Paper ‘The New NHS’ proposes the creation of a National Institute for Clinical Excellence (NICE), which might better have been called the National Institute for Cost Effectiveness! This will, inter alia, generate evidence based practice guidelines for clinicians. Unlike many guidelines these may be based not only on evidence of clinical effectiveness but also with reference to cost effectiveness. If this initiative is well organised, managed and funded, it could produce national guidelines to inform local clinical practice, and make practitioners more accountable in rationing access to care.

The consultation document ‘A First Class Service’ outlines a policy for ensuring ‘quality’ (more efficient rationing in practice) in the NHS, suggesting that standards will be set by NICE and National Service Frameworks; delivered via clinical governance, lifelong learning and professional self-regulation; and monitored through the Commission for Health Improvement (CHI), a National Performance Framework and an annual National Survey of Patient and User Experience.

During the Government’s Comprehensive Spending Review carried out in 1997-98 there has been discussion of the creation of a ‘fourth hurdle’ for pharmaceuticals and medical equipment. At present new drugs have to
surmount three hurdles: safety, efficacy and quality. It has been proposed that new technologies should also have to demonstrate cost effectiveness before they could be used by NHS purchasers. Furthermore this use could be selective, granted for particular patient categories only and not for general use with unfettered discretion for doctors. This could prevent the inappropriate use of some expensive drugs for minor conditions. However, although the consultation document on ‘quality’ in the NHS suggests that evidence on cost effectiveness will be required from pharmaceutical companies introducing new products, it stops short as yet of formally introducing a fourth hurdle, preferring to introduce it gradually through evidence collected by NICE.

The combined effects of NICE and an explicit fourth hurdle could considerably improve resource allocation if decisions are evidence based and enforced by regulatory pressure and incentive mechanisms. Traditionally the medical profession has been poorly regulated. The Royal Colleges, despite the tax breaks provided by charitable status, have lacked either the resources or the inclination to monitor doctors’ performance throughout their life cycle. Instead they regulate, weakly, entry through examination to membership of a specialty, then provide little management of members’ performance over their careers. The case for evidence based reaccreditation procedures every five years is strong and would facilitate more efficient rationing practices by the profession.62 A similar case is now being advanced by the General Medical Council (GMC).63

An additional form of regulation is represented by the disciplinary procedures of the GMC. Whilst its powers have been increased recently, the process of investigating and de-listing deficient practitioners can be both bureaucratic and long. Furthermore its work often comes very late in the day due to the failure of NHS managers, clinical and non-clinical, to report poor practice promptly. A vivid example of this was revealed recently by the paediatric cardiac surgery deaths at Bristol Royal Infirmary, where death rates far higher than the national average were allowed to continue for seven years with the death of 29 children, despite ‘whistle-blowing’ by an anaesthetist to senior clinical colleagues, hospital managers and Department of Health officials.64 In their report on this case, the GMC rejected the view that Chief Executives should not overrule clinical decisions, emphasising that managers must share clinical responsibility and ensure clinical quality.65

This may also be enhanced by the government’s recent statements on clinical governance, defined as:60

a framework through which NHS organisations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish.
Clinical governance gives a new statutory duty for Trusts, accountable via their Chief Executives and Boards, in respect of the quality of the services they provide. This replicates the financial accountability in corporate governance structures for Trusts.

The Government intends to complement the work of NICE and the GMC with a Commission for Health Improvement (CHI). The CHI will review clinical practice, possibly on a random 'hit squad' basis. Provided the evidence base used for such enquiries is adequate this could act as a catalyst for persuading practitioners to keep up-to-date with clinical and economic evidence in their speciality, and practice efficient rationing of access to health care. Thus Government continues to deny publicly that rationing exists, but is developing the structures and incentives within the NHS so that rationing is carried out more efficiently.

### 3.10. Overview of rationing practice

To what extent has progress been made in attempts to ration health care explicitly across the world? All the national efforts have involved identification of the economic criterion of cost effectiveness and recognised, often superficially, that, whilst of importance, it is not the only criterion and has to be traded off against equity goals. The definition of equity in relation to age, lifestyle and justice has tended to be ambiguous. Where more clear, as in the Swedish report with its apparent equity goal of using the health care system to reduce inequalities in lifetime experience of health, equity is still blurred by other national discussions, and it is discussed without explicit trade off with efficiency.

The authors of the reports generally emphasise the need for a greater, better informed public debate, and advocate increased expenditure on research and development to inform the rationing process. In some places (e.g. Oregon, New Zealand) rationing discussions have been associated with increased health care expenditure. Prioritisation takes place at many levels and this is discussed to varying extents in the national reports. Some advocates of evidence based medicine accept the social goal of maximising population health gain from a given budget (by using the allocation criterion of cost effectiveness) at national, regional and institutional levels, but argue that clinical effectiveness should dominate at the individual level. Whilst this debate is evident in many reports there is little attempt to explore more fully the implication of this for public policy. At all levels of prioritisation processes, a goal often sidelined is the involvement of patients. The usefulness of focus groups and other information mechanisms in the process of prioritisation needs more systematic evaluation.

The discussion of the relative efficiency of alternative means of translat-
ing efficiency and equity principles into the practice of rationing is limited. Central committees have been advocated (e.g. in Norway) and used (e.g. in New Zealand and Oregon). Their role has been variously to foster and monitor policy debate and change. Clinical behaviour and public attitudes may be influenced by such processes.

In parallel with the rationing debate there has been a ‘global epidemic’ of health care reform. These reform processes have been targeted at improving microeconomic efficiency in the allocation of health care resources. In particular the logic of GP fundholding in the UK and New Zealand, and from April 1999 Primary Care Groups (PCGs) in the UK, together with devolved clinical budgets in hospitals, is that clinical teams face fixed budgets and activity and quality targets. In this environment such teams, usually dominated by doctors, have to confront the trade offs between cost, outcome and justice, and ration economically and equitably.
4. Problems with rationing

4.1. Principles and practice

The failure to translate the principles of rationing into practice can be explained by a variety of factors. A major problem is the lack of data about the costs and effects of competing interventions. Also there continues to be a failure to articulate and agree principles and processes for rationing. Finally politicians, particularly in the UK, believe that the public are so immature that a public debate about rationing would lose them votes.

4.2. The information problem

4.2.1. Information needs

The UK RAG has suggested that rationing needs to take place whatever the quality of information available, but also that more information and knowledge would help rationing. They listed a number of aspects of information which could assist rationing if improved:

- population health status – distribution of disease, disability, illness and risk factors;
- health care requirements – those needs which are amenable to health care interventions;
- degree of need or ill health deficit – relative degrees of need in different groups;
- capacity to benefit – relative effectiveness of various interventions;
- cost of various interventions;
- current provision – what and why, as a basis for making appropriate changes in the future;
- how rationing is conducted now – what principles and criteria are being used to make choices;
- what people’s values actually are.

This is a considerable resource agenda. Health technology assessment (HTA) has developed rapidly in the 1990s, with international developments like the Cochrane Collaboration. Typically HTA has grown from a biomedical model, where some agreement has emerged about the merits of the systematic review of available data and the extension of the knowledge base by investing in randomised controlled trials (RCTs). This has slowly
but increasingly involved the inclusion of economic and quality of life elements into RCTs so that knowledge about the clinical and cost effectiveness of diagnostic and curative interventions has been increased.

However, the focus of HTA has tended to be narrow. The elicitation of people’s values about treatment options and the relative efficiency of budgeting and payment systems have been relatively neglected even though they are central to the translation of new knowledge into practice. There is increasing development of the scope of HTA, e.g. in England and Wales a new central research and development committee has been initiated to foster the creation of an evidence base on service development and organisation. However, throughout Europe and North America HTA investments remain modest and vulnerable to those who prefer ignorance rather than evidence to inform the practice of resource allocation.

4.2.2. Evaluation techniques
The usual sources of data about the effectiveness of interventions are observational studies and RCTs. The former often lack adequate comparators and as a result the effects of an intervention cannot be determined accurately as bias may be present. RCTs provide the most reliable estimates of clinical efficacy, reducing bias and so increasing the likelihood that differences in outcome can be attributed to treatments. However, trials indicating efficacy can be poor indications of effectiveness in actual clinical practice. RCTs tend to be designed and implemented according to strict protocols which govern not only the interventions but also patient entry. As a consequence their results, which demonstrate efficacy (effects within a strict trial protocol), may not be generalisable. For example, RCTs often exclude the elderly even if it is this group which may subsequently be the major user of the innovation. A demonstration of efficacy in a narrow trial may lead to the use of the new technology not just for the tested population but in much wider use in practice, at the discretion of doctors. Consequently, in general use, the effectiveness of the new intervention may differ from its efficacy as demonstrated in clinical trials.

The use of RCTs in surgery can be difficult, and surgeons have typically been reluctant to evaluate innovations systematically. For instance an editorial in the Lancet commented on a well designed, executed and reported RCT in surgery and argued that this was the exception to the rule, criticising the reluctance of practitioners to evaluate in surgery. The editor quoted a 1926 paper in which ‘Major Greenwood, a medical statistician, opined that “I would like to shame (surgeons) out of the comic opera performances which they suppose are statistics of operations”’. The Lancet editor in 1991 concluded that only when the quality of surgical research improved could ‘the charge that as much as half of the research they undertake is miscon-
ceived’ be refuted.

Another significant problem in surgical trials is that results may be sensitive to expertise and patients treated by juniors in general hospitals may have outcomes which differ significantly from those treated by more experienced surgeons. The effects of skill and experience on outcomes are difficult to control and make the task of systematically reviewing the evidence base complex and subject to bias.

4.2.3. Evaluation biases

Trials are frequently of poor quality and subject to bias and ‘data torture’. Bailar \(^70\) argued that ‘there may be a greater danger to public welfare from statistical dishonesty than from almost any other form of dishonesty’ and this may still be true. Altman \(^71\) has suggested that ‘the scandal of poor medical research’ may be caused by researchers and clinicians being driven by career needs to augment their curriculum vitae by publishing trials.

A pharmaceutical example of the often poor evidence base for clinical effectiveness is that for non-steroidal anti-inflammatory drugs (NSAIDs), used to treat patients with inflammatory diseases such as arthritis, but which can have significant side effects if misused (for example mortality resulting from stomach bleeds). Gøtzche \(^72\) has highlighted the inadequacies of clinical trials of NSAIDs. In his overview of 196 double blind trials of NSAIDs he analysed overt and hidden bias by scoring the quality of analysis against eight criteria. Gøtzche \(^72\) concluded:

> doubtful or invalid statements were found in 76% of the conclusions or abstracts. Bias consistently favoured the new drug in 81 trials, and the control in only one trial.

Another review of recent, manufacturer supported RCTs of NSAIDs \(^73\) came to similar conclusions, finding that in almost all cases claims of equal or superior efficacy and toxicity were made for the manufacturer associated drugs. \(^73\)

> claims of superiority, especially in regard to side effect profiles, are often not supported by trial data. These data raise concerns about selective publication or biased interpretation of results in manufacturer-associated trials.

NSAIDs are widely prescribed throughout the world, and their use imposes high costs on all health care systems and on patients (through significant gastrointestinal and other side effects). It may be possible to reduce expenditure on NSAIDs and avoid significant adverse effects by changing prescribing behaviour. \(^74\) However, any economic conclusions drawn from observation of studies on NSAIDs must necessarily be tentative when clinical evidence is biased and poor.
Pharmaceuticals are not the only area of poor evaluation or lack of evaluation. Similar (or even worse) problems occur in diagnostic technology, surgery, medical equipment and other interventions. For example, minimal access surgery was introduced and diffused rapidly in several surgical procedures without adequate clinical or economic evaluation, based primarily on the enthusiasm of surgeons. This enthusiasm, without RCT evidence and adequate training, led to avoidable surgical complications.\textsuperscript{75}

4.2.4. Economic evaluation

In addition to the paucity and poor quality of trials in some clinical areas and problems of the difference in efficacy and effectiveness, most trials still fail to incorporate cost elements to enable linking of costs with effectiveness to determine the efficiency of an intervention. Archie Cochrane, a vigorous advocate of RCTs, wrote over 25 years ago of the need to include the measurement of both costs and effects.\textsuperscript{76}

Allocations of funds and facilities are nearly always based on the opinions of senior consultants, but, more and more, requests for additional facilities will have to be based on detailed arguments with ‘hard evidence’ as to the gain to be expected from the patient’s angle and the cost. Few can possibly object to this.

Those in the Cochrane Collaboration, which organises the systematic review of RCTs, accept Cochrane’s view, but clinicians and economists often still fail to produce good quality data about the costs and health gains of therapies competing for funding.\textsuperscript{77}

Against a background of often poor quality clinical research, economists have been advocating, with success, the use of economic evaluation. The number of these studies is growing exponentially.\textsuperscript{78,79} However, despite the existence of guides to good practice in this area for over two decades,\textsuperscript{80,81} defects in the practice of economic evaluation remain.\textsuperscript{82,83} An important defect is caused by the uncritical use of clinical data, thus building castles of sophisticated economic models on the sand (or quick sand) of inadequate clinical evidence.\textsuperscript{84}

If rationing is to be accepted as ubiquitous and made more explicit, better research to augment the evidence base is essential. This does not necessarily mean more funding: often it requires the proper design, execution and reporting of trials rather than the waste of research funds on bad science, which if published after poor peer review, corrupts the knowledge base and leads to inefficient rationing of scarce resources. Furthermore, the focus of most economic evaluation, namely efficiency, often obscures or neglects equity aspects of choices. Decision makers at all levels require information about these if resources are to be targeted successfully to achieve efficiency and equity goals.
4.3. Rationing criteria (again!)

Perhaps the imperative of demonstrable cost effectiveness appears harsh to some and, as a consequence, doctors emphasise benefits (clinical effectiveness) and ignore costs to appear humane and reasonable. Politicians, ever anxious for votes, condone this approach. This is well illustrated in the documents of the current Labour government where there is an emphasis on clinical effectiveness with occasional (rather apologetic!) mention of cost effectiveness. If ‘clinical excellence’ and ‘quality’ initiatives are to be useful, they should must be focused on cost effectiveness if the policy goal is the maximisation of health improvements from the limited health care budget. Few in government or in medicine adopt this efficiency approach alone publicly but most admit its relevance in conjunction with other goals of an equity nature.

4.4. Rationing processes

Another obstacle to translating rationing principles into practice is the weakness of incentive structures to induce appropriate behaviour in practitioners. Unless decision makers in clinical teams face the cost consequences of their decisions they will have no effective inducement to ration well and deploy resources efficiently. Power to treat without responsibility for the consequences of the exercise of such power induces clinicians to use scarce NHS resources inefficiently. Efficient rationing processes will not emerge without the introduction of appropriate evidence based budgeting and incentive arrangements.

The system of general practice fundholding (GPFH) which covers over half of patients in the UK (until April 1999), and its replacement by compulsory PCGs (in essence GPFH for all practices, combined in groups covering approximately 100,000 populations) will bring budget management in primary care to the local level. Clinical budgeting in hospitals, with increasingly ‘hard’ budgets, is having the same effects in secondary care. Slowly the clinical teams who ration care are being forced to confront effectiveness and cost choices at the patient level. The learning required to execute these tasks well will require substantial investments in the production of information, training and reaccreditation procedures. The current (Labour) reform of the NHS hints at the need for such investments but provides neither the costing of them nor their appropriate funding.

4.5. Public opinion

There have been a number of surveys of public opinion about rationing, and the results are sometimes ambiguous. The surveys demonstrate the pub-
lic’s relative ignorance of detail, fostered by poor media coverage which focuses on benefits and ignores costs of innovation (e.g. BBC’s Tomorrow’s World and similar scientific programmes) and often sensationalises (e.g. the case of Child B). Possibly influenced by the media, the public rank new technology highly, whereas professionals tend to discount this and favour support of community and long stay care programmes. They, like Cochrane over 25 years ago,76 favour a redistribution of resources from ‘cure’ to ‘care’ by appropriate rationing mechanisms.

4.6. Overview

Rationing procedures remain complicated by:

● a medical profession still influenced by the Hippocratic Oath (manifested more recently in the evidence based medicine movement) which focuses on patient benefit and tends to ignore opportunity cost;

● a political system which seeks to maximise electoral approval for avoiding the inevitable consequences of limited budgets.

These two dominant groups in UK health care, doctors and politicians, find it difficult to identify and agree rationing criteria and explore the inevitable trade offs. Instead they tend to practice delusion and avoidance with a rhetoric which ignores the apparent public awareness of the inevitability of health care rationing.

Whilst other countries have confronted the rationing issue more explicitly, and come to terms with the need to ration, no country has yet managed to invest properly in translating rationing principles into practice. Such an approach would be costly in terms of information needs, political leadership (nationally and within health professions) and the design of appropriate incentives to support explicit rationing structures and would have to be managed carefully to ensure its benefits exceed the substantial costs.
5. The future

The current British government, emulating a trend started by President Kennedy and fine tuned by President Clinton, tends to use focus groups and opinion polls to follow, rather than lead, public opinion. Efficient democratic government in which decision makers, politicians or health care professionals, are held accountable for the resources they allocate, requires a mix of leading and following with investment in the evidence base to facilitate the rationing of health care and the enhancement of public understanding of these unavoidable processes.

At present British politicians tend to deny the existence of health care rationing when it is an everyday occurrence for all professionals in the health service. Williams (1998) described this situation with a military metaphor:

I detect an increasing degree of resentment in the medical profession that, as the foot soldiers at the battle front, they are left to improvise a tactical plan with whatever resources headquarters provides them with, but without any clear guidance about strategic objectives or rules of engagement. In that situation, the infantryman’s role is not a happy one! ..... The world is not flat, it is round. And it is just not a good enough for those in a position of responsibility to say that it looks flat from where I stand.

How can the political generals be persuaded to direct this campaign? If implemented vigorously and thoroughly, the 1997 White Paper may make such behaviour untenable. The purchasers (health authorities) created by the Thatcher government have yet to develop their rationing skills. However from April 1999 they will be assisted in this role by PCGs. GPs ration resources routinely in their practices. There will be pressure from the government for GPs to rationalise management and practice in primary care by NICE, CHI and clinical governance measures. As these mechanisms are developed, rationing rules will become more explicit: guidelines and treatment protocols, based on effectiveness and cost effectiveness data, may be inflationary and require prioritisation (removal of some services) to remain within budgets. Furthermore the conflicting roles of the GP, as patient advocate and rationer of care, will mean that the profession is likely to work together to oblige politicians to accept their joint, if not primary, role as rationers. GPs are increasingly reluctant to see blame for rationing apportioned primarily to them when the efficient use of the £45 billion NHS budget is an enterprise shared by managers, clinical and non-clinical, and politicians.
Privately British politicians and the leaders of the health care professions accept that rationing is ubiquitous and unavoidable. They conspire to reform the NHS to improve the evidence base with the Research and Development programme, NICE, CHI and systems of clinical governance. Such reforms enhance the evidence base for making harsh rationing decisions. Also within the NHS reform movements of the last decade, politicians have recognised the need to locate budgets where choices are made: with clinical teams in primary care and hospitals. The ‘value for money’ imperative of the Conservatives, carried forward by Labour in its Comprehensive Spending Review, is obliging all to improve the evidence base and enhance accountability with improved budgeting and incentive mechanisms. The processes of rationing are being improved even if the rhetoric of the political marketplace forbids the use of the word and disguises the intent of public policy.

The future requires significant investments of time and effort in evidence based rationing in health care. The principles inherent are:

1. to treat equals equally and with due dignity, especially when near to death;
2. to meet people’s needs for health care as efficiently as possible (imposing the least sacrifice on others);
3. to minimise inequalities in the lifetime health of the population.

This provides a starting point for future debate about rationing. Following Williams, need would be defined as the capacity of patients to benefit (in terms of improved health status) per unit of cost. Principles may conflict, and rationers, at all levels, must quantify the trade off between them which is socially acceptable. Thus how much overall health would citizens be willing to sacrifice in order to reduce inequalities in the distribution of health, for example between rich and poor and over the life cycle? A discussion of this policy requires improved knowledge about the determinants of lifetime health inequality and systematic measurement of the current health status of populations.

The discussion of rationing has persisted for decades, with a slowly emerging consensus about the need to base rationing decisions on efficiency and equity, with explicitly stated and quantified trade offs between the two. As a consequence the UK and other governments move slowly towards this destination as officials, public and elected, recognise the three certainties in life: death, taxes and the scarcity of resources. Health care rationing is unavoidable and ubiquitous, and requires systematic analysis and careful measurement. These, hopefully, will be the characteristics of this debate in the new century.
# Glossary of Abbreviations

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<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tr>
<td>CHI</td>
<td>Commission for Health Improvement</td>
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<td>EBM</td>
<td>Evidence based medicine</td>
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<td>GMC</td>
<td>General Medical Council</td>
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<tr>
<td>GP</td>
<td>General medical practitioner (primary care physician)</td>
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<td>GPFH</td>
<td>GP fundholder</td>
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<td>HTA</td>
<td>Health technology assessment</td>
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<tr>
<td>NHS</td>
<td>(The UK’s) National Health Service</td>
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<td>NICE</td>
<td>National Institute for Clinical Excellence</td>
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<td>NSAIDs</td>
<td>Non-steroidal anti-inflammatory drugs</td>
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<td>PCG</td>
<td>Primary Care Group</td>
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<td>QALY</td>
<td>Quality adjusted life year</td>
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<td>RAG</td>
<td>Rationing Agenda Group</td>
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<td>RCP</td>
<td>Royal College of Physicians</td>
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<tr>
<td>RCT</td>
<td>Randomised controlled trial</td>
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References

7. House of Commons Debates. Committee stage of the National Health Service Bill. 18 June 1946; Columns 1561-1562.


37. van de Ven W. Personal communication. December 1995.


61. Maynard A, Bloor K. Regulating the pharmaceutical industry: pricing should be renegotiated to control research costs and encourage cost effectiveness. BMJ, 1997; 315:200-201.
64. BBC TV. Panorama. 1 June 1998.


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