King's Fund

The Rationing Agenda in the NHS

Bill New

on behalf of the
Rationing Agenda Group (RAG)

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Foreword

British governments of all parties have tended to deny that health care is rationed in the NHS. Nevertheless, it always has been: doctors and nurses have been faced with hard choices about whom to treat, in what order, and how to treat them.

What has changed is that, over the years, advances in diagnosis and treatment have generally come faster than the increase in our collective will to pay for them. For many conditions there are now more options available, offering chances of real benefits, than there have ever been before. Moreover our expectations continue to rise – both among professionals and among patients. In addition, one effect of the Thatcher reorganisation of the NHS has been potentially to make rationing decisions more visible, since the dialogue between those commissioning care (whether they are health authorities or GPs) and those providing it is partly about interrelationships between levels of service and costs. By implication it is almost inescapable that rationing decisions will become somewhat less hidden – and a good thing too.

The purpose of the Rationing Agenda Group (which I chair) is to map the issues that need to be taken into account in rationing in the NHS and raise the levels of public understanding and debate. What follows is our first attempt at a comprehensive decision map. The members of the Group come from a wide variety of backgrounds and disciplines, so it would be surprising if we agreed about the substance of issues like whether or not IVF should be available free of charge on the NHS. We have not sought agreement on questions such as this, but have instead attempted to identify where it fits within the map – our answer being that it fits under the heading of whether some needs are (or are not) outside the scope of what constitutes our collective entitlement to comprehensive medical care.

What we agree about as a Group is, first, that within the NHS rationing is unavoidable because – even with more money, greater efficiency and better evidence about impact – one will always have to ask what the best uses are for the resources available, recognising that not everyone can have everything from which they could conceivably benefit. Second, we maintain that health care rationing – the need for it, how it is done, whether the ways in which it is done are fair – should be more openly discussed and understood. Our combined aim therefore is to promote public understanding about rationing and enhance the quality of the debate.

Among our next steps we are commissioning some people to explore controversial issues within the framework of the map. In each case, we will seek at this stage to illuminate differences in view, and the reasons for them, rather than conceal differences. These papers will be published in due course, starting later in 1996. We are also compiling a case file of how rationing actually takes place in the NHS, from the mundane to the dramatic, thereby building up a picture of how rationing is conducted in the 1990s.

Meanwhile, we warmly welcome comments on the framework provided in this paper and any suggestions for improving and developing it.

Robert J Maxwell
Chief Executive
King's Fund

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Introduction

This paper* presents as neutrally as possible all the issues related to rationing in the NHS. We focus on the NHS for two reasons. First, for those of us resident in the UK it is the health care system with which we are most familiar and most concerned. Second, such a focus allows for a more coherent analysis than would be possible if issues in other systems were included. Our concern is with the delivery of health care, not its finance, although the possible effects of changing the financing system of the NHS are discussed. Finally, although our position is neutral, we do hold two substantive views – namely, that rationing is unavoidable, and that there should be a more explicit debate about the principles and issues involved.

We consider the issues under four headings: preliminaries, ethics, democracy and empirical questions. The preliminaries deal with the semantics of rationing, whether rationing is necessary, and with the range of services to which rationing relates. Under ethics and democracy are the substantive issues of principle and theory. The final section deals with empirical questions and those relating to the practicality of various strategies. There are also a number of case studies to illustrate the issues:

- Jaymee Bowen ('Child B') *page 7*
- The treatment of an elderly dying woman *page 14*
- Interferon beta *page 18*
- In vitro fertilisation *page 23*

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* This paper is a slightly modified version of an article which appeared in the *BMJ* on 22 June 1996 (312:1593–1601).

1 Preliminaries

1.1 How does 'rationing' differ, if at all, from 'priority setting' or 'resource allocation'?

The words and phrases 'rationing', 'priority setting' and 'resource allocation' are often used interchangeably, but on some occasions rather specific meanings are implied. Some of the alternative interpretations include the following:

- 'rationing' implies exclusion or denial of a service;
- 'rationing' refers to the withholding, without consent, of potentially beneficial treatment, or to any non-market allocation of resources (this interpretation is common in the US literature);
- 'priority setting' relates to services or client groups; 'rationing' relates to individuals;
- 'priority setting/resource allocation' tends to involve value judgements; 'rationing' tends to be more technical, based on effectiveness (or vice versa).

We believe that these semantic distinctions are merely variations on the same fundamental question relating to the allocation of NHS resources: **how do we choose which beneficial services should be offered to whom, and which should not?** The question of benefit is analysed further below. However, we consider that health care services which are not considered by anyone to be of any benefit, under any circumstances, are not relevant to this topic. In short, the empirical quest to establish which medical interventions have no benefit is not a question of rationing.

In this paper, we use 'rationing' as a summary term to describe this process of choosing between beneficial services. We have adopted this term because it is the one which provokes the greatest public controversy: using alternative terms does not avoid the need to address the fundamental problem, clearly and coherently.

Box 1
Categories of people who may be relevant to various rationing issues

- the general public:
  - as citizens
  - as taxpayers
  - as potential patients
  - others?;
- patients;
- patients' families and friends;
- interest and user groups, or community representatives (for example, Community Health Councils);
- clinicians;
- managers;
- central government: politicians and civil servants;
- local government: elected representatives and officers;
- 'experts' in specific aspects of health and health care (for example, health economists, ethicists or epidemiologists);
- media: press and broadcast;
- industry (for example, pharmaceutical companies);
- groups with 'moral authority' (for example, clergy);
- judiciary.

1.2 Can health care be delivered without rationing?

Our strategy is simply to present the issues, not to take up positions on them. However, on two points we hold substantive views – that rationing is inevitable, and that we need to be more explicit about the principles and issues. But is this allegedly fundamental problem really fundamental at all? If more resources were made available, could this choice not be avoided altogether? Frequently suggested means for making more resources available include the following:

- improve the efficiency with which existing services are provided;
- cease offering things that are of no proven benefit;
- redeploy resources from lower priority public services (defence is a frequently cited potential source for such additional resources);
- raise taxes (that is, redeploy resources from goods and services that people buy for themselves).

We have no doubt that adopting any one or more of these strategies could ease the resource constraints faced by the health care system, and we could then proceed gradually to discover how far it was necessary to go before we exhausted all the beneficial services that the NHS might provide. During this redeployment process, however, the health care system would face the problem of deciding, from among those services that it had previously chosen not to offer, which beneficial services now to offer (and to whom). This also requires a decision on which services still not to offer (yet).

Hence providing more resources still requires the fundamental issues to be faced. The context within which they are faced will be different, and the thresholds will vary. But the principles that are applied will still need analysis if there is to be a well-informed and responsible public debate about which are the more important new things to offer with the extra resources.

1.3 *What is the range of services relevant to issues of health care rationing?*

Typically, two ways of specifying exclusions from NHS provision are proposed: on the grounds of relative ineffectiveness (the service does not produce enough benefit[1]) or lack of relative cost-effectiveness (the service in question does not produce enough benefit relative to its cost when compared to other services). However, it is never suggested that services displaying these characteristics are not, in principle, part of the business of the NHS. Indeed, if circumstances changed – for example, if technological advance made a once very expensive service much cheaper – then the provision of such a service might be supported. In fact, both 'cost' and 'effectiveness' are simply criteria for choosing between competing claims on resources, and using them to specify packages or exclusions is the logical extension of their use as criteria for choosing between individual cases: issues of this kind are discussed in the next section [Issue 2.1].

There is, however, another basis for excluding services from the NHS. Exclusions can be made simply because the type of service concerned, or the type of benefit it produces, is not relevant to the NHS. Exclusions on this basis recognise that not everything of benefit can necessarily claim to be relevant to a health care system. For example, it may be more appropriate to provide them through some other agency such as local government, or through the voluntary sector, or commercially by the private sector. Currently controversial services with regard to this issue include various forms of cosmetic treatment, physiotherapy for sports injuries, dentistry, eye checks and provision of spectacles, long-term nursing, and infertility treatment.

There are at least two subsidiary questions: who should make the decision about what constitutes the range of relevant services (see Box 1, page 4), and what criteria are appropriate for establishing them? The following offer some possibilities for the second question:

- the service should constitute 'health' care (rather than 'social' care, for example);
- the service should display characteristics which make it unsuitable for market exchange (for example, on equity grounds);
- the service should not be appropriate to leave to the responsibility of the person who desires it.

Even if it is possible clearly to specify which services are to be included, this does not mean that they will necessarily be provided to everyone who makes a claim for them. It will then be necessary to ask the question posed in the next section.

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[1] As noted above, in the extreme case of absolutely no benefit this is not a rationing issue at all. However, on occasion the rationale for exclusion may be that a service produces very little or uncertain benefit, or that there is a very small likelihood of success. To exclude on any of these bases would be to undertake a rationing decision, since a choice is being made between people who could benefit – if to differing degrees and with differing expectations of success.

Case study: Jaymee Bowen ('Child B')

Jaymee Bowen, aged 10 ('Child B' at the centre of the recent legal controversy) had acute myeloid leukaemia. She was given some initial treatment, including a bone marrow transplant at the Royal Marsden Hospital, but after a remission her cancer recurred. NHS clinicians at Addenbrooke's Hospital in Cambridge decided that further bone marrow transplantation was inappropriate – that the probability of a successful outcome was very slight (2.5%) and that treatment would also cause considerable pain and distress. However, on advice from abroad that further treatment and a second transplant still offered a significant chance of success Jaymee's father pressed for another transplant, this time from the Hammersmith Hospital, London. Cambridge and Huntingdon Health Authority refused to pay for the extracontractual referral this entailed, on the basis that clinicians at both Addenbrooke's and the Hammersmith felt the treatment was unlikely to succeed and would also cause considerable pain and distress. Jaymee's father took the case to the High Court, where Mr Justice Laws required the health authority to reconsider. However, on appeal, the HA's decision was upheld. Cambridge and Huntingdon HA consistently argued that financial matters did not enter its decision. Treatment was finally offered in the private sector, by Dr PJ Gravett at the London Clinic, but again Cambridge and Huntingdon declined to pay.[2]

The case provoked substantial public attention, including several offers to pay for the treatment, one of which was accepted. However, the treatment ultimately provided for Jaymee by Dr Gravett at the London Clinic was not bone marrow transplantation but a leading edge treatment – namely, donor lymphocyte infusion. There are only about 20 patients who have received this treatment, and Jaymee is thought to have been the only child. The treatment sets up a graft versus host reaction which is intended to attack the cancer cells. It also attacks other parts of the body, such as cells within the lungs. This treatment was effective for a while, and Jaymee's cancer went into remission for over a year. It eventually returned, however, and in May 1996 Jaymee died.

Several issues in this case relate to our agenda, but we must first distinguish one that does not. Imagine the proposed treatment for Jaymee had cost only one penny: would it still be in her interest? If there is a very low probability of benefit, associated with a definite possibility of harm, it may not be appropriate to offer treatment – or it might, in any event, be refused by the patient. Establishing the facts relating to the probability of benefit from a treatment, and who should be involved in making the decision as to whether certain risks should be borne – the child, her parents, the doctors, the HA – are important issues, but they are not questions about rationing. The HA claimed that it had declined to fund further treatment solely on these grounds, even though the family and child concerned desired it.

However, the proposed treatments did cost a significant amount – for example, £75,000 for the second bone marrow transplantation. Regardless of the HA's insistence that their decision was only made on grounds of appropriateness, there is nevertheless a rationing issue about whether it is ethically defensible to use resources in cases with very small probabilities of success and significant probabilities of harm: could more good be done elsewhere *[issue 2.1]*? Or, is the degree of ill-health or 'need' in an individual case an important enough criterion to weigh against the good forgone to others? Does refusing to finance individual cases such as this damage the benefit of reassurance which the NHS provides? Are these sort of judgements applied consistently across the NHS, and is there sufficient explicitness to judge *[issue 3.4]*?

Furthermore, should special consideration be given to treatments which are innovative and promise tangible future benefits? There may be a

(cont. overleaf)

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[2] R Maxwell (ed.) (1995), *Rationing Health Care*, Churchill Livingstone, London.

(cont. from previous page)

case for setting aside a special budget for very leading edge treatments where there is a difficult balance of harm and benefit. The treatment which Jaymee eventually received is not the most expensive on the NHS, and without experiment knowledge will not advance. On the other hand, the prognosis in Jaymee's case was not good. Her life was extended by little over a year and she suffered considerable distress towards the end. Who should decide whether funds should be allocated to these experimental treatments?

Furthermore, there is the question of whose values are to count *[issue 3.1]*. There are two ways in which this issue is relevant to the Jaymee Bowen case. First, there was disagreement as to the precise estimates of probabilities of harm and benefit. This is always likely when the estimate of benefit is so complex [see Box 2 page 10]; further, how do we assess the girl's 'fighting spirit' and the psychological benefit she might gain from being treated? The American advice was of 30 per cent probability of success for a second bone marrow transplant, although it came from the private sector where there are incentives to be optimistic. Cambridge and Huntingdon HA estimated 2.5 per cent on the basis of advice from the treating doctors. There was little debate about probabilities relating to the donor lymphocyte infusion. Who should decide which estimate is the appropriate one on which to base subsequent decisions? The parents and child will clearly favour a higher probability. The HA may be better placed to take a dispassionate view, although their disinterest may also be called into question if resource constraints are pressing. Should others' values have been taken into account?

Second, whose values should be taken into account when deciding whether, given an accepted probability, this justifies the allocation of resources given its cost? The parents' values were set against those of the medical profession and HA managers. Furthermore, the media played a significant role: was this appropriate? Should the views of the general public be taken into account?

There are other issues: was the HA the right body to take the final decision, or should it be doctors, central government – or the public *[issue 3.2]*? Was accountability sufficiently strong, providing checks on how the HA made the final decision? In particular, was the judicial system the appropriate mechanism in a case of this kind? The courts rarely challenge clinical or resource allocation decisions, although, as in this case, they may ask for a decision to be reconsidered. Should there have been another mechanism such as a citizens' jury *[issue 3.3]*?

2 Ethics

Ethical reasoning seeks principles for evaluating policies and decision-making: what are right actions or good states of affairs? Equity, justice and fairness are key ethical concepts in rationing – like patients should be treated equally, and unlike patients unequally to the extent that their differences are morally relevant. The notion of efficiency, as understood in the context of rationing health care, is presented here as an ethical choice, typically concerned with maximising improvements in health for the population as a whole.[3] One question summarises the main ethical concerns with rationing in the NHS:

2.1 What are the objectives of the NHS, and what is the range of ethically defensible criteria[4] for discriminating between competing claims for resources that is relevant to achieving these objectives?

When considering the objectives of the NHS we must first try to specify the range of benefits which the NHS provides. Our concern is with 'outcome' objectives – those which relate to health and other aspects of people's well-being – although it would be possible to focus on 'structure' (facilities and resources) or 'process' (volume and nature of work done).

There seem to be two kinds of outcome objective: 'personal' benefits and 'public' benefits. Personal benefits are those which individuals enjoy exclusively for themselves – when one individual receives an improvement in health-related quality-of-life, for example, no-one else receives this improvement as well. These sorts of benefits derive from health care interventions. Public benefits are those which we all enjoy at the same time, without one person's enjoyment diminishing anyone else's – no-one is, or can be, excluded. These derive from the system of health care rather than a particular intervention. They can be enjoyed by those who may never use the health care system – for example, the reassurance derived from having an accident and emergency department available may benefit someone who never needs it.

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[3] We are not in this paper concerned with efficiency in the sense of eliminating waste in the deployment of resources – that is, minimising the cost at which a given distribution of health care is provided – as we take this as axiomatic.

[4] If objectives are correctly specified and agreed as appropriate, then criteria relevant to achieving them must be 'ethically defensible'. But in the light of difficulties involved in achieving this specification and agreement, discussed briefly below, there may remain a need to assess independently certain criteria on an ethical basis. Furthermore, there may be occasions where objectives are agreed upon, but there are a number of ways of achieving them, not all of which are ethically defensible.

Box 2
Personal benefits in full

Mortality-related

- lives saved (for example, in preventive medicine)
- survival beyond some specified life-stage (for example, intensive care unit deaths, hospital deaths, peri-operative deaths, infant mortality, deaths in childbirth)
- survival beyond some specified time point (for example, one year survival rates)
- improved life expectancy (for example, life years gained)

Morbidity-related

Presence/absence of some:

- disease (for example, prevalence or incidence of stroke, breast cancer, etc.)
- abnormal state (for example, organ or system dysfunction)
- symptom (for example, dizziness, nausea, pain, rash)
- psychological abnormality

Health-related quality-of-life

Reduction of or adaption to:

- abnormal feelings (for example, dizziness, nausea, pain, depression, anxiety)
- restricted physical capacity (for example, mobility, lifting, self-care)
- restricted sensory capacity (for example, sight, hearing, touch, smell)
- restricted mental capacity (for example, speech, understanding, memory)
- restricted social capacity (activities of daily living, work or leisure)

Composites (usually combining mortality with one of the others)

- symptom-free life expectancy
- healthy active life expectancy (HALE)
- disability-adjusted life years (DALY)
- quality-adjusted life years (QALY)

Satisfaction

- with structure (for example, with facilities provided)
- with process (for example, with time spent waiting in the out-patient department, fairness of decision-making process, courtesy, information)
- with outcome (defined in one or other of the ways listed above)

There are also 'morally-related' benefits which need to be taken into account, such as respect for individual autonomy and respect for individual equal moral worth. These could be located within 'satisfaction with process' above, but are emphasised separately here because of their importance.

The following offers some examples of these various types of benefit.

Benefits from health care (personal benefits) – see Box 2

- mortality-related
- morbidity-related
- health-related quality-of-life
- composites (usually combining mortality with one of the others)
- satisfaction
- morally-related

Benefits from the health care system (public benefits)

- security, reassurance, 'tranquillity'
- a sense of social justice
- facilitate central control and accountability for public expenditure on health care

Questions about the objectives of the NHS should be posed in terms of these benefits. Which of these benefits should be the focus of interest in for the NHS? How should personal benefits be distributed, or should they simply be as large as possible? If more than one kind of benefit is judged relevant, in what order of priority are they placed? If they come into conflict, how much of one should be sacrificed in order to satisfy another more fully?

Some possibilities for the **objectives of the NHS** might be:

- maximising health gain (for example, maximising quality-adjusted life years (QALYs));
- minimising health inequalities, for geographical areas, groups or individuals;
- improving the position of the worst off, for geographical areas, groups or individuals;
- 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.

Normally, when we wish to achieve a certain objective, we establish criteria to assist us in making the specific judgements necessary to achieve that objective. For example, if the objective of the NHS is to maximise health gain, then a criterion involving the QALY might be appropriate. However, given that the objectives of the NHS are multiple, and likely to be conflicting, it is difficult to establish which criteria are relevant for each objective or group of objectives. Furthermore, when we consider the 'public' benefits we may be unsure how, precisely, to achieve objectives related to these benefits.

It is, however, possible to outline criteria – all based in some way on characteristics of people (including the effects of health care interventions on them) – which are generally considered to be candidates for discriminating between competing claims for resources. These relate to questions of how to allocate the personal benefits outlined above. The NHS can concentrate on improving the health of the following possible groups:[5]

- the whole population as much as possible (based on *cost-effectiveness* measures);
- those most in *need* – those with the greatest illness or ill-health deficit (for example, triage);
- particular *disadvantaged groups* (for example, ethnic minority communities);
- those on whom *others depend* (for example, those with dependent children);
- those whose *contribution to society is highly valued* (for example, an eminent scientist);
- those who *'deserve'* it (for example, by avoiding unhealthy lifestyles);
- those who have been *waiting the longest*;
- particular *age* groups (for example, those who have most of their life still before them).

Which of these criteria (and the objectives with which they are associated) are ethically defensible and which are not? Can we assign weights to those that are defensible? Whatever the answers, there will always be a need to be sensitive to costs – that is, every choice to treat one person involves a loss of the benefits available to others. Cost is therefore an underlying constraint on all the objectives of the NHS.

There are two final questions in relation to ethics. The first concerns justice to providers: how much can we expect from those who provide health care in the context of implementing rationing decisions? Fair treatment of providers may be a proper constraint on what can and should be done to ration health care. Second, what proportion of current resources should be allocated to future benefits? In other words, what priority should we give to innovative treatments and to research?

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[5] The criteria which are relevant to the respective groups are placed in italics.

3 Democracy

Ethical debates are extremely unlikely to result in unanimity. Though rational discussion is possible, personal values and innate feelings will often prove resistant to change, and may remain persistently polarised among members of a society. In this context there is a need to develop democratic systems of decision-making in order to resolve conflicts. The issues in this section relate to how rationing should be conducted so as to conform to prevailing notions of democratic accountability.

3.1 Whose values might be taken into account?

Given that values are likely to vary widely among the members of a society, whose values might be taken into account? Box 1 (page 4) gives the list of possible candidates. It would probably be difficult to defend a position which gave absolutely no weight to the views of a particular section of the population. Hence the question becomes one of deciding on the appropriate weighting and combination of values, rather than selecting which groups are relevant. We outline below some of the issues involved with various candidates.

- *The general public* is a complex group. Incorporating the views of the public will involve difficulties in establishing the appropriate perspective the people are to take – are they to speak, for example, in their role as citizens, as potential patients, or as taxpayers?
- *Patients'* values are clearly important in understanding how various medical interventions are valued by those receiving them. Patients may, however, be biased toward their own needs in deciding between rival claims.
- *Patients' family and friends* may articulate excessive demands for overly aggressive treatment. On the other hand, they are best placed to articulate the values and needs of those close to them who cannot speak for themselves.
- *Interest and user groups* may tend to speak for the most articulate, or over-represent the views of those suffering from relatively common diseases. However, they are often best placed to articulate the values of their constituencies.
- *Clinicians* may value treatments because they are part of their professional work, but which are nevertheless of no benefit, or actually harmful. *Managers'* values will inevitably feed into the decision-making process, and like other professionals they may hide decisions from the public. However, both clinicians and managers are well placed to understand the nature of the choices which need to be made.

- *Central government politicians* must have an input as they are elected to implement policies related to a (broad) set of values. However, they may wish to avoid certain difficult issues, and governments of any complexion may be too prone to short-term expediency for their values to reflect the long-term interests of citizens.
- *Local government representatives* do not currently have a means for directly communicating their values. Ought they have more influence in order to reflect the views of their community, or would this cause an unhelpful conflict with central politicians' values? Are they also subject to the same concerns as those mentioned above in relation to central government?
- *'Experts'* should inform the debate rather than promote their own values. But might we give special weight to those who are dedicated to studying questions of value-judgement – to ethicists, for example?
- *Media* – the values of the media will inevitably shape the context in which the rationing debate takes place. Though the media are well placed to communicate the values of otherwise marginalised groups or individuals, they will also be motivated by concerns relating to audience satisfaction which may less appropriate to rationing issues.
- *Industry*'s values need to be understood as they will inevitably have a strong influence – for example, through advertising strategies. However, they will be motivated in large measure by commercial imperatives, and these values are not relevant to rationing in the NHS.
- *Groups with moral authority*, such as the clergy, could have their values given undue weight simply because of their position. However, they may have a role in speaking for the otherwise inarticulate disadvantaged.
- *The judiciary* can play a role in distilling principles from test cases, thus providing an opportunity for others to endorse or reject such interpretations.

Case study: the treatment of an elderly dying woman

An 81-year-old woman was admitted to a short-stay geriatric ward, confused and ill after suffering a fall at home. During her stay in hospital she developed diarrhoea and oral thrush. The staff were under pressure and unable to care adequately for these conditions – at one point the woman was claimed to have been handled roughly. It became clear the woman was dying, and the lack of privacy was distressing for both patient and family. The hospital looked decayed and dirty.

In a case like this it can be difficult to disentangle incompetence and improper behaviour from issues of rationing. No patient should ever be handled roughly. However, the context of these events is determined by rationing decisions elsewhere in the system. In particular, what weight should be given to the allocation of resources for the care of elderly patients *[issue 2.1]*? It may be that resources should be devoted to the young – other things being equal – since they have greater life expectancy. Or should age play no part in these decisions? And within the budget assigned to the care of the elderly, is sufficient weight given to dignity and respect for autonomy – or should resources be devoted to improving symptoms or life expectancy?

Such decisions are often highly implicit – that is, it is not clear who is responsible or why decisions have been taken – with consequent implications for accountability *[issues 3.4 & 4.2]*. This raises questions about whose values should count in allocating resources between client groups: why does the geriatric specialty seem to have a low priority? Is it because of public and professional pressure to supply resources to more 'glamorous' areas of medicine? *[Issue 3.1]*

3.2 Who should have responsibility for making rationing decisions?

If the appropriate weighting of values of all the various groups can be established, they will then need to be implemented. In other words, someone will always need actually to make the hard choices involved in allocating resources. But rationing decisions can be made in many different contexts and at many different levels within the NHS. Furthermore, in each of these contexts and at each of these levels certain groups in Box 1 could be given more or less responsibility for making choices. There is therefore clearly a normative question relating to who ought to have responsibility for making rationing decisions, and in which situations.

Taking the range of possible groups listed in Box 1 as our starting point, we outline below the issues for some of those groups.

- *The general public* might not be appropriate to actually make decisions (as opposed to provide a value input) due to problems of establishing representativeness, and having adequate expertise. However, citizens' juries and other participatory devices offer a mechanism for including 'lay' judgement more directly into rationing decisions.
- *Clinicians* have traditionally undertaken the bulk of rationing decisions in the NHS, particularly on day-to-day matters. The NHS reforms have weakened this influence. Is it still too strong, guided by vested interests? Or would further weakening adversely affect the ability of clinicians to make appropriate decisions in individual cases?
- *Managers* traditionally have had comparatively little influence in rationing matters, though with the development of the purchasing function in the NHS this has changed somewhat. Should they have more – for example, by developing clinical guidelines with a managerial perspective? Or does this intrude on the proper role of the clinician?
- *Central government* makes decisions on how finance is distributed around the country, and sets the legal context. Should it do more and develop a national framework for rationing? Or is this inappropriate, and should the NHS operate in a more locally driven way?
- *Local government* representatives may be an appropriate group for making rationing decisions, given their elected status and responsibility for other care agencies. However, this might cause difficulties for a national health strategy, geographical equity, and allocating finance between 'free' health care and means-tested social care.
- *'Experts'* and *those with 'moral authority'* might be given a greater role in advising on clear, rational and morally informed decision-making at all levels. On the other hand, this might give too much influence to a particular set of interests.
- The *judiciary* will inevitably make decisions when a point of law is in dispute. Should this role be encouraged as a check on the actions of other groups? Or is it important that the courts should be used only as a last resort?

3.3 *What accountability mechanisms are appropriate?*

Once the appropriate allocation of responsibilities for implementing rationing decisions has been established, it will be necessary to institute mechanisms for ensuring that these decisions are indeed conducted in a proper manner. This is the role of accountability mechanisms. Accountability involves both giving an account of the decisions which have been, or are planned to be, taken, and the operation or threat of sanctions so that those making decisions can be properly controlled.

Accountability mechanisms can be organised into one of four separate categories:[6] political, organisational, public pressure, and normative.

- *Political* methods are the most formal and are based on the authority of the sovereign lawmaking body – Parliament and European lawmaking bodies. They include agencies and strategies at the disposal of:
  - the legislature (for example, review of funding, review of statutory instruments, Health Select Committee, Health Service Commissioner, National Audit Office)
  - the political executive (for example, fiscal powers, Social Services Inspectorate, Health Advisory Service, Audit Commission, personnel appointments, 1991 reforms);
  - judiciary (for example, Mental Health Review Tribunal, judicial review).
- *Organisational* methods entail the NHS regulating itself, either by strengthening internal discipline and good management (for example, the development of general management within the NHS), or by exercising 'open government' and exposing itself to the influence of publicity and the scrutiny of the media (for example, by publishing how health authority decisions were made or instituting a citizens' jury), or through the operation of a quasi-market system.
- *Public pressure* mechanisms include the activity of pressure groups and complaints mechanisms (for example, MIND, Patients Association, NHS complaints procedure) and statutory bodies (for example, Community Health Councils) as well as the possibility of individual patients switching from one agency to another (for example, changing GP).
- *Normative* methods involve the inculcation of public service ethos within individuals or professional groups, who then police themselves according to internal codes of conduct (clinicians' ethical codes and peer sanction). Systems of clinical audit might also be implemented to promote normative accountability.

In the past the political methods have been the most influential. One option for improving accountability is to continue to develop these political instruments, by giving more power to watchdogs such as the Audit Commission or the select committee. Alternatively, more radical methods could be introduced. More of the decision-making process could be undertaken in public, and the reasons for decisions published more extensively. Aided by the media, this would allow more public scrutiny – though increased openness might make decision-making more difficult and encourage 'capture' by pressure groups. Citizens' juries offer another mechanism for providing the public more influence over the decision-making process. But this could encourage the statutory decision-making authority to evade its legal responsibility as the final arbiter, and thereby weaken accountability. Another option might be for the purchasing role in the NHS to be given over to elected local authorities. But this may, for example, make it more difficult to develop an integrated 'national' health policy. Finally, accountability might be improved by exploiting the potential for clinical audit to ensure that clinical decisions are consistent with NHS policies. However, this would require the results of clinical audit to be made available to managers. Some doctors may consider that these matters should be kept within the peer review network.

Clearly, accountability requires adequate information. This issue is revisited below.

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[6] See B. Guy Peters (1989), *The Politics of Bureaucracy*, 3rd edition, Longman, London.

3.4 *How explicit should be the principles by which rationing is conducted?*

We established at the beginning of this paper that one of our substantive positions is that the principles by which rationing decisions are taken should be more explicit. One mechanism for improving accountability mentioned above – that of openness – would automatically encourage a more explicit debate, which we support. However, there are important issues relating to the degree to which explicitness and openness is necessarily helpful, particularly for the working of the NHS.

Those who argue for retaining a degree of implicitness cite the following:

- Rationing is morally and methodologically impossible to resolve to everyone's satisfaction. The trust the public currently have in the medical profession could be damaged by the explicit acknowledgement of this. Furthermore, the public could make matters worse by becoming directly involved.
- Such a situation could threaten public confidence in the NHS, particularly if individual cases or forms of treatment were excluded publicly on the basis of 'abstract' principles.
- Being explicit about principles cannot accommodate the heterogeneous nature of health care, and the complexity of individual cases.

On the other hand, those who argue for explicitness counter these points by arguing that:

- In a democracy citizens must be allowed to influence decision-making, both to develop their own moral commitment to democracy, and in order to improve decision-making itself by providing feedback to decision-makers.
- By being explicit, vested interests are discouraged from making decisions on the basis of tradition, prejudice or whim, or in response to vocal, articulate, powerful or wealthy groups.
- If rationing is 'messy', then it is better or be open about this than to risk the consequences of deceiving the public.
- Explicit principles do not codify behaviour, they merely place moral boundaries on the decisions to be taken in individual cases.

We have stated our position in favour of being open and explicit in terms of rationing issues. Whatever principles are thought to be appropriate should be publicly articulated, and these should constitute the framework within which rationing takes place – though RAG does not collectively hold a view as to what these principles should be.

Nevertheless, there remain important issues around the degree of explicitness in specifying principles which is sensible or possible, and the degree to which these principles should be articulated in the context of an individual consultation.

Case study: Interferon beta

Interferon beta is a drug for the relapsing-remitting form of multiple sclerosis. Evidence for licensing the drug comes from a single trial which showed that it seemed to reduce the number of exacerbations of the disease by about one third, but had no effect on progression. There have been some doubts about the methodology used in the trial. The drug is expected to cost about £10,000 per patient per year. There are estimated to be 85,000 patients with multiple sclerosis in the UK of whom 45 per cent are thought to have the relapsing-remitting form. If all these were treated the total cost could be as much as £380 million – that is, 10 per cent of the drug bill.[7]

The evidence on the efficacy of interferon beta is weak and disputed. More information is necessary about its costs and benefits in order to hold those who make decisions on its use accountable *[issue 4.2]*. Licensing authorities do not need to take account of evidence on cost-effectiveness when granting a licence.

Even given the best evidence available, is expenditure on interferon beta a good use of NHS resources *[issue 2.1]*? It seems likely that more benefit could be derived elsewhere from the resources required; however, a specific group would be denied potentially beneficial treatment. If some HAs decline to fund it, what implications would this have for the NHS objective of geographical equity? How should the values of those authorities be weighed against the values of others in assessing the resources to be devoted to this drug *[issue 3.1]*?

A key question is who should be responsible for undertaking rationing *[issue 3.2]*. Once licensed, a drug can in general be prescribed by any doctor. If this is a GP the budget will not be cash-limited, and resources may be taken from other areas of the NHS without the GP having to take this into account. On the other hand, hospital neurologists operate under cash-limits. Should hospital clinicians' freedom to prescribe be further limited by the HA? Should the government have a role? (Apparently an executive letter was circulated to HAs advising against restricting the prescription of interferon beta.) What role should the judiciary have? They may have a role in adjudicating if an individual doctor prescribes against the advice of the HA or central government.

Accountability mechanisms seem weak *[issue 3.3]*. The work of the licensing authority is not widely publicised. If individual clinicians take the rationing decisions, there are few mechanisms for ensuring the proper democratic control of their actions. If the HA attempts to restrain prescribing its legal position is unclear. HA decisions may not themselves be made in an accountable manner. Finally, many decisions related to the rationing of interferon beta are likely to be made in a highly secretive way *[issue 3.4]*. Improved information is needed in order to make the process more explicit and accountable *[issue 4.2]*. But what implications are there for being explicit in the individual consultation if only a few courses of the drug are available for prescription in any one location? Will this damage trust in the doctor-patient relationship, or encourage a mature and responsible partnership?

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[7] T Walley, S Barton (1995), 'A purchaser perspective of managing new drugs: interferon beta as a case study', *BMJ*, 311: 796-9.

4 Empirical Issues

Empirical or factual issues include comparatively uncontroversial questions relating to descriptive analyses of how the process of rationing currently works in practice in the NHS. But they also include issues relating to how much information is necessary to make rationing more accountable, and whether we have enough knowledge to implement specific rationing strategies.

4.1 Who undertakes rationing and what mechanisms are used?

Any group listed in Box 1 might influence rationing decisions, either because their values are taken into account directly, or because they constitute part of an accountability mechanism, or because they influence the system in some other way. But in practice the bulk of rationing decisions in the NHS as it currently operates are taken by either health care professionals or managers. In addition, central government sets the overall framework for making choices by specifying how purchasing power is distributed to regions. The centre also issues annual planning and priorities guidelines, executive letters and exhortatory initiatives (such as those relating to waiting lists), and sets the legal framework for charging and the overall range of NHS responsibilities.

If rationing is taking place, those concerned must be making use of mechanisms, whether formal or informal, statutorily based, or administrative. The following suggestions as to how rationing is effected in practice are split between the national, institutional and individual levels.

At the **national** level rationing is effected by:

- changes to the legal framework (for example, allocating tax revenue between NHS and other health promoting activities, such as housing policy);
- exercising executive powers (for example, devising geographical allocation formulae; setting prescription charges);
- exhortatory initiatives (for example, *The Health of the Nation* and the annual planning and priorities guidance).

At the **institutional** level rationing is effected by:

- government agencies exercising delegated authority in allocating resources – for example, health authorities commissioning care (and possibly excluding services such as cosmetic surgery) and making decisions on extra contractual referrals;
- pricing (for example, of packages of care to be purchased by health authorities);
- managed care strategies (for example, clinical guidelines).

At the **individual** level the GP acts as the principal 'gatekeeper' to care in the NHS. This serves to mediate the delivery of care both between doctor and patient and between generalist and specialist clinicians. But whenever an individual comes into contact with the NHS, one of five methods may be used to bring the demand for care into line with the available supply:[8]

- *Denial* – that is, not providing treatment at all for more or less justifiable reasons (for example, refusal by certain GPs to register homeless people or drug abusers, and non-provision of treatments claimed to be ineffective or inappropriate);
- *Deflection* – that is, encouragement to use other agencies for care (for example, substitution of 'social' for 'health' care for patients with long term needs);
- *Delay* – that is, not providing all forms of care immediately which provides a kind of holding area to 'buffer' excess demand (for example, waiting to obtain a GP or consultant appointment; waiting lists for secondary care; waiting in A&E departments);
- *Dilution* – that is, reducing quality in order to allow existing resources to go further; this may or may not also represent a more efficient use of NHS resources (for example, not using the most expensive prostheses or downgrading the skillmix in nursing teams);
- *Deterrence* – even when services are nominally 'free' there will be certain costs to the individual which may deter them from obtaining care (for example, distance, such as living a long way from a GP's premises; poor information or information only provided in English; and hostile staff or environments).

Among other mechanisms, a lottery system could be implemented in certain circumstances to make a choice between claims considered to be morally equal; and a system of rights could be instituted whereby choices would need to be made with reference to a codified system of individual entitlements to health care, adjudicated by the judicial system.[9]

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[8] See S Harrison and D Hunter (1994), *Rationing Health Care*, IPPR, London.

[9] L Doyal (1995), 'Needs, rights and equity: moral quality in healthcare rationing', *Quality in Health Care*, 4: 273-283.

4.2 What additional information would be required to make rationing more explicit and those responsible more accountable? Is there sufficient knowledge to implement particular rationing strategies successfully?

There is little doubt that more information and knowledge would help rationing. It is also clear that rationing needs to take place whatever the quality of the information available – there is no question of there being insufficient information to ration. Information can never be complete, and we will always be operating with a less than perfect understanding of the state of the world. Indeed, striving for perfect information may not itself be a sensible goal: collecting information involves costs, which means that resources cannot be used to provide benefits of other kinds.

The first question posed above therefore relates to this last point: where should there be a priority for improving the level of information in order to improve explicit and accountable rationing? Some of the possible areas where better information might be valuable include the following:

- Population health status – that is, the current distribution of disease, disability, illness and risk factors;
- Health care requirements – that is, those needs which are amenable to health care interventions;
- Degree of need, or ill-health deficit – that is, information about relative degrees of need in different groups;
- Capacity to benefit – that is, information about the relative effectiveness of various interventions (for example, information relating to individual preferences or utilities for health states as one measure of benefit);
- Cost – that is, information about the costs of various interventions;
- Current provision – that is, information about what is currently provided and why, as a basis for making appropriate changes in the future.

There may also be a need to improve the level of information about how rationing is conducted now: what principles and criteria are currently being used to make choices? Furthermore, there is the question of how much effort should be devoted to attempting to elicit, through various research methods, an accurate understanding of what people's values actually are.

This leads to the second question above: do we have enough information or knowledge to undertake certain strategies with reference to rationing? For a strategy to succeed there needs to be clarity about the objective. As we have seen, there is little consensus about what the objectives of the NHS are. And attempts to collect some kinds of information may be so beset with difficulties that we should proceed with caution in using them for rationing decisions to ensure that they do not lead to worse outcomes than by simply continuing with more familiar data.

Incrementalist models of decision-making argue that 'synoptic' decision-making, which strives for completeness, may end up with worse outcomes than 'muddling through'. However, there is clearly a need to improve the levels of information and knowledge at our disposal to improve explicitness and accountability. We must ensure that the best available data are deployed even if they are imperfect, for everything else is bound to be worse. The appropriate balance needs to be struck.

4.3 How does the system of financing health care affect the practice of rationing?

One response to the proposition at the beginning of this document – that rationing is inevitable – is to argue that if we altered the system of financing then we might avoid the problem of rationing altogether. This kind of argument assumes that rationing only occurs in cash-limited, taxation-based systems such as the NHS. In fact, all health care systems involve the allocation of scarce resources between those who might benefit from them; all involve rationing in this sense.

Private insurance-based systems ration care by making households decide how much of their resources they wish to spend on insurance premiums; some may wish to spend none. Tax-based systems which introduce charges also partly shift the burden of payment out of government budgets directly onto households; 'earmarked' contributions are forms of disguised taxation. But they all involve decisions about how to use households' resources.

The only difference will be in the particular set of financial incentives which play on the actors involved. In a largely private, insurance-based system such as that in the United States this may encourage inefficiency – that is, over-supply for some and no supply for others. Social insurance systems such as those in France and Germany may also be over-resourced. Proposing other forms of finance is no escape from the fundamental issue; it merely alters the way in which the actors involved respond to inevitable scarcity.

In conclusion it is worth making clear that we do not propose any fundamental changes in the methods by which the NHS is financed. We support the continuation of a publicly financed NHS. However, we wish to promote an ongoing, open and informed debate on how to make the hard choices about who should benefit from its limited resources.

Case study: In vitro fertilisation

In a study of 114 purchasing plans for 1992-93 six HAs were found to explicitly state that they would not be buying any in vitro fertilisation or gamete intrafallopian transfer (GIFT) treatment for their populations. At the same time other purchasers were continuing to buy in vitro fertilisation and some even planned to put extra money into the service.[10]

For some purchasing authorities this issue was one of relevance – is in vitro fertilisation the sort of intervention (does it produce the sort of benefit) which is relevant to the business of the NHS *[issue 1.3]*? Arguably, being unable to conceive children is not an illness and if people wish to benefit from in vitro fertilisation they should purchase it in the private sector. On the other hand, there is clearly some physiological dysfunction and there may be severe psychological distress. Does this not indicate a medical condition for which the NHS should take responsibility?

If in vitro fertilisation is considered relevant to the NHS, then the question of allocating resources arises *[issue 2.1]*. In particular, does geographical equity demand that all HAs should provide some level of service, so that a patient's place of residence does not have a decisive influence on likelihood of treatment? How should the benefits of in vitro fertilisation be weighed against other treatments if some level of provision is required? In this context, who should make choices about its provision *[issue 3.2]*?

If HAs and clinicians are responsible some localities may have no service at all; if the government institutes a national policy this will dilute the local nature of decision-making in the NHS. Whose values should count in whether or not to include in vitro fertilisation as an NHS service *[issue 3.1]*? Certain sections of the population may not be sympathetic – for example, men or those who do not desire children.

Furthermore, some doctors may not view infertility as an illness. On the other hand, those patients unable to conceive and their friends and representatives may value their own needs highly simply because they have direct experience of the condition. Although only a few HAs have explicitly stated that they will not purchase fertility services, there may be others that are doing so implicitly. Is this an appropriate way for decisions to be taken in the NHS? What sort of information and how much more do we require for these decisions to be more open *[issues 3.4 &4.2]*? How can accountability be exercised in this setting *[issue 3.3]*?

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10 S Redmayne, R Klein (1993), 'Rationing in practice: the case of in vitro fertilisation', *BMJ*, 306: 1521-4.

The Rationing Agenda in the N

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