

fact." Jurors felt they would have benefited from background briefings, both relating to the overall question at stake and the individual witnesses' presentations. There may be a case for supplying the jury with a briefing paper from a neutral expert before the jury convenes, and encouraging witnesses to supply a one page summary of their argument, also in advance. The difficulty is ensuring that this information is neutral.

Clarifying questions from jurors about points of fact is even more problematic. There could be an "expert" on hand to provide this information, but no individual is all-knowledgeable, and having a single person undertaking the role might introduce bias. However, some procedure for dealing with factual inquiries is necessary.

RECRUITMENT AND REIMBURSEMENT

The jurors were selected at random to represent the sociodemographic characteristics of their community. Although this did not present problems in Huntingdon, in other areas there may be a need to resolve difficulties for jurors for whom English is not their first language.

It was felt that significantly more than the 16 jurors who were recruited would have made the sessions hard to manage; however, more experience is needed of other jury sizes. To retain impartiality it may also be necessary to vet jurors to ensure that none has a vested interest: for example, should a clinician be allowed to take part in a jury discussing issues of priority setting when he or she

might stand to benefit from a particular decision? Jurors were reimbursed with £250 for the four days. They seemed satisfied with this payment—no juror dropped out and attendance was almost 100% over the period the jury sat.

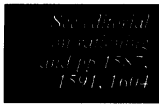
Conclusion

The Cambridge and Huntingdon citizens' jury has shown that, given enough time and information, the public is willing and able to contribute to the debate about priority setting in health care. We are hopeful that this method, in conjunction with the more traditional techniques, may offer us a meaningful way of involving the public in decisions about priority setting in health.⁵ Decision makers at a local and national level should seize this opportunity to show that they are willing not only to listen to but to act on the voice of the public.

- 1 Redmayne S. *Reshaping the NHS: strategies and priorities and resource allocation*. Birmingham: National Association of Health Authorities and Trusts, 1995.
- 2 Bowling A. Health care rationing: The public's debate. *BMJ* 1996;312:670-4.
- 3 Coote A, Kendall L, Stewart J. *Citizens' juries*. London: Institute for Public Policy Research, 1994.
- 4 Royal College of Physicians. Setting priorities in the NHS: a framework for decision making. *J Coll Physicians Lond* 1995;29:379-80.
- 5 Cooper L, Coote A, Davies A, Jackson C. *Tackling the democratic deficit in health*. London: Institute for Public Policy Research, 1995.

The rationing agenda in the NHS

Bill New, on behalf of the Rationing Agenda Group



The Rationing Agenda Group has been founded to deepen the British debate on rationing health care. It believes that rationing in health care is inevitable and that the public must be involved in the debate about issues relating to rationing. The group comprises people from all parts of health care, none of whom represent either their group or their institutions.

RAG has begun by producing this document, which attempts to set an agenda of all the issues that need to be considered when debating the rationing of health care. We hope for responses to the document. The next stage will be to incorporate the responses into the agenda. Then RAG will divide the agenda into manageable chunks and commission expert, detailed commentaries. From this material a final paper will be published and used to prompt public debate. This stage should be reached early in 1997.

While these papers are being prepared RAG is developing ways to involve the public in the debate and evaluate the whole process.

We present as neutrally as possible all the issues related to

rationing and priority setting in the NHS. We focus on the NHS for two reasons. Firstly, for those of us resident in the United Kingdom the NHS is the health care system with which we are most familiar and most concerned. Secondly, focusing on one system alone allows more coherent analysis than would be possible if issues in other systems were included as well. Our concern is with the delivery of health care, not its finance, though we discuss the possible effects of changing the financing system of the NHS. Finally, though our position is neutral, we hold two substantive views—namely, that rationing is unavoidable and that there should be more explicit debate about the principles and issues concerned.

We consider the issues under four headings: preliminaries, ethics, democracy, and empirical questions. 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.

"rationing" relates to individual cases

- "Priority setting/resource allocation" tends to entail value judgments; "rationing" tends to be more technical, based on effectiveness (or vice versa).

We believe 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 that are not regarded by anyone as beneficial 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.

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Preliminaries

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

The terms "rationing," "priority setting," and "resource allocation" are often used interchangeably, but in some instances specific meanings are implied. These other interpretations include the following:

- "Rationing" implies exclusion or denial of a service
- "Rationing" refers to withholding, without consent, potentially beneficial treatment or to any non-market allocation of resources (this interpretation is common in the United States)
- "Priority setting" relates to services or client groups;

Summary issues

- What is the range of services relevant to issues of health care rationing?
- What are the objectives of the NHS and what is the range of ethically defensible criteria for discriminating between competing claims for resources?
- Whose values should be taken into account?
- Who should undertake rationing?
- What accountability mechanisms are appropriate?
- How explicit should be the principles by which rationing is conducted?
- What additional information would be required to make rationing more explicit and those responsible more accountable?
- Is there enough knowledge to implement particular rationing strategies successfully?

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 provokes the greatest public controversy: using alternative terms does not avoid the need to address the fundamental problem clearly and coherently.

Can health care be delivered without rationing?

Our strategy is simply to present the issues, not 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 of making more resources available include the following:

- Improve the efficiency with which existing services are provided
- Stop offering services that are of no proved benefit
- Redeploy resources from lower priority public services (defence is a frequently cited potential source)
- 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 we needed to go before exhausting all the beneficial services that the NHS might provide. During this redeployment process, however, the health care system would be faced with deciding which of those beneficial services that it had previously chosen not to offer, 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 services to offer with the extra resources.

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

Typically, two ways of specifying exclusions from NHS provision are proposed. The first is on the ground of relative ineffectiveness—that is, the service does not produce enough benefit. As noted above, in the extreme case of absolutely no benefit this is not a rationing issue.

However, occasionally 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, as a choice is being made between people who could benefit—if to differing degrees and with differing expectations of success.

The second way proposed to specify exclusions is on the ground of lack of relative cost effectiveness—that is, the service in question does not produce enough benefit relative to its cost when compared with other services. However, it is never suggested that services with either of 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 these services might be supported. Both "cost" and "effectiveness" are simply criteria for choosing between competing claims on resources; using them to specify packages or exclusions is the logical extension of their use as criteria for choosing between cases. Issues of this kind are discussed below.

There is, however, another basis for excluding services from the NHS. Exclusions can be simply because the type of service concerned or 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 a service through some other agency such as local government or 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) and what criteria are appropriate for establishing them? The following offer some possibilities for the second question:

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
- Health care professionals—clinicians or non-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

- 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. It will then be necessary to ask the question posed below.

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. Our concern with efficiency here is not 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.

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

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 in achieving this specification and agreement there may remain a need to assess independently certain criteria on an ethical basis. Furthermore, there may be occasions when objectives are agreed on but there are several ways of achieving them, some of which may not be ethically defensible.

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 wellbeing—though we could focus on “structure” (facilities and resources) or “process” (volume and nature of work done).

There seem to be two kinds of outcome objectives: personal benefits and public benefits. Personal benefits are those which people enjoy exclusively for themselves—for example, when one person receives an improvement in health related quality of life, 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 benefits 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.

Examples of these various types of benefits are listed as follows:

Personal benefits from health care (see box 2)

- Mortality related
- Morbidity related
- Health related quality of life
- Composites (usually combining mortality with one of the others)

- Satisfaction
- Morally related.

Public benefits from health care system

- Security, reassurance, “tranquillity”
- 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

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, perioperative 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 or absence of:

- 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, leisure activities)

Composites (usually combining mortality with one of the others)

- Symptom free life expectancy
- Healthy active life expectancy
- Disability adjusted life years
- Quality adjusted life years

Satisfaction

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

Morally related benefits

There are also “morally related” benefits that 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” but are emphasised separately because of their importance

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, 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 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 Health Authority refused to pay for the extracontractual referral that this entailed on the basis that clinicians at both Addenbrooke's and the Hammersmith thought the treatment was unlikely to succeed and would 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 health authority's decision was upheld. Cambridge Health Authority consistently argued that financial matters did not enter its decision. Treatment was finally offered in the private sector, by Dr P J Gravett at the London Clinic, but again Cambridge Health Authority declined to pay.

The case provoked considerable public attention, including several offers to pay for the treatment, one of which was accepted. However, the treatment ultimately provided by Dr Gravett was not bone marrow transplantation but a leading edge treatment—namely, donor lymphocyte infusion. Only about 20 patients 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. The treatment was effective for a while and the cancer went into remission for over a year. It eventually recurred, however, and in May 1996 Jaymee died.

Several issues in this case relate to our agenda, but first we must 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 included in making the decision on whether certain risks should be borne—the child, her parents, the doctors, the health authority—are important issues, but they are not questions about rationing. The health authority 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 substantial sum—for example, £75 000 for the second bone marrow transplantation. Regardless of the health authority's insistence that its decision was made only 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? 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 treatment in individual cases such as this damage the benefit of reassurance which the NHS provides? Are these sorts of judgments applied consistently across the NHS and is there sufficient explicitness to judge?

Furthermore, should special consideration be given to treatments which are innovative and promise tangible future benefits? There may be a case for setting aside a special budget for very leading edge treatments when there is a difficult balance of harm and benefit. The treatment which Jaymee Bowen eventually received is not the most expensive in 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?

should be the focus of interest for the NHS? How should personal benefits be distributed, or should they simply be as large as possible? If two or more kinds of benefit are judged relevant, in what order of priority should they be placed? If they conflict how much of one should be reduced in order that another may be satisfied more fully?

Some possibilities for the objectives of the NHS might be:

- Maximising health gain (for example, maximising quality adjusted life years)

- Minimising health inequalities for geographic areas, groups, or individuals
- Improving the position of the worst off for geographic 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 help us in making the specific judgments necessary to achieve that objective. For example, if the objective of the NHS is to maximise health gain, then a criterion including quality adjusted life years 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:

- The whole population as much as possible (based on cost effectiveness measures)
- People most in need—those with the greatest illness or ill health deficit (for example, triage)
- Particular disadvantaged groups (for example, ethnic minority communities)
- People on whom others depend (for example, those with dependent children)
- People whose contribution to society is highly valued (for example, an eminent scientist)
- People who "deserve" it (for example, those who avoid unhealthy lifestyles)
- People who have been waiting the longest
- Particular age groups (for example, people who have most of their lives 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. Secondly, 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?

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 of democracy relate to how

rationing should be conducted so as to conform to prevailing notions of democratic accountability.

Whose values might be taken into account?

Given that values are likely to vary widely among members of a society, whose values might be taken into account? Box 1 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 with various candidates.

The general public is a complex group. Incorporating the views of the general public will involve difficulties in establishing the appropriate perspective the people are to take—are they to speak, for example, 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 towards their own needs in deciding between rival claims.

Patients' families 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 overrepresent the views of patients with fairly 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 may actually be harmful.

Managers' values will inevitably feed into the decision making process and like other professionals managers 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 to 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 judgment—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 be 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. Industry, however, will be motivated in large measure by commercial imperatives, which 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 part in distilling principles from test cases, thus providing an opportunity for others to endorse or reject such interpretations.

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 to actually make the hard choices 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 listed in box 1 could be given more or less responsibility for making choices. There is therefore clearly a normative question relating to who should 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 these groups.

The general public might not be appropriate to actually make decisions (as opposed to provide a value input) owing to problems of establishing representativeness. They may also lack adequate expertise in matters of technical complexity. However, citizens' juries and other participatory devices offer a mechanism for including "lay" judgment more directly into rationing decisions.

Health care professionals have traditionally (and implicitly) 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 promoting 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 Britain 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 arguably be a more 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, geographic equity, and allocating finance between "free" health care and means tested social care.

"Experts" and *groups 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?

What accountability mechanisms are appropriate?

Once the appropriate allocation of responsibilities for implementing rationing decisions has been established it will be necessary to institute appropriate mechanisms for ensuring that these decisions are made in a proper manner. This is the role of accountability mechanisms. Accountability entails 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 four separate categories—political, organisational, public pressure, and normative.¹

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 (a) the legislature (for example, review of funding, review of statutory instruments, Health Select Committee, Health Service Commissioner, National Audit Office); (b) the political executive (for example, fiscal powers, Social Services Inspectorate, Health Advisory Service, Audit Commission, personnel appointments, 1991 reforms); (c) the 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 quasimarket system.

Public pressure mechanisms include the activity of pressure groups and complaints mechanisms (for example, SANE, 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 doctor).

Normative methods include 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 giving 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.

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 are 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 has in the medical profession could be damaged by the explicit acknowledgment 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 favour explicitness argue 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 to 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.

Case study: Treatment of an elderly dying woman

An 81 year old woman was admitted to a short stay geriatric ward confused and ill after falling at home. During her stay she developed diarrhoea and oral thrush. 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 allocating resources for the care of elderly patients? It may be that resources should be devoted to young people as they have greater life expectancy. Or should age play no part in these decisions? And within the budget assigned to the care of elderly patients is enough 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. This raises questions about whose values should count in allocating resources between client groups: why does geriatrics seem to have a low priority? Is it because of public and professional pressure to supply resources to more glamorous areas of medicine?

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 doubts about the methodology used in the trial. The drug is expected to cost about £10 000 per patient a year. There are estimated to be 85 000 patients with multiple sclerosis in the United Kingdom. Of these, 45% are thought to have the relapsing-remitting form. If all these patients were treated the total cost could be £380m—that is, 10% of the drug bill.⁵

Evidence for 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. 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? 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 health authorities declined to fund it what implications would this have for the NHS objective of geographic 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?

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

Accountability mechanisms seem weak. 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 health authority attempts to restrain prescribing its legal position is unclear. Health authority 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. Improved information is needed in order to make the process more explicit and accountable. But what implications are there for being explicit in individual consultations 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?

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 articulated publicly, and these should constitute the framework within which rationing takes place—though the Rationing Agenda Group does not collectively hold a view about what these principles should be.

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

Empirical issues

Empirical or factual issues include fairly 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.

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 clinicians or managers. In addition, central government sets the overall framework for making choices by specifying how purchasing power is distributed to regions. Central government 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 about how rationing is effected in practice are split among the national, institutional, and individual levels.

At the *national level* rationing is effected by (a) changes to the legal framework (for example, allocating tax revenue between NHS and other health promoting activities, such as housing policy); (b) exercising executive powers (for example, devising geographic allocation formulas and setting prescription charges); and (c) specific initiatives (for example, *Health of the Nation* and the annual planning and priorities guidance).

At the *institutional level* rationing is effected by (a) 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 extracontractual referrals; (b) pricing (for example, of packages of care to be purchased by health authorities; and (c) managed care strategies (for example, clinical guidelines).

At the *individual level* the general practitioner 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 patient comes into contact with the NHS one of five methods may be used to bring the demand for care into line with the available supply²—namely:

- Denial—that is, not providing treatment at all for more or less justifiable reasons (for example, refusal by certain general practitioners 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" care 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 general practitioner or consultant appointment; waiting lists for secondary care; and waiting in accident and emergency departments)
- Dilution—that is, reducing quality in order that existing resources may go further; this may or may not also represent a more efficient use of resources (for example, by 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 individual patients which may deter them from seeking care (for example, distance, such as living a long way from a general practitioner's premises; poor information or information only 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.³

Case study : In vitro fertilisation

In a study of 114 purchasing plans for 1992-3 six health authorities explicitly stated that they would not be buying in vitro fertilisation or gamete intra-fallopian 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.⁶

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) that is relevant to the business of the NHS? Arguably, inability to conceive 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. In particular, does geographic equity demand that all health authorities should provide some level of service so that a patient's place of residence does not have a decisive influence on the likelihood of treatment? How should the benefits of in vitro fertili-

sation be weighed against those of other treatments if some level of provision is required? In this context who should make choices about its provision? If health authorities and clinicians are responsible for providing the service 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? Certain sections of the population may not be sympathetic—for example, men and people 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.

Though only a few health authorities have explicitly stated 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? How can accountability be exercised in this setting?

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 entails 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? Possible aspects in which improved 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 with worse outcomes than by “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.

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

One response to the proposition at the beginning of this paper—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 occurs only in cash limited, taxation based systems such as the NHS. In fact, all health care systems entail allocating scarce resources among those who might benefit; all include rationing in this sense.

Private insurance based systems ration care by making households decide how much of their resources they wish to spend on 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 on to households; “earmarked” contributions are forms of disguised taxation. But all involve decisions about how to use households' resources.

The only difference will be in the particular set of financial incentives that affect the people concerned. In a largely private, insurance based system such as that in the United States this may encourage inefficiency—that is, oversupply for some and no supply for others. Social insurance systems such as those in France and Germany may also be overresourced. Proposing other forms of finance is no escape from the fundamental issue. It merely alters the way in which the people concerned 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.

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- 1 Peters BG. *The politics of bureaucracy*. 3rd ed. London: Longman, 1989.
- 2 Harrison S, Hunter D. *Rationing health care*. London: Institute for Public Policy Research, 1994.
- 3 Doyal L. Needs, rights and equity: moral quality in healthcare rationing. *Quality in Health Care* 1995;4:273-83.
- 4 Maxwell R, ed. *Rationing health care*. London: Churchill Livingstone, 1995.
- 5 Walley T, Barton S. A purchaser perspective of managing new drugs: interferon beta as a case study. *BMJ* 1995;311:796-9.
- 6 Redmayne S, Klein R. Rationing in practice: the case of in vitro fertilisation. *BMJ* 1993;306:1521-4.

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Lesson of the Week

Addison's disease presenting as reduced insulin requirement in insulin dependent diabetes

Lynne Armstrong, Patrick M Bell

Recurrent severe hypoglycaemia in patients with previously well controlled diabetes may be due to Addison's disease

Diagnosing Addison's disease requires a high degree of clinical suspicion since it is rare and its presenting symptoms are often non-specific. An association between Addison's disease and insulin dependent diabetes is well recognised. Whereas about 10-18% of patients with Addison's disease have insulin dependent diabetes, Addison's disease remains relatively rare among patients with insulin dependent diabetes.¹⁻³ We report two cases of patients with previously well controlled diabetes presenting with recurrent severe hypoglycaemia despite reduction in insulin doses.

Case 1

A 43 year old man with a 15 year history of insulin dependent diabetes well controlled with a stable regimen of twice daily injections of human insulin was referred to the diabetic clinic, Royal Victoria Hospital, complaining of increased frequency of hypoglycaemic episodes on waking. On one occasion he required intramuscular glucagon administered by his wife. On a second occasion he collapsed at work and required medical assistance. He also complained of tiredness and nausea. He was advised to reduce his evening dose of long acting insulin and was given an appointment for further review.

Before this date he was referred back by his general practitioner with further episodes of severe hypoglycaemia despite decreasing his insulin dose from a total of 30 units to 15 units. Tiredness, nausea, and vomiting had become more prominent, and he had noted a weight loss of about 6 kg in the preceding two weeks. Admission was arranged for stabilisation of diabetes and assessment of autonomic function in view of his apparent lack of hypoglycaemic awareness.

On admission he was noted to be pigmented, thin and dehydrated. Pigmentation was present particularly in the palmar creases and buccal mucosa. Postural hypotension was demonstrable. Investigations revealed serum concentrations of sodium 128 mmol/l, potassium 6.6 mmol/l, and urea 10.2 mmol/l. Primary adrenal failure was confirmed with a short synacthen test (0.25 µg intramuscularly)—plasma cortisol concentration was 91 nmol/l at baseline and 89 nmol/l at 30 minutes. Adrenocorticotrophic hormone concentration was 590 ng/l, and adrenal and gastric parietal cell antibodies were present. Antibodies to thyroglobulin and thyroid microsomes were not detected.

The patient rapidly recovered after treatment with intravenous fluids and hydrocortisone. His insulin requirements increased to 36 units daily. He remains well with replacement therapy of hydrocortisone 30 mg and fludrocortisone 0.1 mg daily.

Case 2

A 31 year old woman with insulin dependent diabetes diagnosed at two years of age presented at her routine diabetic clinic review complaining of increased hypoglycaemia despite repeatedly decreasing her insulin dose. She generally took a careful interest in her diabetes, with frequent monitoring of blood glucose and a multiple pen injection regimen resulting in levels of haemoglobin A_{1c} of 5.6-6.7% (normal <6%) over the previous two years.

She was noted to be pigmented, and her blood pressure was 130/90 mm Hg supine and 80/60 mm Hg standing. A short synacthen test (0.25 µg intramuscularly) carried out at the clinic confirmed the diagnosis of Addison's disease (plasma cortisol concentrations at baseline and 30 minutes both <40 mmol/l). Adrenal

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