THE UNIVERSITY of York

CENTRE FOR HEALTH ECONOMICS

The state of health care priority setting and public participation

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DISCUSSION PAPER 154

The state of health care priority setting and public participation

Findings from a survey of health authorities in England, Wales and Scotland

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June 1997

The authors acknowledge the help and stimulating discussion from the participants in a session during the Health Economists' Study Group Meeting at Brunel University, July 1996. The study was carried out while KO was a visiting researcher at the Centre for Health Economics in York. The hospitality and support of the institution is greatly appreciated. KO holds a grant from the Deutsche Forschungsgemeinschaft (Ob 101/1-1).

ABSTRACT

A structured questionnaire survey of all 131 health authorities in England, Wales and Scotland was carried out between September 1995 and January 1996. The priority setting questionnaire was sent to chairpersons or chief executives of each health authority, although respondents had a variety of job titles. The objectives of the survey was to assess (i) To assess the extent to which health authorities in England, Wales and Scotland perceive themselves as involved in setting priorities for health service resource allocation; (ii) the importance of different criteria and sources of opinion in current resource allocation priority setting by health authorities, the importance of additional information needs and changes in the input of different sources of opinion; (iii) the involvement of the public in priority setting. 121 health authorities completed and returned the questionnaire (92% response rate). Priority setting was claimed not to be adopted in only 4 authorities. High numbers of important/very important ratings were given for equity, health gain and cost-effectiveness criteria, and clinicians, GPs, public health doctors and health authority managers sources of opinion. Over 75% of authorities wanted more input in priority setting from the public, although health authority experience of involving the public was generally mixed.

The pursuit by health authorities of explicit priority setting in resource allocation is generating needs for more information on key decision making criteria, and the structured input of a variety of sources of opinion, especially the public. Achieving these aims are likely to be fraught with difficulty. In a discussion section, we focus on the conceptual and practical difficulties facing the greater involvement of the public in priority setting.

INTRODUCTION

The need to set priorities in health care has been accepted as a necessity in the United Kingdom by the Government and local health care purchasers. (Health Committee 1995) There has been a substantial amount of debate concerning the appropriate criteria and whom to involve in moving to a system of explicit priority setting.

Priority setting exists at all levels - at the broadest level the Government makes decisions regarding the priority to be given to the health service relative to other public sector services in its annual allocation of funds to the NHS. At the other extreme, clinicians and other health professionals are making priority setting decisions when deciding which patients to treat first or whom to exclude from treatment. In between these extremes, health care purchasers (health authorities and General Practitioners (GP) fundholders) have to make decisions concerning priorities for resource allocation between and within types of health services. The degree of explicitness of decisions and the amount of public involvement may vary considerably at each of these levels. (Klein and Redmayne 1992, Hunter 1993)

Recently, a committee has met to attempt setting up a national mechanism for priority setting (Bridle 1995). In contrast, the Rationing Agenda Group (1996) has stressed that debates about ethical dilemmas should be undertaken openly and in a democratic fashion. Our starting point was the rising interest in many health authorities to involve the general public in decisions concerning not only the delivery but also the rationing of medical services (Redmayne 1996). Moreover, there are signs that the public has a genuine interest in being consulted before decisions are made (Dean 1995).

This paper reports the findings from a survey of priority setting in district health authorities, health commissions, health boards and health agencies in England (including Jersey), Wales and Scotland (for simplicity we will refer to each body as health authorities in the rest of this paper).

The survey had the objective of addressing a number of general questions:

- Do health authorities perceive themselves as involved in priority setting?

- What criteria do health authorities rate as most important in their current priority setting, and what additional information is most important/wanted?
- What sources of opinion do health authorities rate as most important in their current priority setting, and what changes are desired in the level of involvement of different sources?
- How should priorities be implemented by health authorities?

The study had a further specific aim: This was to assess the extend to which public opinion is included in current priority setting, whether it is regarded as useful and whether more involvement is desired by health authorities. The discussion section focusses on this aspect by reviewing the literature on the role (and practical problems) of public involvement in health care priority setting.

METHODS

We developed a 9 question self-completion questionnaire (see Appendix I) and sent it to chairmen/-women (or to the chief executive if no chairperson could be identified) of all 131 health authorities in England, Wales and Scotland (as of March 1995 - the health services yearbook was used for the names and addresses). Two reminders were subsequently sent out at approximately 6 week intervals. The chairperson or chief executive was asked to either complete the questionnaire themselves or pass it onto an alternative appropriate person or persons in the authority, suggesting that they might be located in the purchasing or contracts department. Space for additional comments and suggestions was given and the provision of more and detailed information was encouraged.

The survey was carried out between September and December 1995. The data for each authority was anonymised, entered onto a computer database and analysed using SPSS software.

RESULTS

Response rate and responders

After three reminders 121 health authorities returned the questionnaire, mostly fully completed, some authorities only answering parts of it. This represents a 92% response rate. Three respondents replied refusing to participate in the survey for various reasons and the remaining did not respond in any way. The survey was planned to be anonymous, therefore the health authorities were not asked to identify themselves, although some did.

Table 1 - Job titles of respondents

Job Title	Number	Percentage
Chair of Health Authority	27	22%
Director of Planning/Corporate Development and Planning/Planning and Contracting/Contracting	22	19%
Director of Commissioning	15	12%
Director of Public Health	14	12%
Chief Executive	11	9%
Director of Purchasing/Purchasing Manager	5	4%
Other[1]	27	22%
Total	121	100%

The main respondent was the Chair of the health authority, who completed the questionnaire in 27 health authorities (22%). The chief executive completed the questionnaire in 11 health authorities (9%). The questionnaires returned by the remaining 84 participants were completed by individuals with a variety of job titles, The respondents are listed in table 1.

Is priority setting practiced

[1] "Other" covers Director of Health Care Development, Director of primary Care and Commissioning, Head of Consumer and Corporate Relations, Deputy Director of Finance, Board General Manager, Service Quality Manager, Team Leader-Performance Management/Contracting, Corporate Affairs Manager, District Health Manager, Contracting Marketing Analyst, Director of Public Affairs, Health Policy Manager, Director of Corporate Management, Projects Manager, Vice Chairman. Missing = 3.

Only 4 authorities (3%) stated that priority setting was not yet adopted in their authority. Forty-four participants (36%) claimed that priority setting was formally conducted for all services in their authority, 42 (35%) stated it covered only some services, and 25 (21%) stated it covered only new service proposals. Two of the respondents ticked more than one box and 4 did not complete this question.

What criteria are most important

Table 2 presents the responses to this question. The importance of key criteria is evident in this table. Equity considerations had the largest number of participants claiming this to be *very important or important* (118 authorities, 98%). Health gain (e.g. life years gained, QALYs), quality of delivery criteria, public acceptability, cost-effectiveness criteria (e.g. cost per life year gained, cost per QALY gained) and cost criteria were rated as *important* or *very important* in 85% to 93% of authorities.

The largest proportion of respondents claimed that health gain criteria and cost-effectiveness criteria were *very important* in their authorities' priority setting decisions, with 81 and 68 stating this respectively. A lower proportion of participants claimed equity considerations or quality of service delivery were very important (51 and 48 respectively). Only 32 authorities stated cost criteria were very important, and 24 claimed this for public acceptability.

Other criteria that could be used for priority setting were examined and found to be of much lower importance (e.g. programme budgeting/marginal analysis, retaining historical patterns). None of these criteria were rated as *very important* in more than 7% of authorities. A wide range of additional criteria were specified, e.g. accessibility to large rural population, ethnic minority interests, national priorities, prevention over treatment and care, alternative treatments (e.g. homeopathy), public and professional values, pressure from the government.

Table 2 - Importance of various criteria for priority setting in health authorities.

Criteria	Importance of criteria for current resource allocation priority setting[1]				
	Very important	Important	Low importance	Not used/known	Missing
Health Gain	81 (66.9%)	31 (25.6%)	2 (1.7%)	5 (4.1%)	2 (1.7%)
Cost	32 (26.4%)	71 (58.7%)	12 (9.9%)	1 (0.8%)	5 (4.1%)
Cost-effectiveness	68 (56.2%)	39 (32.2%)	4 (3.3%)	7 (5.8%)	3 (2.5%)
Equity considerations	51 (42.1%)	67 (55.4%)	1 (0.8%)	0 (0%)	2 (1.7%)
Quality of delivery	48 (39.7%)	63 (52.1%)	3 (2.5%)	3 (2.5%)	4 (3.3%)
Public acceptability	24 (19.8%)	84 (69.4%)	7 (5.8%)	1 (0.8%)	5 (4.1%)
Pressure from media/politicians	4 (3.3%)	39 (32.2%)	59 (48.8%)	16 (13.2%)	3 (2.5%)
Retaining historical patterns	0 (0%)	13 (10.7%)	81 (66.9%)	23 (19.1%)	4 (3.3%)
Patient group characteristics	7 (5.8%)	56 (46.3%)	28 (23.1%)	25 (20.7%)	5 (4.1%)
PBMA	7 (5.8%)	49 (40.5%)	20 (16.5%)	38 (31.4%)	7 (5.8%)
Other	19 (15.7%)	8 (6.6%)	0 (0%)	0 (0%)	94 (77.7%)

A subsequent question asked was how important would more information on a number of the items included in table 2 be for helping the health authority in its decisions. Table 3 presents the responses to this question. The table demonstrates the importance given to more information relating to all the criteria listed, but highest numbers of *important/very important* ratings were given for health gain (118 authorities, 98%) and cost-effectiveness criteria (116, 96%). These have also received the highest proportion of authorities rating more information on them as *very important* (90 and 86 respectively). More information on equity and quality of delivery was also

[1] Rows total 121 health authorities (100%)
PBMA: Programme Budgeting & Marginal Analysis

desired, with 112 authorities (93%) stating this was *important/very important* for each criteria. However, fewer said more information on these was *very important* with 62 authorities for equity considerations and 55 authorities for quality of delivery.

Table 3 - Importance of more information on various criteria for priority setting in health authorities.

Criteria	Importance of more information on criteria[1]			
	Very important	Important	Low importance	Missing
Health Gain	90 (74.4%)	28 (23.1%)	0 (0%)	3 (2.5%)
Cost	37 (30.6%)	67 (55.4%)	13 (10.7%)	4 (3.3%)
Cost-effectiveness	86 (71.1%)	30 (24.8%)	3 (2.5%)	2 (1.7%)
Equity considerations	62 (51.2%)	50 (41.3%)	4 (3.3%)	5 (4.1%)
Quality of delivery	55 (45.5%)	57 (47.1%)	6 (5.0%)	3 (2.5%)
Public acceptability & satisfaction	47 (38.8%)	64 (52.9%)	7 (5.8%)	3 (2.5%)
Other	9 (7.4%)	1 (0.8%)	0 (0%)	111 (91.7%)

What sources of opinion are most important

Table 4 shows that most respondents rated clinicians, GPs (both fundholding and non-fundholding), public health doctors and health authority managers as *important/very important* sources of opinion for priority setting in their authority. In each case over 109 respondents (90%) gave this rating for each of these groups. However, only 39 stated clinicians were *very important* sources of opinion. Outside medical opinion, 101 authorities (84%) claimed public opinion was *important/very important*, 99 (82%) gave this rating for political influence and 104 authorities (86%) gave this rating for literature sources. However, public influence was rated as *very important* by 26% of the respondents, and political influence was rated as such by 21% of respondents.

Table 4 - Importance of various sources of opinion in priority setting in health authorities.

Source of opinion	Importance of each source of opinion[1]				
	Very important	Important	Low importance	Not used/known	Missing
Clinicians	39 (32.2%)	73 (60.3%)	3 (2.5%)	1 (0.8%)	5 (4.1%)
Fundholding GPs	64 (52.9%)	49 (40.5%)	2 (1.7%)	1 (0.8%)	5 (4.1%)
Non-fundhol-ing GPs	71 (58.7%)	45 (37.2%)	2 (1.7%)	0 (0%)	3 (2.5%)
Other health care professionals	17 (14.0%)	71 (58.7%)	25 (20.7%)	3 (2.5%)	5 (4.1%)
Public Health Doctors	64 (52.9%)	51 (42.1%)	3 (2.5%)	0 (0%)	3 (2.5%)
Health authority managers	31 (25.6%)	78 (64.5%)	8 (6.6%)	0 (0%)	4 (3.3%)
NHS Trust Managers	16 (13.2%)	58 (47.9%)	38 (31.4%)	3 (2.5%)	6 (5.0%)
Health economists	4 (3.3%)	41 (33.9%)	36 (29.8%)	36 (29.8%)	4 (3.3%)
Expert Committees	19 (15.7%)	53 (43.8%)	18 (14.9%)	28 (23.1%)	3 (2.5%)
Local Purchasing Consortium	23 (19.0%)	43 (35.5%)	10 (8.3%)	29 (24.0%)	4 (3.3%)
Patients	17 (14.0%)	57 (47.1%)	23 (19.0%)	15 (12.4%)	9 (7.4%)
Pressure groups	2 (1.7%)	48 (39.7%)	59 (48.8%)	8 (6.6%)	4 (3.3%)
Charities & Voluntary organisations	4 (3.3%)	65 (53.7%)	40 (33.1%)	6 (5.0%)	6 (5.0%)
Literature	39 (32.2%)	65 (53.7%)	33.1% (10)	2 (1.7%)	5 (4.1%)
Political initiatives	25 (20.7%)	74 (61.2%)	15 (12.4%)	3 (2.5%)	4 (3.3%)
The Public	31 (25.6%)	70 (57.9%)	9 (7.4%)	5 (4.2%)	6 (5.0%)
Other	5 (4.1%)	6 (5.0%)	0 (0%)	0 (0%)	110 (90.9%)

Other *important/very important* sources of opinion stated most frequently by authorities were other health care professionals, NHS Trust managers, current patients, expert committees,

[1] Rows total 121 health authorities (100%)
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charities and local purchasing consortiums. Sources of opinion most frequently stated to be of *low importance* in current priority setting were pressure groups, charities, NHS Trust Managers, health economists and current patients. *Not used* or *not known to be used* was most often claimed for health economists and expert committees.

We then asked whether there was a need for more, less or no change in the level of involvement and input from these sources of opinion. Table 5 presents the responses. A source of opinion to which an *increase in involvement* was desired by the majority of authorities was the public, with 92 authorities stating this (76%). In addition, 60% wanted to see an increase in involvement from non-fundholding GPs and health economists and about half (52%) an increased involvement from current patients. The sources of opinion participants most favoured a *decreased involvement* from were political influence and pressure groups.

In which service areas is public involvement currently practised?

There were a number of services for which around 50% of the authorities stated that public involvement was practised (table 6): Maternity services, learning disabiliy services, mental health services and services for the elderly. In very "technical" services, like intensive care or clinical, scientific and diagnostic services less than 5% of the authorities indicated any public involvement. Only 1-6% of the respondents ticked "don’t know" when answering the question but there was an unusual high number of missing answers. Several additional service areas were mentioned, such as infertility, carers service, breast surgery and sexual health services.

Table 5 - Changes desired in level of involvement of various sources of opinion in priority setting in health authorities.

Source of opinion	Change desired in level of involvement of each source of opinion[1]				
	Increase	Keep the same	Decrease	Don't know	Missing
Clinicians	38 (31.4%)	72 (59.5%)	6 (5.0%)	0 (0%)	5 (4.1%)
Fundholding GPs	58 (47.9%)	52 (43.0%)	3 (2.5%)	0 (0%)	8 (6.6%)
Non-fundholding GPs	73 (60.3%)	41 (33.9%)	3 (2.5%)	0 (0%)	4 (3.3%)
Other health care professionals	58 (47.0%)	57 (47.1%)	0 (0%)	1 (0.8%)	5 (4.1%)
Public Health Doctors	22 (18.2%)	88 (72.7%)	7 (5.8%)	1 (0.8%)	3 (2.5%)
Health authority managers	9 (7.4%)	103 (85.1%)	5 (4.1%)	1 (0.8%)	3 (2.5%)
NHS Trust Managers	9 (7.4%)	91 (75.25)	16 (13.2%)	1 (0.8%)	4 (3.3%)
Health economists	72 (59.5%)	38 (31.4%)	2 (1.7%)	6 (5.0%)	3 (2.5%)
Expert Committees	25 (20.7%)	77 (63.6%)	7 (5.8%)	7 (5.8%)	5 (4.1%)
Local Purchasing Consortium	39 (32.2%)	57 (47.15)	3 (2.5%)	11 (9.1%)	11 (9.1%)
Patients	63 (52.1%)	46 (38.0%)	3 (2.5%)	2 (1.7%)	7 (5.8%)
Pressure groups	4 (3.3%)	76 (62.8%)	33 (27.3%)	3 (2.5%)	5 (4.1%)
Charities & Voluntary organisations	29 (24.0%)	82 (67.8%)	4 (3.3%)	2 (1.7%)	4 (3.3%)
Political initiatives	8 (6.6%)	58 (47.9%)	49 (40.5%)	2 (1.7%)	4 (3.3%)
The Public	92 (76.0%)	22 (18.2%)	0 (0%)	3 (2.5%)	4 (3.3%)
Other	5 (4.1%)	2 (1.7%)	0 (0%)	1 (0.8%)	113 (93.4%)

[1] Rows total 121 health authorities (100%)

Table 6: Public involvement in resource allocation in specific service areas[1]

service area	services covered (%)	not covered (%)	don't know/ not yet/ missing
intensive care	7 (6.0)	57 (49.1	52
acute, non-intensive, surgery	35 (30.2)	29 (25.0)	52
acute, non-intensive, medicine	32 (27.6)	33 (28.4)	51
pharmacy	14 (12.1)	44 (37.9)	58
maternity	76 (65.5)	1 (0.9)	39
children's	62 (53.4)	9 (7.8)	45
learning disabilities	71 (61.2)	4 (3.4)	41
mental health	77 (66.4)	1 (0.9)	38
dental	19 (16.4)	39 (33.6)	58
physical disabilities	60 (51.7)	9 (7.8)	47
clinical, scientific & diagnostic	6 (5.2)	55 (47.4)	55
screening, school health immunisation	30 (25.9)	35 (30.2)	51
special (e.g. cancer, stroke)	57 (49.1)	13 (11.2)	46
HIV	48 (41.4)	18 (15.5)	50
community nursing	30 (25.9)	33 (28.4)	53
primary care	46 (39.7)	22 (19.0)	48
physiotherapy, speech therapy	25 (21.6)	38 (32.8)	53
elderly	64 (55.2)	9 (7.8)	43
opthalmic	17 (14.7)	41 (35.3)	58
neurological	34 (29.3)	29 (25.0)	53
other	11 (9.5)	0 (0)	105

How should priorities be implemented?

The most popular response was that *waiting lists* could be used to implement priorities for health services with 57 authorities (47%) stating this. A total of 55 (46%) stated that providing *no coverage for lower priority services* could be appropriate. In addition, *the introduction or an increase in patient payment for certain services* was given as appropriate by 21 authorities

[1] Lines total 116 authorities (100%), 5 authorities did not respond to this question.

(17%). A range of other approaches was suggested (by 29% of the respondents). In particular, 6 authorities stated the use of national guidelines or protocols on efficacy and effectiveness. In addition, 13 authorities thought priority setting should be implemented primarily through the use of evidence based medicine. Other suggestions included the targetting of resources, NHS-led policy, reviewing skillmix to deliver services, applying clinical criteria to determine priority, removal of politicial, clinicial and pressure group influence from the process, fiscal incentives to use private health insurance and strategic assessment of need.

The experience with public involvement in priority setting

The perceived experience of authorities in attempting to involve the public in priority setting was in general mixed. Sixty percent of the Health Authorities stated this, while 6% had very positive, 18% positive and only 4% negative and 1% very negative experiences. 9% of the answers were missing. Respondents were asked to give a reason for their response. There were some strongely held opinions and worries regarding public involvement. Examples of comments are in appendix II.

Only 5 respondents (4%) claimed that the public were not involved in priority setting in their authority, and data was missing for a further 5. However, of the remainder the overwhelming majority stated that one route of public participation was via the Community Health Council (CHC, 106 authorities). These were first set up in 1974 as a vehicle for representing the interests of the public and health interest groups (eg Age Concern) in local health service policy and they also serve as complaint institutions. Besides the CHC, in a significant numbers of authorities public participation was claimed to be achieved through public discussions/forums, surveys and collaboration with community groups (table 7). Other routes mentioned included focus group of service users, meetings with elected representatives, rapid appraisal, free telephone line to receive calls, advertorials in the local press, neighbourhood planning process, bulletins, workshops and seminars.

Table 7 - Methods of involving the public in priority setting in health authorities.

Form of Public involvement	Number	Percentage
Public not involved	5	4.1%
Survey	71	58.7%
Public Discussions/forums	94	77.7%
Committees involving members of the public	67	55.4%
Community Health Council	106	87.6%
Collaboration with community groups	85	70.2%
Other	17	14.0%
Missing	5	4.1%

DISCUSSION

One of the aims of our survey was to identify the current state of public participation in priority setting in the view of health care managers in Health Authorities. What are the current forms of priority setting, how do purchasers try to integrate public views in their health care spending and most important, what additional information do they need?

General results from the survey demonstrate the importance of the key criteria of equity, health gain and cost-effectiveness in current decision-making as well as the need for more information in these fields. There is a shift intended in the sources of opinion: towards more influence of the public, non-fundholding GPs, health economists and current patients. There is strong committment to involve the public in one form or another in priority setting. Community Health Councils were most often mentioned as a mechanism for this. The appropriate way of implementing priorities was mainly seen as the use of waiting lists and limiting coverage for lower prioritized services. The increase of patient payments was given as appropriate by a minority of respondents only. The high level of approval of waiting lists may indicate that more credence be given to the use of waiting lists for the management of non-hospital care. Additional comments made on the questionnaire showed a desire for a greater use of guidelines and protocols on effectiveness and cost-effectiveness in order to help implement priorities.

The Rationing Agenda Group (1996), consisting of a wide range of professionals from academia, management and clinical work as well as lay people, recently described in detail the

main aspects of "the rationing agenda in the NHS". "Rationing", "priority setting" and "resource allocation" were seen as merely semantic distinctions of the underlying fundamental question of how to allocate funds and that, despite continuous efforts to increase efficiency and shifting resource towards the health care system, rationing is inevitable. Rationing is defined by the group as choosing from *medically beneficial* interventions.

The Health Committee of the British House of Commons (1995) distinguishes sharply between a role of public in priority setting and obtaining views from patients and consumers on existing services. It argued strongly against the former:

"The public's role in priority setting raises a very different set of issues. We do not suggest that the public actually decide local priorities. [...] In terms of methodology there are clear problems in gaining representative, reliable views on priorities. [...] When it comes to using surveys to assess broad priorities, the added value seems to us less clear, for example to ask the public to rank a range of unrelated services would seem to us to be entirely futile. The results are known to be crucially dependent on how these surveys are designed and on how the public are briefed - witness commented on the public's lack of knowledge of health and health service issues." (p. lv)

On the other hand, as the results on public participation in different service areas indicate, there is increasing interest in the Health Authorities to use well-tried marketing instruments in order to adapt and improve existing services to patient/consumer demands. Maternity services, services for the elderly and handicapped are typical areas where public opinion might be sought. These are related to the provision of specific services rather than to the assessment of overall priorities (Health Committee 1995, p. lii-liv).

A recent survey showed that 40 out of 129 health authorities in Britain had introduced explicit rationing, this development happening rapidly and not being limited to non-essential treatment or those with doubtful clinical value (Dean 1995). The survey found evidence of public acceptance that the NHS purse is not bottomless but that public opinion should be taken into account in the use of NHS funds. In her 1996 analysis of health authorities' purchasing plans, Redmayne states that explicit rationing is increasing with the increasing use of effectiveness

criterion to exclude services. In addition, local populations are becoming more and more involved in allocation decisions.

Priorities for health services differ according to who is consulted: The public, managers or the health care professionals (Heginbotham, 1993; Tolley and Whynes, 1995). Prioritisation might be affected by lack of information, sheer prejudice, the effects of media campaigns and gender-driven genuine beliefs (Heginbotham, 1993). Klein (1993), more optimisticly, focuses on the importance of the structure of the discussion; economists, ethicists and epidemiologists could all contribute to a reasoned and pluralistic debate. The Royal College of Physicians (1995) issued a statement calling for a National Council for Health Care Priorities, to consist largely of experts but also with a lay representation. Similarly Klein (1995), after considering what can be learned from other countries, argued for an institutionalised priority setting.

So, assuming that rationing should be undertaken explicitly[2], what is the role for the public? Should the public be involved at all?

Studies on public participation in priority setting

"There are a number of reasons for involving local people in the purchasing process. If health authorities are to establish a 'champion of the people' role, their decisions should reflect, so far as practical, what people want, their preferences, concerns and values. Being responsive to local views will enhance the credibility of health authorities, but, more importantly, is likely to result in services which are better suited to local needs and therefore more appropriate [...]" (NHS Management Executive, 1992)

Initial guidance on public participation's came from the NHS Management Executive (1992) where an overview of existing approaches was published and hints were provided on ideas and techniques to involve the public in an informed local debate about health issues.

[2] Which is not a settled question. See as an example of the intense debate about explicitness vs. implicitness in rationing the discussion in the British Medical Journal (Vol. 311, issues of 24. June, 9. September, 23. September; Vol. 312, issue of 20. January). See also Coast and Smith (1996) who describe a "disutility" of explicit rationing and Mechanic (1995).

Numerous local studies have investigated how best to involve the public in health authority priority setting procedures. Anonymous postal questionnaires (Richardson et al. 1992, Meredith 1995), interviews with a random sample of the population (Bowling et al. 1993), public ranking exercises (Carrol 1993), the use of focus groups (Field and Richardson 1994) and combinations thereof (Conlan and Rogers 1995, Wiles and Gordan 1995) have all been used to elicit public preferences. The implementation of public health fora (North Essex HA), a regular survey of a representative panel (West Yorkshire HA, Huddersfield HA) or holding a "consumer day" (Redbridge HA) have also been tried (Health Committee 1995, lii; Klein and Redmayne 1992; Hunter 1993). Focusing on specific health services (Conlan and Rogers 1995), 5-year-plans (Essex Family Health/North Essex Health Authority 1994), sophisticated strategic planning approaches/policy papers (Hertfordshire Health Agency 1995, Jersey Health and Social Services 1995, Northern Ireland Board of Health and Social Services 1995), the use of a standing health panel (Dowswell et al. 1995) or sending an information brochure including a questionnaire (Mid Essex Health Authority, Department of Public Health 1991) are other ways that have been used to determine public preferences.

Bowling (1996) presented data from a priority setting exercise (interview survey) based on a random sample of the British population as a whole. In addition, her survey addressed public attitudes towards high cost technology, "self-inflicted diseases", government guidelines about when not using livesaving treatment/ technology and the influence of age.

Recently, Lenaghan and co-workers (1996) have conducted an experiment to employ selected citizens in a jury to discuss issues in local rationing decisions. These issues covered the criteria for purchasing health, the role of effectiveness of treatments, the level where priorities should be set and who should be involved in decision making. There are two models for those juries: a "deliberate" one, which involves discussion on guiding policy and a "decision making" one, where a concrete set of options need to decided upon. The authors highlight the choice of questions, group dynamics and the crucial role of the moderator.

Virtually all authors have emphasized the complex nature of the procedure, the many unresolved methodological issues and the preliminary nature of their findings. Apart from rather general statements, such as "treatments for children with life-threatening diseases should be given high

priority", no universally applicable practical results have been generated so far and the need for more research has been repeatedly demanded. Recently, preliminary inquiries into theoretical as well as practical aspects of public involvement in the rationing of medical care have been made (Harrison 1995, McIver 1995, Jacobson and Bowling 1995).

Practical problems

Ensuring the rational and pragmatic involvement of the public in health care priority setting has several practical problems.

Firstly, there are problems in defining who and what the rather nebulous entity "the public" covers. Should it be the total community, the voters, the patients, the community health councils or similar institutions? (Donovan and Coast 1994). If one adopts a community view, how can less organised and less vocal sections of the community be reached and involved? There are problems defining the role for Central Government and local health authorities in facilitating the involvement of public input (Charles and DeMaio 1993). Is public participation the empowerment of an oppressed group or rather the subordination of a dominant one, mainly physicians?

Secondly, if one assumes a dichotomy between central and local priority setting, what should be done by the former and how much influence should be left to the latter? (Health Committee 1995, p. xv-xxiv). It may reasonably be argued that the approval of new drugs and technologies should be left to central government. National priorities may be set up to achieve general targets and outline a vision about the role and status of health care, while being aware of potential conflicts between different goals. Rationing at the local level is influenced by numerous forces (Health Committee 1995, p. xix), the purchaser-provider split being but one, albeit important determinant (Harrison and Wistow 1992). The different structures, historical patterns, local "needs" and available resources all indicate the need for some form of priority setting at the local level.

Thirdly, there may be concerns over the value or weighting to be attributed to public opinion as against empirical evidence of effectiveness in priority setting (Charles and DeMaio 1993). It has been argued that creating a forum where arguments are tested against evidence and where

conflicts between different values and preferences are explored may be important in itself (Klein 1993). What can lay people sensibly be asked about? The very complex nature of health care needs careful balancing between what can be decided upon in open deliberation and what is best left to experts. Ill-informed public involvement may lead to falsely legitimise rationing procedures carried out through quasi- or non-governmental organizations (Pfeffer and Pollock 1993). In addition, Harris (1993) has pointed out that

> "the cynical might suggest that it serves the government's purpose if community health councils are implicated in controversial and potentially unpopular decisions. But the responsibility for a decision is not automatically shared by consulting about it. [...] What is not acceptable is for these decisions to be taken secretly without the opportunity for any public debate." (p. 165)

Fourthly, there are difficulties in obtaining and ranking public preferences for health care. For example, a vignette approach has been proposed where a "sample of the treatment universe" is used to determine values (Fowler et al. 1994). The importance of the wording of questions when trying to obtain support is well documented (Moser and Kalton 1979, Rasinski 1989). There are also practical problems in identifying the information needs of health care purchasers and decision-makers to assist informed judgment. The cost of information and its effective dissemination has to be taken into account. Maynard (1994) has emphasised the need for evidence-based health care, stressing the importance of data from good quality clinical and economic evaluations for purchaser priority setting. McKeon and colleagues (1994), on the other hand, have criticised the push for a technically oriented solution which can provide a neutral, mathematical formula for setting priorities, the epitomization of which is the QALY (quality adjusted life year). They propose a shift to a value-laden and -ridden process with a community-based health needs assessment as the cornerstone of purchasing activity.

Finally, one has to be aware what Klein and Redmayne (1992) call the distinction between "aspirational priorites" - declarations of intent without any financial committment and the "funded priorities" - those actually receiving monies. On the other hand, local as well as national pressures may force the Health Authorities to "spread the money round" instead of concentrating on well-developed targets.

CONCLUSIONS

The existence of rationing has to be accepted (Sheldon and Maynard 1993). As a counter to this proposition Harris (1993) has argued that "people can have too much of anything, and that certainly includes medicine and surgery. [...] Many people have a refreshing distrust of the medical profession and do not lightly commit themselves to its care." (p. 158). Intuitively and empirically, it is less easy to argue a strong case for a "myth of infinite demand" (Harris 1993, Frankel 1991). Of course, no-one deliberately undergoes a surgical procedure or takes psychotropic pills just because he/she does not have to pay, but health care consists not only of pills and surgery but of a wide and sophisticated range of diagnostic and therapeutic options. The interests of providers and the preferences of patients can easily and quickly shift demand to new areas of health care.

The discussion on practical difficulties for involving the public in priority setting in this paper is not intended to be comprehensive nor has it been set up to resolve any controversies. They represent a number of ideas which may help interpretation of empirical data on public involvement in priority setting across health authorities. It should be kept in mind that "grassroot decisionmaking" is but one component of a theory of justice in health care and not a substitute for it (Lindeman Nelson 1994).

Certainly, more qualitative research is necessary to explore this field of study and to identify currently unknown features here as well as to investigate more in-depth the experiences of the Health Authorities. But, as Fitzpatrick and Boulton (1994) in their concise overview of qualitative methods state: "Qualitative research depends upon not numerical but *conceptual* analysis and presentation" (italics in original). Which philosophical, sociological, political and economic approaches might be useful to develop a coherent theoretical framework which can serve as a basis for determining the institutional settings and decision-making processes for priority setting? What type of concept is dominant or is likely to be dominant in the way health care priorities are set in the UK or elsewhere?

One interesting aspect of our survey was the large number of additional comments recorded on the questionnaire, in particular relating to the slow progress made towards explicit rationing. See Appendix III for a list of selected comments.

The high response rate in our survey provides a good "snapshot" of the current state of affairs and possible future directions in priority setting and rationing in UK health authorities. Certainly, the survey had limitations. In particular, there is the danger, as one respondent put it, that the questionnaire might be filled out quickly and superficially. The extensive amount of comments and the wide range of the responders' job position, though, indicate otherwise. Another respondent thought of the questionnaire as "a lazy way of research leading to superficial articles." Other limitations are the influence of the question wording: Who would indicate he/she is *against*, say, health gain or public participation? Furthermore, the views of the person who filled out the questionnaire must not necessarily agree with the Health Authority's policy. In retrospect, it would have been of interest to ask the individuals what *they think* priority setting is, how they would describe it, what they think it entails although that would have required a larger questionnaire and potentially lower response rate. We deliberately choose to use the term "priority setting" instead of "rationing" as we thought the latter might lead to more semantics and less openess and co-operation. Rationing is a difficult political issue which most Health Authorities, politicians, managers and clinicians try to avoid.

This survey has focused only on priority setting by one set of purchasers - health authorities. Further research might focus on the rationing decisions at the level of the GP fundholders - as there is only rudimentary knowledge of the processes, important criteria and public involvement at this level (Petchey 1995).

Redmayne and co-workers conclude in their 1993 survey on priority setting in the NHS that implicit rationing is still very strong and that explicit rationing remains the exception. Public consultations were held by only a third of the purchasers, and in only a few instances this consultation had some influence on the priority ranking. "It is therefore difficult to avoid the conclusion that consultation [of the public] is chiefly used to legitimate decisions already taken - perhaps inevitably so, given that the process is likely to generate so many different and competing views - leaving it to the purchasers to select from among them." (p. 17) His conclusion needs more in-depth analysis - at least from the purchasers' point of view there seems to be an interest to share responsibility as well as influence with the public.

In conclusion, our results indicate a number of areas for development:

a) The interest of health authorities in more involvement of the public in health care allocation decisions, not only commenting on existing services but also in setting priorities.

b) More, and applicable, data concerning health outcome and cost-effectiveness.

c) More political and economic discussion concerning rationing issues and the underlying fundamental concepts as to how a priority setting process could be developed/designed, and rational approaches to public involvement.

d) More debate on how priorities can be implemented: excluding services, increased patient payments, waiting lists or a combination thereof?

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Appendix I. The questionnaire

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Priority Setting and Resource Allocation by Health Authorities, Health Boards and Health Commissions in the UK

Questionnaire

No..... (for internal use only)

Please complete as many questions as possible - all the questions are related to the decision making process in your health authority/ board/ commission. All data will be confidently handled so that it will not be possible to identify individual responses.

What is your job title? .....

1. Does the health authority/board formally set priorities for the allocation of resources? (Please tick one box only)

- ❑ Priority setting covers all services
- ❑ Priority setting covers only new service proposals
- ❑ Priority setting only in selected service areas
- ❑ Priority setting is not yet adopted

2. How important are each of the following criteria in setting priorities for the allocation of resources? (Please tick one box on each line)

	very important	important	low importance	not used	don't know
• Health gain (e.g. lives saved, QALYs)	❑	❑	❑	❑	❑
• Costs	❑	❑	❑	❑	❑
• Cost-effectiveness (e.g. cost per live saved/QALY)	❑	❑	❑	❑	❑
• Equity considerations (e.g. access to health care)	❑	❑	❑	❑	❑
• Quality of delivery	❑	❑	❑	❑	❑
• Public acceptability	❑	❑	❑	❑	❑
• Retaining historical patterns of allocation	❑	❑	❑	❑	❑
• Patient group characteristics (e.g. age, life-style)	❑	❑	❑	❑	❑
• Programme budgeting/ marginal analysis	❑	❑	❑	❑	❑
• Other (please specify)					
.....	❑	❑	❑	❑	❑
.....	❑	❑	❑	❑	❑

3. How important are each of the following sources of opinion in setting priorities for the allocation of resources? (Please tick one box on each line)

	very important	important	low importance	not used	don't know
• Clinicians	❑	❑	❑	❑	❑
• GPs	❑	❑	❑	❑	❑
• Other health care professionals (nurses, physiotherapists, etc.)	❑	❑	❑	❑	❑
• Public health doctors	❑	❑	❑	❑	❑
• Managers (of health authorities)	❑	❑	❑	❑	❑
• Health economists	❑	❑	❑	❑	❑
• Committees without members of the public	❑	❑	❑	❑	❑
• Local purchasing consortium	❑	❑	❑	❑	❑
• (Current) patients	❑	❑	❑	❑	❑
• Pressure groups	❑	❑	❑	❑	❑
• Charities	❑	❑	❑	❑	❑
• Literature (e.g. Effective Health Care Bulletin)	❑	❑	❑	❑	❑
• Political initiatives/ agendas	❑	❑	❑	❑	❑
• The public	❑	❑	❑	❑	❑
• Other (please specify)					
.....	❑	❑	❑	❑	❑
.....	❑	❑	❑	❑	❑

4. If you do involve the public in setting priorities for the allocation of resources, how do you obtain information?

❑ Public not involved - go straight to question 7

(please tick one or more boxes)

❑ Survey (e.g. questionnaire, telephone)

❑ Public discussions/forums

❑ Committees involving members of the public/ lay representatives

❑ Community Health Council

❑ Collaboration with community groups/ "grassroot"-organisations

❑ Other (please specify)

.....

.....

5. In which service areas is public involvement in setting priorities for the allocation of resources currently practised?

❑ General allocation to service areas

❑ Allocation within service areas (please specify below, tick one box per item)

	Public Involv	No Public Involv.	Don't know		Public Involv	No Public Involv.	Don't know
Intensive Care	❑	❑	❑	Clinical, Scientific and Diagnostic Services	❑	❑	❑
Acute, non-intensive Care - Surgery	❑	❑	❑	Screening Serv., School Health, Immunisation	❑	❑	❑
Acute, non-intensive Care - Medicine	❑	❑	❑	Special Services (e.g. Cancer, Stroke, HIV)	❑	❑	❑
Maternity Services	❑	❑	❑	Community Nursing	❑	❑	❑
Childrens' Services	❑	❑	❑	Primary Care Services	❑	❑	❑
Mental Handicap Services	❑	❑	❑	Physioth., Speech Th., Dietician, etc.	❑	❑	❑
Mental Illness Services	❑	❑	❑	Services for the Elderly	❑	❑	❑
Dental Services	❑	❑	❑	Ophthalmic Services	❑	❑	❑
Physical Handicap Services	❑	❑	❑	Neurological Services (e.g. MS, Parkinson's Disease)	❑	❑	❑
Other (please specify)							
.....	❑	❑	❑	.....	❑	❑	❑

6. Overall, what is in general <u>your</u> experience of public involvement in setting priorities for the allocation of resources? (Please tick one box only)

❑ very positive

❑ positive

❑ mixed

❑ negative

❑ very negative

❑ cannot assess

Please explain your reason for response

.....

.....

7. Would you like to see a change in the level of involvement of the following groups? (Please tick one box on each line)

	Increase	Keep the same	Decrease	Don't know
• Clinicians	❑	❑	❑	❑
• GPs	❑	❑	❑	❑
• Other health care professionals (nurses, physiotherapists, etc.)	❑	❑	❑	❑
• Public health doctors)	❑	❑	❑	❑
• Managers (of health authorities)	❑	❑	❑	❑
• Health economists	❑	❑	❑	❑
• Committees without members of the public	❑	❑	❑	❑
• Local purchasing consortium	❑	❑	❑	❑
• (Current) patients	❑	❑	❑	❑
• Charities	❑	❑	❑	❑
• Pressure groups	❑	❑	❑	❑
• Politicians	❑	❑	❑	❑
• The public	❑	❑	❑	❑
• Other (please specify)				
.....	❑	❑	❑	❑
.....	❑	❑	❑	❑

8. How important would <u>more</u> information on each of the following be for helping decisions in setting priorities for the allocation of resources? (Please tick one box on each line)

	very important	important	low importance	don't know
• Health gain (lives saved, QALYs, etc.)	❑	❑	❑	❑
• Costs	❑	❑	❑	❑
• Cost-effectiveness (cost per live saved/QALY)	❑	❑	❑	❑
• Equity considerations (e.g. access to health care)	❑	❑	❑	❑
• Quality of delivery	❑	❑	❑	❑
• Customer satisfaction	❑	❑	❑	❑
• Other (please specify)				
.....	❑	❑	❑	❑
.....	❑	❑	❑	❑

9. What do you think is the most appropriate way of implementing priorities?
(Please tick one or more boxes)

- ❑ Waiting lists for less urgent services
- ❑ No coverage of a service, if this service falls below a certain “level” of priority
- ❑ Increasing patient payment for lower priority services
- ❑ Other (please specify)

.....

.....

This space may be used for any further comments

.....

.....

.....

.....

MANY THANKS FOR YOUR HELP!

PLEASE RETURN THE QUESTIONNAIRE IN THE POSTAGE PAID ENVELOPE.