Health care rationing: the public's debate

Ann Bowling

Abstract

***Objective*—To elicit the views of a large nationally representative sample of adults on priorities for health services.**

***Design*—An interview survey based on a random sample of people aged 16 and over in Great Britain taken by the Office of Population Censuses and Surveys.**

***Subjects*—The response rate to the survey was 75%, and the total number of adults interviewed was 2005.**

***Main outcome measures*—A priority ranking exercise of health services supplemented with attitude questions about priorities, who should set priorities, and budget allocation.**

***Results*—The results of the main priority ranking exercise of 12 health services showed that the highest priority (rank 1) was accorded to "treatments for children with life threatening illness," the next highest priority (rank 2) was accorded to "special care and pain relief for people who are dying." The lowest priorities (11 and 12) were given to "treatment for infertility" and "treatment for people aged 75 and over with life threatening illness." Most respondents thought that surveys like this one should be used in the planning of health services.**

***Conclusions*—The public prioritise treatments specifically for younger rather than older people. There is some public support for people with self inflicted conditions (for example, through tobacco smoking) receiving lower priority for care, which raises ethical issues.**

Introduction

Prioritisation or rationing of health services is on government agendas across the world; different countries have adopted different approaches, ranging from policies of rationing by exclusion of specified treatments to rationing by guidelines.[1-4] The British approach to setting priorities or rationing in health care has been described as "rationing by muddling through"[5] and takes place at different levels.[6] The 1995 House of Commons health committee report on priority setting in the NHS suggested that a preferable alternative to rationing by a "policy of exclusion" is to base policy on the health needs of local populations and to focus purchasing of health care on effective treatments.[7] The government's response restated its commitment to encouraging a knowledge based NHS and maintained that rationing is not an issue while scope remains for improved effectiveness,[8] although a national framework for rationing NHS treatments will probably eventually emerge.

The committee's report explicitly stated that the NHS must "remain responsive to shifting public concerns and debate."[7] The criteria that should influence rationing have become a commonplace subject in the British press, as well as in other forms of media, particularly since the case of "child B," who had leukaemia and was denied treatment (as opposed to palliative care) by Cambridge and Huntingdon Health Commission on the grounds of its high chance of failure.[9] Nicholson recently called for a public debate on health priorities and for the establishment of a Royal Commission on Priorities, with the public represented along with politicians and the medical profession.[10] A recent study of the five year purchasing plans of 66 district health authorities in England shows a considerable increase in the number of purchasers adopting explicit policies on rationing health care. For example, 11 of the 66 plans specified treatments that will not be purchased, in contrast with four in the team's previous survey, and many others conceded that similar rationing may be unavoidable.[11] These developments highlight the need to measure public opinion on rationing.

Several local surveys of the priorities of the public and doctors have been conducted in the United Kingdom.[12-15] Apart from one survey based on a quota sample drawn by a market research company,[16] however, there have been no published nationally representative surveys of health care priorities anywhere in the world. The studies in the United Kingdom have consistently shown that acute interventions that are perceived to be life saving are prioritised very highly by the public compared with many preventive initiatives (such as family planning and health education and promotion) and care for people with chronic illnesses and disabilities (such as people with mental illnesses and older people). In the United States the public consultation exercises of the Oregon health commission also found that the highest ranking priorities were for treatments for life threatening conditions (particularly acute conditions), maternity care, preventive care (but only for children), and palliative care.[1]

Obtaining a representative response from the public can be difficult.[12] Rapid appraisal techniques that may be useful at neighbourhood level[17] are relatively resource intensive across a whole population and are not a substitute for the need for representative information which deals with specific questions. This study aimed to obtain the views on priorities for health services of a random sample of the British population and used the Office of Population Censuses and Surveys omnibus survey as the vehicle.

Subjects and methods

The study design was an interview survey that was based on a random sample of people aged 16 and over in Great Britain taken by the Office of Population Censuses and Surveys for their May-June omnibus survey. The sampling frame for the survey was the postcode address file of "small users," which includes all private household addresses. It was stratified by region, housing tenure, and socioeconomic group. The postal sectors were selected with probability proportionate to size, and, within each sector, 30 addresses were selected randomly. If an address contained more than one household, the interviewer used a standard procedure to select just one household randomly. Within households with more than one adult member just one person aged 16 or over was selected with the use of random number tables. Because only one household member was interviewed, people in households that contained few adults had a better chance of selection than those in households with many. A weighting factor was applied to correct for this unequal

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probability, and the individual adult was the unit of analysis. The number of selected addresses was 3000; this contained 328 ineligible addresses (for example, non-domestic). At the remaining 2672 addresses, 376 people refused to take part (14%), 23 were incapable of interview (1%), 268 were non-contactable (10%), and 2005 were interviewed, giving a response rate of 75%. Interviewing was completed within two weeks.

QUESTIONNAIRE DESIGN

The questionnaire was based on an earlier version developed and extensively piloted and tested for the City and Hackney survey[12] and on questions from surveys in the United States.[3] The original pilot survey tested respondents' understanding and acceptability of different forms of question wording and methods of prioritising on 326 members of community groups in Hackney. Full details of the process of refinement have been reported elsewhere.[12] To make it suitable for use in a large national population survey, with up to 100 interviewers and around 2000 respondents, I worked with survey experts at the Office of Population Censuses and Surveys to simplify it for this national application. The number of services listed was reduced from 16 to 12, and services were listed without any examples in brackets (such examples were given in the City and Hackney survey) because examples may have caused bias. The service items were deliberately biasing—for example, treatments for life threatening illness were itemised separately for children, for people aged 75 and over, and with no age specification to assess age biases in relation to these treatments. Respondents were asked to look at a card displaying the 12 services and "choose the four services that you consider the most essential," then they were asked to "choose the four services that you consider the next most important." The bottom four services, by deduction, were the four remaining services, and respondents were asked to check the order—"may I just check, that leaves. . . ." The services were coded in the order that they were selected by respondents. The frequency distributions for each service's priority codes were also converted into averages and the averages listed in order of priority to provide the ranking.

Respondents were asked about the extent of their agreement or disagreement (strongly disagree to strongly agree) with six statements about priorities ("I am now going to read out a series of statements about health priorities, please tell me whether you agree or disagree. Choose your answer from this card"). They were asked who they thought should set priorities and asked to select their preference from a precoded list of doctors at local level, the public at local level, local NHS managers, local health authorities, and politicians or government at national level ("If health services rationing is inevitable, who should have most say in setting priorities for health services?"). Finally, they were asked about how they themselves would allocate £100 000 ("If you were in charge of a health authority with £100 000 left to allocate for your health budgets, which of the following would you choose to do?"). These further sets of questions on priorities were developed for use in the studies in Hackney and the United States and, as with the main priority ranking exercise, subjected to the same process of wording refinement during piloting[3 12] and discussions with experts in survey methodology at the Office of Population Censuses and Surveys.

The standard questions of the Office of Population Censuses and Surveys on self rated state of health ("excellent," "very good," "good," "poor," "very poor") and on the prevalence of longstanding illness, disability, or infirmity were asked, clarified as ". . . anything that has troubled you over a period of time or that is likely to affect you over a period of time?" Sociodemographic data were also collected. Results were analysed by the sociodemographic characteristics of the sample and by state of health.

Table 1—*Sociodemographic characteristics of sample in comparison with general household survey sample. Figures are percentages (numbers)*

Characteristic	Office of Population Censuses and Surveys omnibus (aged ≥ 16 years) sample	General household survey 1993 sample* (results for those aged ≥ 16 years only)
Age:		
16<45	49 (984)	51 (9449)
45<65	31 (616)	29 (5360)
≥65	20 (404)	21 (3884)
Sex:		
Male	49 (979)	47 (8812)
Female	51 (1026)	53 (9881)
Marital status:		
Married or cohabiting	66 (1327)	64 (11 971)
Single	19 (382)	21 (3861)
Widowed, divorced, separated	15 (294)	15 (2847)
Ethnic group:		
White	95 (1904)	95 (17 675)
Black or other	5 (97)	5 (911)
Housing tenure:		
Owner-occupier	73 (1465)	67 (6544)*
Rented from local authority or housing association	20 (390)	25 (2426)
Rented privately or with job	7 (145)	9 (853)
Economic activity:		
Working (full or part time)	58 (1164)	54 (9945)
Unemployed or inactive	42 (831)	46 (8443)
Health status:		
Reported longstanding illness, disability or infirmity	27 (534)	39 (7238)
None reported	73 (1443)	61 (11 222)
Total	1977-2005†	9852-18 693†

*General household survey totals reflect numbers of individuals aged ≥ 16 in survey (total was 18 693). Question on housing tenure used household as its base and number of households in survey was 9852, of whom 9823 provided information on housing tenure.
†Varying totals reflect varying numbers of "no answers" (missing information).

Results

SOCIODEMOGRAPHIC CHARACTERISTICS OF SAMPLE

Comparisons between respondents' age and sex and mid-term estimates for the age and sex structure of the population derived from census data show that respondents were similar to the population as a whole.[18] If anything, as with the general household survey,[19] there was a slight under-representation of people aged under 30 years but by less than 1% in each band. Table 1 compares some of the sociodemographic and health characteristics of the sample with those of the sample members aged 16 and over from the most recently published British general household survey.[19] This shows that the responders to each survey were similar in their sociodemographic characteristics, as would be expected given that sampling methods are the same and both the omnibus survey and the annual general household survey are conducted by the Office of Population Censuses and Surveys. The general household survey is able to link with census data for most of the households sampled, and analyses of the linked data show that the general household survey, and by comparison the omnibus survey, slightly underrepresents people who live in London (by < 1%) and people living in single occupancy households in comparison with households with two or more people (the non-contact rate was 5·3% in comparison with 2·6% for the latter). Otherwise, the only notable difference is with the proportion who reported a longstanding illness, which is lower in the omnibus survey. Apart from fluctuations in affirmative responses by month of

questioning, the total proportion of people reporting a longstanding illness over time is fairly stable in surveys conducted by the Office of Population Censuses and Surveys. The omnibus staff suggested that the difference arose between these two surveys because the question was asked at the end of the omnibus questions rather than at the beginning and was not in the context of a battery of questions about respondents' own health. It was also asked after complex questioning on health service priorities, perhaps leading respondents with milder conditions to reconsider whether they should be labelled as a "longstanding illness, disability or infirmity."

PRIORITISATION EXERCISES

Table 2 shows the frequency distributions and the mean priority rankings for the 12 services and treatments. The table shows that the highest priority (rank 1) was accorded to "treatments for children with life threatening illness," the next highest priority (rank 2) was accorded to "special care and pain relief for people who are dying." "Preventive screening services and immunisations" were ranked next highest (3). "Psychiatric services" was given a middle ranking (6) as was "high technology surgery" (7); "health promotion" was given a middle to low ranking (8). The lowest priorities were assigned to "treatment for infertility" (11) and "treatment for people aged 75 and over with life threatening illness" (12).

A further question on attitudes was asked in which respondents were asked if they strongly disagreed to strongly agreed (on a five point scale) with each of six statements. Table 3 shows the responses to these statements. Most respondents agreed or strongly

Table 2—*Priority rating of health services. Figures are percentages (numbers)*

	Priority rank													
Priority	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**Mean**	**Mean p rank**
Treatments for children with life threatening illnesses	34 (674)	21 (409)	9 (185)	7 (143)	10 (196)	6 (119)	3 (64)	3 (59)	2 (36)	3 (63)	1 (14)	1 (3)	3·2	1
Special care and pain relief for people who are dying	23 (442)	6 (127)	7 (129)	9 (183)	19 (377)	6 (104)	6 (124)	8 (153)	12 (241)	1 (26)	1 (26)	1 (25)	4·8	2
Preventive screening services and immunisations	9 (174)	15 (301)	15 (302)	10 (198)	7 (140)	10 (195)	9 (181)	5 (92)	2 (39)	7 (127)	7 (135)	3 (67)	5·3	3
Surgery, such as hip replacement, to help people carry out everyday tasks	4 (82)	12 (232)	11 (213)	8 (164)	8 (160)	13 (259)	12 (223)	7 (135)	2 (49)	11 (207)	10 (195)	2 (31)	6·0	4
District nursing and community services/care at home	4 (72)	7 (141)	12 (235)	17 (337)	8 (152)	10 (196)	11 (219)	12 (237)	1 (21)	2 (30)	4 (74)	12 (240)	6·1	5
Psychiatric services for people with mental illness	3 (68)	10 (201)	9 (183)	6 (109)	11 (222)	16 (311)	11 (219)	8 (153)	4 (79)	13 (247)	5 (106)	3 (51)	6·2	6
High technology surgery, organ transplants and procedures which treat life threatening conditions	7 (145)	7 (140)	9 (190)	18 (345)	7 (124)	6 (114)	9 (175)	14 (73)	2 (39)	2 (48)	2 (44)	17 (326)	6·3	7
Health promotion/education services to help people lead healthy lives	8 (164)	8 (157)	6 (115)	6 (106)	11 (206)	9 (167)	6 (108)	6 (118)	11 (223)	22 (430)	6 (108)	3 (51)	6·7	8
Intensive care for premature babies who weigh less than 680 g with only a slight chance of survival	3 (56)	6 (111)	9 (167)	7 (133)	5 (87)	7 (144)	8 (156)	8 (154)	4 (70)	16 (309)	20 (392)	8 (169)	7·7	9
Long stay hospital care for elderly people	2 (44)	4 (70)	7 (144)	7 (146)	5 (98)	7 (135)	12 (223)	15 (287)	3 (52)	4 (77)	10 (205)	24 (469)	7·9	10
Treatment for infertility	1 (24)	1 (14)	1 (13)	1 (22)	6 (117)	4 (83)	4 (69)	5 (104)	53 (1028)	11 (221)	5 (90)	8 (162)	8·4	11
Treatment for people aged 75 and over with life threatening illness	2 (30)	3 (69)	5 (96)	4 (83)	3 (65)	6 (113)	9 (179)	9 (175)	4 (71)	8 (162)	29 (346)	18 (346)	8·7	12
No of respondents	1975	1974	1972	1969	1944	1941	1939	1939	1949	1945	1944	1940		

Table 3—*Attitudes about health priorities.* Figures are percentages (numbers)*

Possible answers	**Strongly disagree**	**Disagree**	**Neither disagree or agree**	**Agree**	**Strongly agree**	**No of respondents**
High cost technology (for example, transplantation and kidney machines) should be available to all regardless of age	2 (32)	11 (216)	7 (133)	55 (1092)	25 (505)	1978
People who contribute to their own illness—for example, through smoking, obesity, or excessive drinking—should have lower priority for their health care than others	10 (188)	33 (656)	15 (289)	33 (656)	9 (186)	1975
The responsibility to ration health care spending should rest with the doctor rather than a hospital manager, health authority, politician, or government minister	1 (30)	14 (271)	10 (196)	48 (946)	27 (524)	1966
The government should issue guidelines to doctors about when not to use lifesaving medical treatment/technology	28 (548)	49 (962)	8 (165)	12 (245)	2 (47)	1968
If resources must be rationed, higher priority should be given to treating the young than the elderly	5 (94)	24 (476)	21 (422)	40 (776)	10 (203)	1971
The patient's quality of life should be considered in determining whether or not to use lifesaving treatment/technology	2 (52)	12 (237)	12 (227)	51 (1004)	23 (451)	1971

*"I am now going to read out a series of statements about health priorities, please tell me whether you agree or disagree. Choose your answer from this card."

agreed that high cost technology should be available to all, regardless of age, which somewhat contradicts their bottom ranking of treatments for people aged 75 and over with life threatening illness (table 2), illustrating the complexity of prioritisation by age group. In agreement with earlier research,[12] however, most respondents agreed or strongly agreed that the patient's quality of life should be considered. More consistent with the priority ranking exercise of the 12 services, half (979) of respondents agreed or strongly agreed that if resources are to be rationed then higher priority should be given to treating the young rather than elderly people.

Table 3 also shows that respondents were more evenly divided on whether people who contribute to their own illness (for example, through smoking, obesity, or drinking) should have lower priority for health care, although 42% (842) agreed or strongly agreed with this. Most respondents agreed or strongly agreed that the responsibility for rationing spending on health care should rest with doctors rather than managers, health authorities, or the government, echoing a similar direct question asked (see below). Consistent with this again most people disagreed or strongly disagreed with the statement that the government should issue guidelines to doctors about rationing lifesaving treatments.

PRIORITY SETTING

Respondents were asked who should set priorities and shown a precoded list: 56% (1104) said "doctors at local level," 19% (377) said "local health authorities," 17% (336) said "the public at local level," 5% (89) said "local NHS managers," and 3% (61) said "politicians and the government at national level." In reply to a separate question 88% (1739) said that they thought that "surveys of the general public's opinions, like this one, should be used in the planning of health services," 7% (149) disagreed with this, and 5% (91) said that they did not know.

They were also asked how they themselves would allocate £100 000. Seventy one per cent (1393) of respondents selected "a health screening and education programme which could prevent a large number of people needing lifesaving operations in the future (for example, screening for cancers)" and 26% (521) selected "12 extra immediate lifesaving operations this year (for example, heart bypass)"; (3%: 65 said they did not know).

There were few associations between health service priorities and sociodemographic characteristics, although those that were found did make theoretical sense. For example, 44% (426) of people aged between 16 and 45 prioritised as their first choice "treatments for children with life threatening illness," in comparison with 26% (218) of people aged between 45 and 75 and 21% (30) of people aged 75 and over ($\chi^2=79{\cdot}29$; df=2; $P<0{\cdot}001$); and whereas just 1% (15) of people aged under 75 years prioritised as first "treatments for people aged 75 and over with life threatening illness," 10% (14) of people aged 75 and over prioritised this as first ($\chi^2=75{\cdot}13$; df=1; $P<0{\cdot}001$). Forty six per cent (300) of people with one or more children aged under 16 and 28% (375) of those with no children ranked as first "treatments for children with life threatening illness" ($\chi^2=64{\cdot}77$; df=1; $P<0{\cdot}001$).

Key messages

- There are increasing calls for involving the public in the debate about health service rationing
- This study is the first exercise in health service priorities based on a random sample of the British population
- The highest priority of the public was the treatment for children with life threatening illness followed by special care and pain relief for people who are dying
- The lowest priorities were for treatment for infertility and treatment for people aged 75 and over with life threatening illness
- Most respondents thought that surveys of the public's opinions, like this one, should be used in planning health services

Discussion

The study presented here is the first prioritisation exercise based on a random sample of a total (national) population. The methodology of ranking lists of treatments and services may be criticised as superficial in relation to the complexity of the decisions to be made about health service priorities, which necessitate consideration of the costs and effectiveness of treatments and care programmes rather than sole reliance on values that may include prejudices. The prioritisation exercise presented here mostly entailed the ranking of broader treatments and services for specific groups of people rather than ranking individual procedures and diagnostic groups as in the Oregon experiment.[1] This focus was deliberate to measure the public's values in relation to specific groups of patients and age groups. In the context of a lack of adequate knowledge about the costs and effectiveness of much medical care it is important to be democratic and involve everyone in an open debate about rationing. One first step must be to measure baseline public opinions and values. If the public's values seem to conflict with firm medical evidence on effectiveness or to be prejudiced against certain groups then open debate and the provision of sound, unbiased information for public consumption and education is even more essential.

Probably the most important shortcoming of the setting of public priorities is that priorities chosen by the public do not necessarily offer the most equitable solutions in relation to the original aspiration of the NHS of equal treatment for equal need. Overall, this research confirms the results of earlier surveys which showed that the public's priorities are not value free—they are most likely to prioritise treatments specifically for younger rather than older people and particularly lifesaving treatments[12 13 16]; it also shows some public support (42%) for people with self inflicted conditions receiving lower priority for care, which raises ethical issues. It clearly shows that different groups of people —for example, age groups—hold different values that need to be reconciled in policies on rationing. The debate about how to weight different value systems in every decision on the allocation of resources is in its infancy as is the education of the public when prejudices are detected in their priority setting. These issues were not satisfactorily resolved in the largest exercise on rationing health care in Oregon.[1]

Finally, most people wanted to be involved in the planning of health services. Three quarters thought that the responsibility of rationing spending on health care should rest with doctors rather than managers, health authorities, or the government. Health authorities should listen to the public's views on health priorities to add legitimacy to their decision making, given their own position as democratically unaccountable bodies. They also need to be seen by the public to be working with and not against their clinical colleagues in prioritisation or rationing exercises to retain the trust of the public.

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Control of hydatid disease in Wales

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Abstract

***Objectives*—To evaluate the success of the south Powys hydatid control programme by analysis of trends in cystic disease in humans and sheep and dog infestation.**

***Design*—A review of hospital admissions for human hydatid disease in 1984-90, abattoir prevalence surveys of hydatid cysts in adult sheep, arecoline acetarsol and coproantigen surveys of prevalence of *Echinococcus* infestation in dogs.**

***Setting*—All hospitals in England and Wales, three abattoirs, and dog populations in mid and south east Wales.**

***Subjects*—Residents of England and Wales admitted to hospital between 1984 and 1990 with a new diagnosis of human hydatid disease (*International Classification of Diseases* (ICD), ninth revision, code 122) acquired in the United Kingdom.**

***Results*—The average annual incidence of human hydatid disease in Powys, mid-Wales, fell from $3{\cdot}9\times10^{-5}$ in 1974-83 to $2{\cdot}3\times10^{-5}$ in 1984-90. Age specific incidence rates in Wales declined over this period only in children, and no cases occurred in children (<15 years) in Powys. Two Welsh children who lived in Gwent and mid-Glamorgan were infected. Prevalence of hydatid cysts in old sheep from south Wales declined during the control period, but in 1993 prevalence of cysts was 13%. Prevalence of *E granulosus* infestation was zero in the control area in 1993, but it was 2·4% in Powys dogs outside the control area in 1989 and 9·2% in dogs in Gwent in 1991.**

***Conclusions*—Human hydatid disease has been successfully controlled in south Powys but cystic echinococcosis is still endemic in sheep in mid-Wales, and there is a focus of infection in humans, sheep, and dogs in the bordering areas of Gwent and mid-Glamorgan. There is considerable potential for an upsurge in human cases if control measures are relaxed.**

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Introduction

The south Powys control scheme[1 2] was set up in 1983 to eliminate the main endemic focus of human echinococcosis in the United Kingdom[3 4] and was based on supervised dosing of dogs at six weekly intervals with praziquantel (Droncit; Bayer). The programme was replaced in 1989 by a health promotion campaign. We have evaluated the success of the control programme by following World Health Organisation guidelines.[5]

Subjects and methods

Data on hospital admissions for England and Wales for 1984-90 (*International Classification of Diseases* (ICD), ninth revision, code 122) were collected and reviewed as in our earlier study.[4] Clinical details of 407 (84%) of 483 possible cases were obtained. We also reviewed serology records from Cardiff Public Health Laboratory, histopathology records from the Welsh and English borders, and hospital radiology records in a hydatid reference centre. We assessed trends in incidence in adults and children by using Poisson regression analysis in GLIM.[6 7]

The prevalence of cysts in lungs and liver of slaughtered adult sheep was measured in the only local abattoir known to receive sheep from the control area between 1984 and 1989.

The coproantigen test[8 9] was applied to faecal samples collected from dogs who had not received anthelmintic treatment in the previous two months from all farms in Llangenny, Powys (outside the control area) in May 1989; the Vales of Ewyas, Gwent in November 1991; and five valleys in the south Powys control area in May 1993.

Results

TRENDS IN HUMAN INFECTION

A total of 49 Welsh and 40 English residents were identified as new confirmed cases acquired in the United Kingdom. In addition, 14 other cases were found from serology records at Cardiff Public Health Laboratory (n=6), histopathology records from the Welsh and English borders (n=1), and records from the hydatid reference centre (n=7). In total, 62 Welsh and 41 English residents were identified as cases.

In Wales, excluding Powys, the average annual