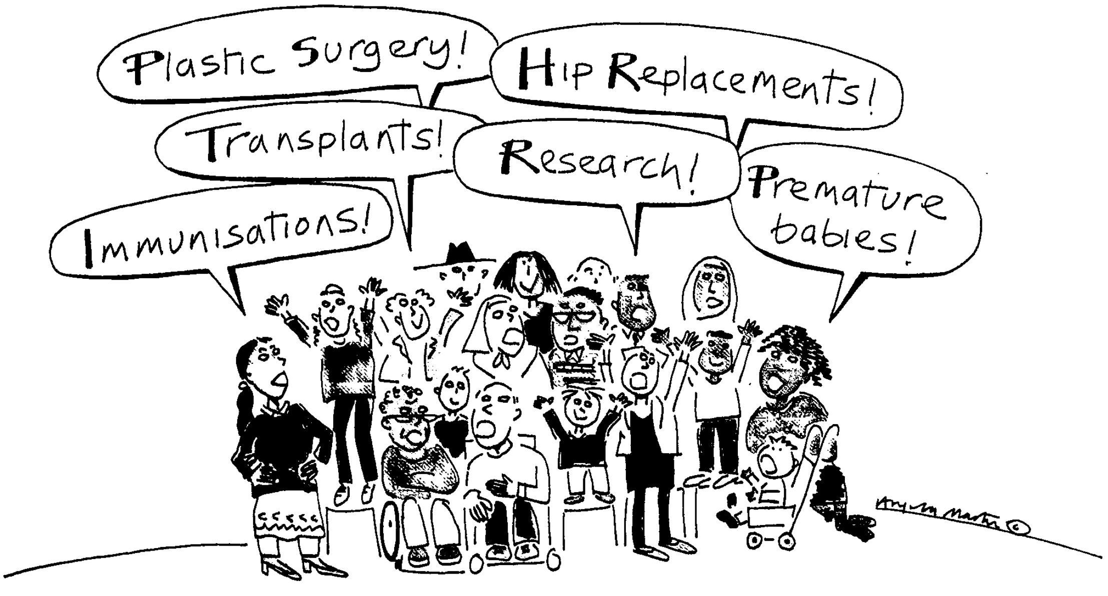
What people say about PRIORITISING health services



ann bowling

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The King's Fund Centre is a service development agency which promotes improvements in health and social care. We do this by working with people in health and social services, in voluntary agencies, and with the users of these services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences, information services and publications. Our aim is to ensure that good developments in health and social care are widely taken up. The King's Fund Centre is part of the King's Fund.

CONTENTS

FOREWORD

The debate about involving lay people in health care planning and assessment has been present since the inception of the NHS but it has taken on a new momentum during the last few years.

Community Health Councils were set up during the 1974 NHS reorganisation to represent the views of local users because it was felt that the NHS was too professionally dominated.

Nearly ten years later in 1983, the Griffiths Report considered that the NHS was still not paying enough attention to the views and experiences of health service users. During the early 1990s, there has been a rapid growth of interest in public and user participation in health care, although how much of this will have a real impact upon the NHS remains to be seen. One result of the attention given to the subject has been a proliferation in methods for getting user views. However, few comparisons of the strengths, weaknesses and costs of the various methods used in different circumstances have been carried out.

Another aspect of the debate has been the increasing number of areas being opened for public consultation and user involvement. One of these is the rationing of resources and the consequent need to set treatment and service priorities.

This book makes a useful contribution to the literature on lay involvement in health care generally, and to the two topics of methods and public involvement in priority setting, in particular. The reader will find postal and interview surveys and attendance at community group meetings compared for effectiveness, with details of the cost, time and expertise involved in each made clear. They will also find an interesting investigation into how different groups of people (lay people of different categories, GPs, consultants and public health doctors) prioritise health services.

The discussion about ethical considerations in obtaining public views about health treatment priorities should provoke thought. Hopefully the empirical material will be stimulating enough to encourage attempts at dialogue with the public, even though these may take a different form to the examples given.

What the reader will not find here is 'the answer' to the problem of prioritising health services. What they will find is an informative discussion of the issues involved and an eye-opening empirical study.

Shirley McIver
Consumer Feedback Project
King's Fund Centre

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This study was completed with the help of Morag Farquhar, MSc, Juliet Formby, DCR, Gillian McAllister, BSc, Richard Kelly, MSc, and Michael Shiner, BSc. I am grateful to each of them for their assistance with coding, data entry and interviewing. I would also like to thank the following for their enthusiastic help with the questionnaire design and administration: Lisa Burnett; Devon Burnett; Doris Otowmewo; members of the Public Health Department, particularly Dr Jane Leaver and Dr Bobbie Jacobson for their enthusiastic support; representatives of the Turkish, Asian, Chinese and Vietnamese communities for help with translation; Professor Lesley Southgate, Mr George Leahy, Dr Anne Mackie and Miss Gina Inkley for advice, and the public, without whom this exercise would not have been possible. We would finally like to thank our colleagues and fellow researchers for their helpful advice, in particular Shirley McIver from the King's Fund Centre. The study was funded by the King Edward's Hospital Fund for London.

The quotes which appear throughout the book are taken from the group discussions and do not necessarily relate directly the main text. They illustrate people's feelings, only.

Unless otherwise stated, attention has only been drawn to differences between groups where the probability of the finding occurring by chance was less than 5 in 100.

We use the term 'Black' to refer to people from racial or other minorities who may by disadvantaged because of their racial backgrounds.

Ann Bowling

Reader

June 1993

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SUMMARY OF THE RESEARCH OBJECTIVES AND DESIGN

OBJECTIVES

- To explore the feasibility of involving members of local community groups in priority setting exercises as a method of consulting the public.
- To analyse community group members' priorities for health service provision.
- To test the representativeness of responses by survey of a random sample of people in the same population.
- To compare the public's priorities with those of doctors by a postal questionnaire survey of the latter.

DESIGN

- Self-administered questionnaire to community groups, followed by group discussion.
- A postal and home interview survey of randomly sampled adults.
- Postal questionnaires to consultants, general practitioners and public health doctors in the same health district.

MAIN OUTCOME MEASURES

- Ranking of health services in priority order.
- Measurement of values for health care.

SECTION 1

BACKGROUND

Prioritisation of services within the new NHS

Some form of rationing of health services which are paid for out of taxation is arguably inevitable[1]. Rationing takes place either implicitly or explicitly and has always occurred. The British Medical Association voted, at a special conference to consider the NHS reforms on 26 March 1992, to back a composite resolution:

That this meeting accepts that rationing of health care is inevitable and that governments must be pressed by the BMA to accept their responsibility for rationing decisions and to invite all interested parties, not least the public, into a debate to define mechanisms by which equitable rationing may be applied.[2]

The government, meanwhile, has indicated that it has no intention of taking a central initiative on rationing[3].

A major reorganisation of the NHS has been taking place with a view to making it more efficient and responsive to patients. The emphasis on greater patient responsiveness and accountability to them and the introduction of purchasers and providers[4,5] have focused public attention on decision-making involving resource allocation. In the past, the allocation of resources, at least within specialties, was assumed to be based largely on clinical judgement, even though this was financially constrained. Resource allocation and priority setting have not been explicitly defined: services have been rationed by means of waiting lists, the sizes of which have depended on the special interests of the doctors, the resources available and ease of patients' access to services[6,7]. It has been suggested that doctors are less shocked by rationing than the public – they have been involved in it for years[8].

Sectors of the national press regularly publish articles on cancelled operations due to lack of resources and now give publicity to the new system of contracting and negative effects on service provision (for example, *The Guardian*, 26 January 1991, 'NHS patients face "rationing" for treatment'; *The Guardian*, 11 February 1991, 'Cash ban stops woman's surgery').

The purchasing powers of district health authorities (DHAs) now enable them, in theory, to base resource allocation on explicit criteria, which is regarded as more honest, and therefore more ethical, than the current system of implicit rationing. With a nationalised health service some consensus now has to be obtained over which services and treatments are purchased at the expense of others. With contracting, then, priorities will be visible and thus health authorities will have to be explicit about their decisions[9].

Current debate focuses on who should do the rationing and how[10] and the criteria that should be used when setting priorities[11-13]. Jessop (1991)[14] has suggested that severity and cost-effectiveness should form the basis of logical decisions, although such data are lacking for most conditions[15]. Others advocate the use of QUALYS in decision-making, although QUALYS have still not been subjected to rigorous testing for reliability and validity based on large random samples of the population[16].

In addition, the Department of Health (1991) and the NHS Management Executive (1992) have suggested that DHAs should not operate independently but should work with other groups when setting local priorities, including local people, general practitioners, providers and their clinical staff, other local agencies (for example, family health service authorities), regional health authorities and the NHS Management Executive[17,18]. Health authorities are encouraged to give local people a 'real voice'. While experts within medical and health care specialties and professions can advise on technical 'facts' in priority setting, only members of the local community can express community health values. There is a strong case for involving the public in guiding health authorities about the services they should be purchasing, how much of them and where[19,20].

Community health councils (CHCs) have been encouraged to make the public aware of the purchasing intentions of health authorities and FHSAs and consult the public over these in order to make the purchasing of health services more sensitive[21]. Forrester (1991) has criticised professionals for setting the health agenda without openly consulting the public (or only with structured questionnaires which are biased towards professionals' perceptions of need)[22]. He suggested a move away from professional control of needs assessment, that is., the 'professional' knows what people need and how needs are best met) to community control (that is, the people know what their needs are and the 'professional' seeks to discover these). A survey of 704 residents of Bath undertaken by Richardson, Charney and Hanmer-Lloyd (1992) showed that 65% agreed that the public should have more say in making the decisions[23]. The issue of concern to many DHAs is how to involve consumers in decision-making about purchasing.

A further problem relates to the limited amount of information available on cost-effectiveness and outcomes of treatments. While those in favour of public consultation are unlikely to disagree with Macalister-Smith's (1991) argument that the public need to be given information on the outcomes of medical care before they can be consulted on need and purchasing decisions, this information is often simply not available[21].

There are several methods of obtaining consumer views. Consumer feedback can be obtained by means of regular meetings with patients (the users), public meetings, consumer representation on committees or setting up user groups, local interview or postal surveys, or telephone surveys in areas of high telephone ownership. Observation techniques can also be used in care settings where patients find difficulty in expressing views (for example, frail elderly people; very young children).

The Oregon experiment

The increasing emphasis on ascertaining consumer opinion has led to interest in the UK in the Oregon experiment in the United States[24,25]. This arose because of a shortfall in the funding of services for Medicaid recipients. It was the first attempt to develop an explicit method of rationing health care.

The Oregon Health Services Commission was composed of a group of 11 consumers and health care professionals (three family doctors, an obstetrician, a paediatrician, a public health nurse, a social worker and four lay people). It was appointed as required by the Oregon Basic Health Services Act 'to report . . . a list of health services ranked by priority from the most important to the least important, representing the comparative benefits of each service to the entire population to be served.' Prioritisation would be finally decided by the legislature, which would determine the extent to which the list of services could be funded to provide health care for Medicaid recipients. Whether the Oregon experiment can help to resolve the difficult decisions that are are being made in the United Kingdom is the subject of much debate[26].

The ethical justifications on which the Oregon approach stands are:
1. It is more equitable to assure everyone basic health care than to offer a larger but unevaluated collection of benefits to some of the poor while excluding others from anything but emergency care.
2. Explicit, publicly accountable choice is better than the hidden rationing that now occurs.
3. Health care priorities should combine authentic values of the community with expert technical judgements about health services. [27]

Many public meetings have been set up and have already completed their reports; others are still planned with the aim of consensus building[27,28]. The meetings involved a slide show, the collection of demographic information and the participation of individuals in ranking health services in priority order, followed by explorations of the values that guided their priorities and of how consensus was reached. The aim of these meetings was to generate for the commission publicly examined statements about what makes health care important to members of a community for whom health care has a 'shared value': members were asked to think in terms of 'the common good' associated with health care. Thus the aim was not to seek specific opinions about health care, but rather to make explicit the value systems people use in reaching their decisions and formulating their opinions. The community meetings also tested the validity of the hypothesis that lay people have sensible and important moral intuitions relevant to dilemmas of health policy.

The method for these meetings was:

1. An introductory presentation set the context and tasks of the meeting.
2. Small group discussions for:
   (a) individual judgements about priorities of a list of nine categories of health services;
   (b) discussion to identify values underlying judgements on priorities;
   (c) identification by the group of key shared values regarding health care as a common good.
3. Large group 'sharing' to:
   (a) identify key values from all the small groups, and
   (b) identify what value themes would constitute the 'authentic message' to the commission from this community.
4. After each meeting, the leaders sent a written report of the community's message to the Oregon Health Department office.
5. Staff of the department collate and summarise the reports into a final report for the Health Services Commission[27,29,30].

A large number of people were involved in setting up the public meetings. A 29-member project advisory panel was appointed to develop a slide show and the mechanisms for the public meetings; 25 facilitators, 24 co-ordinators and 9 facilitator/co-ordinators, all volunteers, were recruited from communities throughout the state to assist with the project. Attendance was actively encouraged through door-to-door canvassing by grass-roots health organisations. Forty-seven meetings were held, involving over a thousand citizens[30].

Garland and Hasnain (1990) reported that the main values advanced at the meetings included:

- prevention (based on the values of cost-effectiveness, enhancement of quality of life, improvement of community life and benefits to large numbers of people);
- quality of life (intertwined with length of life, rather than length of life as an alternative to quality);
- cost effectiveness (it was also believed that this should not be the all-determining value);
- ability to function, which is a component of quality of life; and
- equity (government's obligation to guarantee a basic or adequate level of health care to all)[29].

These values were all given moderately high to very high ratings to be used when prioritising services. Values achieving medium ratings included effectiveness of the treatment, the number of benefits of the treatment and personal choice. Community compassion, impact on society, length of life and personal responsibility achieved medium to low ratings. These were regarded as valuable considerations by the commission, as the values of prevention, community compassion and equity had been omitted in the cost-benefit formula (based on a 'Quality of Well Being' formula, QWB).

The information gathered from these community meetings apparently served as an important qualitative determinant in the final 'fine tuning' of the list[28].

One problem of the community participation meetings was the unrepresentativeness of the attenders, who were largely college-

educated, Caucasian, in higher income brackets, medical students and health professionals[20, 29]. Only 4.4% of participants were Medicaid recipients and only 9.4% were uninsured[30]. There have been several other criticisms of the wider Oregon experiment, in particular that it was based on unethical principles and that the method was *a priori* vitiated by injustice because it was aimed at the poor. The cost-benefit approach has been labelled as 'pseudo-science' and there is agreement that it is fraught with difficulties due to the unavailability of accurate cost and outcome information; the QUALY-type calculations are extremely sensitive to minor changes in the assumptions fed into them, as well as being based on the 'average patient' and thus not allowing for heterogeneity within conditions. It has been ridiculed on the grounds that it is impossible to rank services in a rational, logical way on the basis of a cost–benefit formula derived from population health outcomes. This feeling was supported by the flaws, aberrations and errors present in the pilot study lists, and these have been called 'nonsensical'[19, 27,28, 31-34].

It was this disquiet that led to the development of a simpler exercise based on just 26 general disease categories ranked by the Oregon Health Services Commission (HSC) on the basis of the importance to the individual, the importance to society and whether the category was basic or essential to a health care plan. A modified Delphi technique was used to reach a consensus which allowed for the inclusion of the public's values[28]. Finally, Oregon listed 17 categories of care in rank order based on grouping of community values. Conditions and treatments were paired and ranked by cost and benefit criteria and any anomalies within these 17 were debated by an expert panel until consensus was reached[35]. The cost–benefit formula used has been briefly summarised by Bowling (1992)[24,25], and is described in Appendix I.

Despite the controversy so generated, the need to prioritise health services appears to have been generally accepted in the United States and currently several states are considering similar exercises. Vermont has already scheduled 70 public meetings, held as part of the regular programmes of established community groups[36]; New Jersey has held over 300 community and professional forums and has conducted two public opinion surveys[37]; California has established a Health Decisions group which has been focusing on the guidelines on which treatment decisions should be based (for example, ability to pay, quality of life, patient self-determination)[38]. The future has been envisaged as one of increasing credibility and power for the 'national community health decisions movement'[39].

Attempts to obtain consumer views of prioritisation of health services in the United Kingdom

While the importation of the entire Oregon experiment to the United Kingdom is not feasible since it is the product of a quite different health care and political system, it may be possible for the NHS to learn from the public forum exercises in relation to developing health care priorities which have support from professionals and the public.

There is a small but increasing literature in the United Kingdom based largely on surveys in which patients or members of the public are asked to rate states of ill health[40,41]. From the limited evidence to date it appears that, in the United Kingdom, people regard younger people and those who are married as having priority over older and unmarried people for treatments for leukaemia, heart disease and kidney failure[41]. A survey of a non-random sample of people (labelled a 'convenience sample') by Williams (1992), found that while 40% said that there should be no discrimination in the provision of health care, for 60% the preferred bases of discrimination were whether or not people had cared for their own health. This was followed by a preference for the young[42]. As Williams suggested, this type of research is an 'ethical minefield'. However, he adds: 'I think it is our duty to rush in where others fail to tread, even if in the process we find ourselves being maligned as insensitive troublemakers and even if the misguided criticise our analytical techniques because they require quite strong ethical assumptions to be made.' Undoubtedly, researchers must be explicit about their ethical assumptions, but, as Williams says, so must their audiences be explicit about the 'ethical assumptions in their worlds'.

Ong, Humphris, Annett and Rifkin (1991) developed the Rapid Appraisal method, which is a combination of public forums (including professionals) and interview survey methods[43]. They applied this technique to South Sefton in an attempt to find out what problems were perceived by representatives of the community and community leaders. Respondents were asked to list their priorities in relation to identified community problems. The authors emphasised the need for these exercises to be part of a continuing dialogue with the community, given that the community sometimes fails to prioritise items which are known, scientifically, to be essential (for example, their respondents failed to mention vaccination and immunisation of children as important). The authors concluded that, despite the problem that priorities identified by the community cannot always be accepted at face value, the method was a useful instrument in attempting to understand the strength of feeling in a community about 'priority problems'.

Several health authorities have carried out consumer surveys or consultation exercises or are currently planning them. For example, an attempt to hold local NHS forums and to sample public opinion using surveys every six months is being made by South Western Regional Health Authority, although there is concern about the cost (estimates of between £30,000 and £90,000 for each survey), the raising of public expectations and the exclusion of the local community health council from the forums[44]. The exercise is still at the planning stage.

The director of public health in Mid-Essex, along with a research associate, has initiated a series of public health forums attended by members of voluntary organisations, the community health council and representatives of the health authority. Other forums have been held with general practitioners. The results to date show a large area of common agreement with the results from the Oregon public health forums, suggesting that individuals hold many values, attitudes and beliefs in common about health care: for example, the importance of preventive care for children. Other questions completed by participants include the questionnaire developed for public health physicians for the television programme *Public Eye*. This asked respondents to rate, in order of priority, hip replacements, cataract removal, heart by-pass, renal dialysis, hernias, breast screening, treatment for AIDS, neonatal care (800g), treatment for advanced Parkinson's disease, treatment for advanced lung cancer, and heart and liver transplants. The priority ordering by the Essex respondents was generally similar to the physicians' ratings (the above sequence is in order of the physicians' ratings)[45]. Attempts have been made to consult the public by leaving the questionnaire in GPs' surgeries and other public places. The Department of Public Health has so far used the higher-than-expected support for mental health services, detected at the meetings, as justification for spending some NHS growth funding on these services.

The Department of Public Health in North-East Essex commissioned a market research company to run a number of focus groups, using similar priority measures to those used in Mid-Essex, and to conduct a random population survey of 354 adults. The values expressed appeared similar to those in Mid-Essex[46].

Members of the Department of Public Health in Bath sent a postal questionnaire to 1,430 residents of the district. To preserve anonymity they did not send out reminder letters, but this meant that the response rate was low – at less than half[23]. They asked respondents how important they believed a selection of 10 services were. Kidney dialysis, special-care baby units and vaccinations were rated as very important by between 69% and 81% of respondents; hip replacements were rated as very important by 45%; school medical services and long-stay geriatric care were so rated by 33-35%; day hospitals and family planning services by 23-26%, and varicose vein surgery and help for those who want to stop smoking by 4-8%. The authors commented: 'A wish to obtain the greatest good for the greatest number was not apparent.' The authors noted that a barrier to the democratisation of decision-making is the lack of information provided to the public. When asked, 58% of the respondents agreed that 'decisions should be left to the doctors and other experts at the health authority' and 65% agreed that 'the public should have more of a say in making the decisions'. However, 68% also agreed that 'local people are not able to influence the decisions'.

Despite the difficulties of such approaches, it is likely that there will be an emphasis in the future on systematic attempts to obtain information about societal preferences for medical treatments and care. The lesson to be learnt from Oregon is that priority setting is extremely complex and that the information on medical outcomes that is currently available does not facilitate such exercises. Even if it is felt that one cannot reasonably expect members of the lay public or professionals expertly to rate specific medical conditions and their treatments in priority order without the necessary information to justify this, public values can still be explored qualitatitvely in a way similar to that undertaken in Oregon. The purpose of that experiment was to develop information on why members of the community judge certain health services to be particularly important for that community – in other words, whether people share a set of values about health care that can help to define a set of health services as constituting some common good[29].

An NHS Management Executive document (1992) has also listed several local initiatives undertaken by a number of health authorities, ranging from patient satisfaction surveys to setting up local consultation groups[18]. Readers are referred to this document to obtain further information.

Methods of consulting the public

As previously pointed out, there are several methods of obtaining public opinions[18,23,45,46]. A survey approach using standard sampling frames might need to be combined with booster samples of key groups which might otherwise be unrepresented (for example, people from Black populations) or represented in insufficient numbers for sub-group analysis. Various kinds of surveys can achieve wide population coverage. Postal surveys have lower response rates than interview surveys, particularly on complex issues[23], but they are more economical than the interview system. The highest response rates are, however, undoubtedly achieved with interview surveys[47].

In contrast, community meetings are centred on face-to-face interaction with the aim of reaching consensus about values through exploration of questions and opinions. Such meetings, known by market researchers as focus groups, can provide a more suitable methodology for ascertaining what makes health care important to members of a community (for example, quality of life, length of life, prevention of illness)[27-30]. Another advantage of holding public meetngs within existing community groups is that those people who are unlikely to respond to postal questionnaires or who may not be represented on sampling frames (for example, the electoral roll) can be targeted more easily with careful inclusion of groups representing them.

One problem of community-based meetings is the unrepresentativeness of the attenders, exemplified in the Oregon experiment[20,29]. Even where a panel is set up to include representatives of the community, the lay members can easily become 'experts', and therefore atypical, after a while. Concerns have been expressed in some districts about the likely high costs of holding public meetings and interview surveys[44].

SECTION II

THE COMMUNITY GROUPS STUDY

The area of the study

City and Hackney Health District is situated in the East End of London. The City has relatively few residents, although it has a daytime commuter population of about 300,000. About 190,000 of the 200,000 people covered by the district live in Hackney.

City and Hackney scores as second highest of the 16 districts in North East Thames Regional Health Authority using deprivation scores derived from the 1981 and 1991 Censuses[48]. The City is much more affluent. The population of the district is young (57% are under 35, in comparison with 49% for England and Wales, and 12% are over 65, in comparison with 16% nationally).

The 1981 and 1991 censuses, plus local data, showed that Hackney has a significant Black population, with large numbers of Black Caribbean people, Asians, orthodox Jews, and, in particular, Kurdish and Turkish immigrants and refugees. It is estimated that almost 2,000 families are homeless and they are recognised as a priority for re-housing.

Patterns of morbidity and mortality are high and have been documented in the district's annual public health reports. In particular, City and Hackney has high standardised mortality ratios (SMRs) for infant mortality, childhood accidents, respiratory disease in childhood, sudden infant death syndrome and endocrine and related diseases in childhood. Among adults, the SMRs are particularly high in the district for accidents, infectious diseases (for example, tuberculosis), stroke and other diseases of the circulatory system, lung cancer, cancer of the cervix, diabetes, cirrhosis of the liver, chronic renal failure, mental illness and diseases of the blood. Among people aged 65 and over the district has particularly high SMRs for tuberculosis, chronic bronchitis/ emphysema, lung cancer and diabetes. The epidemiological literature indicates that a number of these diseases have a large social component in relation to origin. City and Hackney has the classic features of an inner-city environment known to have a negative impact on health, such as poor housing and a high rate of unemployment.

The district has 121 general practitioners providing primary health care alongside other primary and community care professionals. St Bartholomew's Hospital and the Homerton Hospital are the main provider units for hospital care (about half of the patients treated at St Bartholomew's are local residents, and almost all of the Homerton's patients are local residents). The Hackney Hospital is the main provider unit for care of elderly people and mentally ill people in the district.

Aims

The aims of this part of the study were to explore the feasibility of involving members of local community groups in priority setting exercises, and to analyse their priorities for health service provision.

Subjects: pilot and main community group studies

The researchers were concerned about reflecting the ethnic and social mix of the area among the groups visited. A total of 204 people were questioned in the first pilot study and 32 in the second, which tested some further modifications to the questionnaire. The respondents consisted of individuals and representatives of a wide range of community groups.

For the main study of community groups, a further 27 community group meetings and tenants' association meetings were arranged and a further 350 participants in these completed the questionnaires. (The item response varied from 290 to 350, reflecting the complexity of the issues explored.) As well as attending council tenants' association meetings in each postal area of the district, the Barbican Estate Residents' Committee also participated in the study in order to represent the more affluent, albeit small, City section. The community groups which participated in the pilot and main studies are shown below; the researchers also had a stall displaying the study at the annual Hackney Show in the summer of 1992 and, in conjunction with the Public Health Department, held a public meeting on priorities.

The researchers negotiated with each community group to attend one of their routine meetings or to be there at times when members would be on the premises. With the exception of the special public meeting organised by the researchers, the number of people at each community group session who completed the questionnaire ranged from 6 to 51. Each meeting lasted about an hour; respondents took an average of 20 minutes to complete the questionnaire and the remaining time was taken up with usually heated and lively group discussions. Community group leaders assisted with the translation of the

Groups visited for the first (pre-pilot) study were:
The Sam and Annie Cohen Centre for the Elderly and Disabled
Claudia Jones Organisation (Black women's community care group)
The London Hospital Accident and Emergency Department
Rehabilitation Centre for the Mentally Ill
A group of media students at Queen Mary and Westerfield College
The student refectory at Queen Mary and Westerfield College
Centreprise Bookshop
Dalston shopping centre
Those responding to a door-to-door survey in Hackney
Whitbread brewery staff
Fire officers
Police officers
Bank workers

Groups visited for the second pilot study were:
Wenlock Improvement Scheme (tenants' association)
Wyke and Gascoyne Co-ordinated Advisory Committee (tenants' association)

Groups and organisations visited for the main community group study, using the finalised questionnaire, were:
Wenlock Improvement Scheme (tenants' association)
Wyke and Gascoyne Co-ordinated Advisory Committee (tenants' association)
Pembury Estate Tenants' Association
Stamford Hill Tenants' Association
Woodberry Down Tenants' Association
Haggerston Tenants' Association
Barbican Estate Residents' Association
Roots Pool Development Project
Springdale Day Centre
Hyderbad School
The Factory (group for elderly people)
The Factory (child care group)
Huddlestone Centre (parents' support group)
Hoxton Health Group
Hackney Computer Access
Christian Fellowship
Christian Community Centre, Middleton Road
Vu Khanh Thanh, An Viet Foundation
North East London Jewish Day Centre
Agudas Israel Community Service (mother and toddler group)
Turkish and Kurdish Community Centre
Afro-Caribbean Project

questionnaire into Turkish and Chinese languages and interpretation with Vietnamese and other Asian languages.

One of the (main study) group meetings consisted of a public meeting organised by the research team and representatives of the Public Health Department. This was held in a local health centre and the public were invited to attend by means of leaflets distributed to 3,000 households surrounding the centre and to public buildings in the district and advertisements in community group newsletters and the local press. However, just 14 people attended, only two of whom had no professional health service or related connections. Unlike the attendance at the community group meetings, this latter exercise was judged to be a failure.

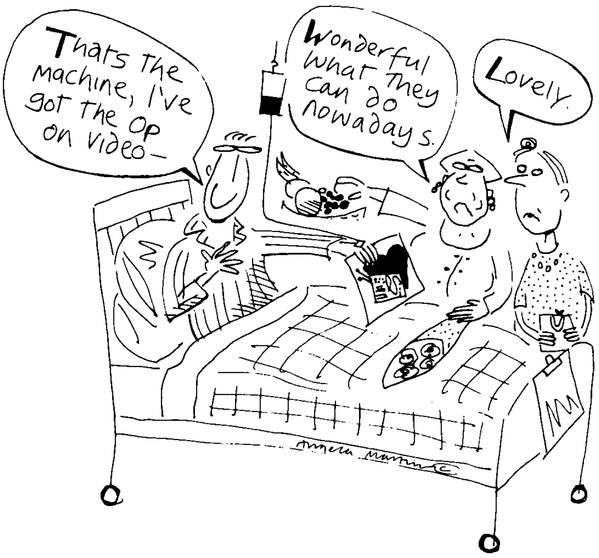
The secretary of the local community health council was initially represented on the advisory group to the project, but later withdrew because the CHC voiced its opposition to the study on the grounds that it was about 'cuts to the NHS'. Negative publicity in the CHC newsletter circulated in the week before the public meeting may have led also to non-attendance by those members of the public with an active interest in health service issues.

Weighting of results has not been applied as this survey was not an attempt to achieve a random, representative sample of the population but an attempt to consult key groups of local people through their community organisations. Thus it was important to ensure that different age and ethnic groups and both sexes were included, but no quotas on numbers could be attached.

Methods

The research took place in three phases: two pilot phases by a group of 30 medical and dental students and a social scientist to develop the questionnaire, followed by a main study with the revised instrument. A questionnaire listing a wide range of different services and broad treatments (with examples in brackets) was developed by members of the Public Health Department and piloted in two phases. The questionnaire items included services and treatment areas relevant to a teaching hospital district in a socially deprived inner-city area. It was based on questionnaires developed for use in Mid-Essex[45] and North-East Essex[46]. The Essex questions were based largely on questions used in Oregon. Respondents were asked to make their rankings in relation to their local community's needs, not just their own.

The first pilot study showed that people found it difficult to prioritise a list of 12 treatments/services from 1 to 12 (1 = highest and 12 = lowest). A second pilot used a three-category ranking method, which assigned high, medium and low ratings. These were given scores, averaged and ranked accordingly. Due to respondents' difficulties with this, a third pilot was carried out in which they were asked to rank the four services judged to be essential, the four which were very important, the four which were important and the four which were less important.



Respondents felt that it was necessary that each category should include the words 'essential' or 'important' because, as some people said: 'All these things are important'. A rank of 1 to 4 was allocated to each of the 16 services according to their ranking (1 = essential to 4 = less important). Average scores were calculated for each service and the 16 services ranked in a priority order. This was the method used in the main study.

Questions were also asked which attempted to measure the values respondents held about health states and treatment in relation to quality of life, length of life, prevention, mental health, physical health and costs. Respondents were asked for their age, sex, ethnicity, occupation, the standard self-assessment of their health as excellent, good, fair or poor for their age and about any longstanding illness, disability or infirmity that has 'troubled them over a period of time' or is likely to affect them 'over a period of time' (this was the Office of Population Censuses and Surveys General Household Survey Question[49]). Health ratings were important in order to assess any influence this had over respondents' ratings.

Correlations to test the validity and reliability of the questionnaire were carried out at both the community group and survey stages; inter-item correlations for similar or opposing statements were weak to moderately good and ranged between -0.157 and 0.302 but all were statistically significant ($p<0.01$ to $p<0.001$). It would not be expected that these correlation values would be greater, given that the items were taken from different questions where the items were ranked in relation to different types and numbers of treatments/services. Examples of correlations for specific question pairs are given in Appendix IV.

RESULTS

This section presents the detailed results of the main study of community groups, referring to the pilot studies where appropriate (n = 350 people in 27 groups for the main study).

Table 1a: Characteristics of the group attenders

	%	(Number)
Sex		
Males	55	(185)
Females	45	(149)
Age$^+$		
<30	26	(82)
30<40	28	(89)
40<50	16	(53)
50<60	7	(21)
60$^+$	23	(73)
Ethnic group		
White European	35	(116)
Total Black:	65	(217)
Black African	8	(25)
Black Caribbean	27	(89)
Asian	5	(18)
Turkish/Kurdish	6	(20)
Jewish	10	(33)
Black UK	1	(4)
Black other	1	(2)
Vietnamese	1	(4)
Chinese	4	(13)
Other	2	(9)
Economically active		
Yes	54	(169)
No	46	(145)
Socio-economic class		
I	4	(11)
II	20 >48	(49)
III NM	24	(61)
III M	29	(73)
IV	17 >52	(42)
V	4	(9)
Other	2	(4)
Self assessed health status		
Excellent	24	(78)
Good	46	(150)
Fair	27	(87)
Poor	3	(11)
Longstanding illness		
Yes	26	(83)
No	74	(232)
Number of respondents + Age range 17 - 94; mean 46	314 - 350	

Table 1b: Characteristics of the group attenders in comparison with 1991 census data for Hackney

	Responders	Total population (Hackney) 1991 census estimates:
Sex	% (no)	%
Women	45 (149)	51
Men	55 (185)	49
Ethnic group		
White UK/European	35 (116)	52
Total Black:	65 (217)	48
African	8 (25)	5
Caribbean	27 (89)	17
Asian	5 (18)	7
Cypriot	_ _	5
Turkish/Kurdish	6 (20)	1
Orthodox Jewish	10 (23)	7
Other	9 (32)	6
Age		
<30	26 (82)	48
30<60	51 (163)	37
60+	23 (73)	15
Total	318-335	185,336

+ The census figures for ethnicity relate to 1981 estimates as there was a high rate of non-returns for the 1991 census in Hackney, with the result that ethnic status figures are unreliable.

DEMOGRAPHIC AND PERSONAL CHARACTERISTICS

Table 1 shows the numbers of people in different ethnic age and sex groups and those who were working as well as those who were economically inactive (see Table 1a).

There was some over-representation of African-Caribbean people and a corresponding under-representation of indigenous White people. In comparison with local population projections, based on the last census, males and females were represented according to their expected distribution in the local population and there was a slight under-representation of people aged under 30 (see Table 1b).

Many of the Black people in the sample commented negatively on the pre-coded response choices for ethnic status, which offered 'Black African, Black Caribbean and Black – other'. They felt very strongly that they were Black British, or Black UK, and that ethnicity codes should reflect this.

The proportions assessing their health as excellent, good, fair or poor for their age were similar to those of a national sample of adults surveyed by Cartwright and Anderson (1981)[50]. Slightly fewer reported long-standing illness, in comparison with over a third of adults in the 1988-89 General Household Surveys[49].

In addition, respondents were asked if they had undergone any higher education, and 50%, more than would be expected said they had.

Priority rankings: main group study

Table 2 shows the priority rankings from the main group study using the finally revised questionnaire. Some respondents omitted an item from their rankings, but comparison of the respondents who fully completed the question with those who made minor omissions showed no differences in mean rankings; thus the rankings taking all ratings into account are presented. There were no differences in socio-demographic characteristics or socio-economic group and full or partial completion of this question.

Scores were averaged to derive the ranks shown. The table shows that treatments which saved life were ranked highest, along with special care and pain relief for people who are dying and medical research for new treatments.

The services which ranked middle-high were preventive services, surgery to help people with disabilities (for example, hip replacements), therapy to help people with disabilities and services for people with mental illnesses.

The services which ranked middle-low were intensive care for premature babies unlikely to survive, long-stay care, community care services and health education services.

The services ranked lowest were family planning services, treatments for infertility, complementary medicine and cosmetic surgery. These distributions were very similar to those of the pilot studies (see Appendix II).

Differences between ethnic groups

Cross-tabulations in relation to ethnic group were carried out with the community group sample because these groups were intentionally targeted. We can't tell how representative of the local population their views are, but we anticipated that there would be insufficient numbers of Black people from the random sample of the public (n=454) to merit detailed analysis of that sample; in our opinion analyses with ethnic status with the community group sample would provide an indication of any differences.

Care of the dying – why should people suffer? – is most important.

Table 2: Priority rankings of health services by main study groups n=322-335

	1. Essential % (no)	2. Very important % (no)	3. Important % (no)	4. Less important % (no)	Mean	Rank
Treatments for children with life threatening illnesses (eg leukaemia)	71 (239)	22 (74)	6 (19)	1 (3)	1.361	1
Special care and pain relief for people who are dying (eg hospice care)	53 (177)	30 (102)	15 (49)	2 (7)	1.660	2
Medical research for new treatments	50 (160)	26 (85)	19 (60)	5 (17)	1.795	3
High technology surgery and procedures which treat life threatening conditions (eg heart/liver transplants)	45 (149)	31 (101)	16 (52)	8 (25)	1.856	4
Preventive services (eg screening, immunisations)	40 (133)	31 (104)	23 (75)	6 (19)	1.940	5
Surgery to help people with disabilities to carry out everyday tasks (eg hip replacements)	22 (73)	43 (144)	32 (107)	3 (10)	2.162	6
Therapy to help people with disabilities carry out everyday tasks (eg speech therapy, physiotherapy, occupational therapy)	27 (91)	31 (105)	37 (122)	5 (15)	2.183	7
Services for people with mental illness (eg psychiatric wards, community psychiatric nurses)	21 (69)	33 (109)	41 (137)	5 (16)	2.302	8
Intensive care for premature babies who weigh less than one and a half pounds and are unlikely to survive	29 (95)	27 (89)	25 (83)	19 (163)	2.345	9
Long stay care (eg hospital and nursing homes for the elderly)	20 (65)	39 (126)	28 (90)	13 (44)	2.348	10
Community services/care at home (eg district nurses)	24 (78)	30 (99)	31 (104)	15 (48)	2.371	11
Health education services (eg campaigns encouraging people to lead healthy lifestyles)	14 (45)	18 (60)	26 (85)	42 (137)	2.960	12
Family planning services (eg contraception)	11 (36)	14 (46)	25 (82)	50 (163)	3.138	13
Treatments for infertility (eg test tube babies)	8 (25)	9 (31)	34 (114)	49 (160)	3.239	14
Complementary/alternative medicine (eg acupuncture, homeopathy, herbalism)	7 (23)	11 (35)	18 (59)	64 (207)	3.383	15
Cosmetic surgery (eg tattoo removal, removal of disfiguring lumps and bumps)	4 (14)	7 (24)	13 (41)	76 (245)	3.596	16

Different ethnic groups expressed different priorities.

Asian people were more likely than the other ethnic groups to prioritise as essential 'special care and pain relief for people who are dying'.

Turkish and Kurdish respondents and those in 'other' ethnic groups were more likely than others to prioritise as essential 'health education services'.

Jewish respondents and those in 'other' ethnic groups were more likely than all others to prioritise as essential 'services for people with mental illnesses'.

White Europeans were more likely than other groups to prioritise as essential 'surgery to help people with disabilities to carry out everyday tasks'.

Black Africans were more likely than members of other ethnic groups to prioritise as essential 'intensive care for premature babies who weigh less than one and a half pounds and are unlikely to survive'.

Turkish and Kurdish people were far more likely than other groups to prioritise as essential 'family planning services'.

Turkish and Kurdish people, Jewish people and those in 'other' ethnic groups were more likely than others to prioritise as essential or very important 'complementary/alternative medicine'.

Black Caribbean and Black African people and those in 'other' ethnic groups were more likely than others to prioritise as essential 'medical research for new treatments'.

Asian people were most likely to prioritise as essential 'long-stay care'.

The groups least likely to prioritise 'community services' as essential were Black Africans and Black Caribbeans.

If a child is really unlikely to survive it really does seem a bit naive to plough a lot of money into it.

I've ranked health education as middle as it's going to save the NHS money in the years to come. If you can educate 50 people to give up smoking that's 50 people in the future. . .

Alternative medicine is marvellous. . . but no NHS money should be spent on it.

Health values

We wanted to explore people's relative values concerning different states of health, so respondents were asked to rank items according to their importance in relation to their effect on quality of life (1 = most important to 6 = least important). Table 3 shows that respondents were most likely to value 'being free from pain or discomfort', followed by being able to 'walk freely'. The item which was ranked as, relatively, least important was 'being able to pursue social and leisure activities'.

White Europeans, Asians and those in 'other' ethnic groups were least likely to rank as most important 'being able to walk freely'.

Jewish people, White Europeans, Black Caribbeans and those in other ethnic groups were most likely to rank as most important/important 'being free from stress/nerves/anxiety/depression'.

There should be more money ploughed into care at home so hospitals can stick to operations and so on rather than caring for people who could be at home.

Table 3: Ranking of items which affect quality of life (numbers in brackets; row %)

	1 (most important)	2	3	4	5	6 (least important)	Mean	Rank
1. Being free from pain or discomfort	30% (91)	27% (83)	15% (47)	16% (48)	7% (23)	5% (15)	2.493	1
2. Being able to walk freely	27% (80)	19% (57)	27% (81)	12% (34)	11% (33)	4% (13)	2.738	2
3. Being able to care for yourself (eg able to wash and feed yourself)	20% (59)	20% (60)	26% (76)	16% (49)	15% (46)	3% (8)	2.956	3
4. Being free from stress/nerves/anxiety/depression	13% (38)	22% (66)	15% (46)	30% (90)	13% (38)	7% (20)	3.282	4
5. Being able to do main activity (eg work, study, housework)	7% (20)	8% (25)	14% (41)	22% (65)	39% (118)	10% (29)	4.084	5
6. Being able to pursue social and leisure activities	3% (9)	2% (5)	3% (9)	4% (12)	13% (39)	75% (224)	5.480	6

Number of respondents = 298

Turkish/Kurdish and Jewish respondents and those in 'other' ethnic groups were least likely to rank as most important/important 'being free from pain or discomfort'.

Finally, **Turkish/Kurdish** respondents and those in 'other' ethnic groups were most likely to rank as least important 'being able to pursue social and leisure activities'.

We asked respondents to rank different types of treatments relating to quality and quantity of life, mental health care and prevention of illness. Table 4 shows that respondents rated as highest the type of health care which both 'prolonged life and reduced pain among people who are severely ill or disabled'; this was followed by prevention. The two lowest-ranking services in this brief list were, respectively, mental health care and treatment which prolonged life without reducing pain or disability.

Some differences with ethnicity were found in responses to the question shown in Table 4.

Mental health is important but there are other things that are more important. With mental health, sometimes there is no success at the end, is there? They spend all this money on them and there's nothing to show for it.

Table 4: Priority ratings of treatments (numbers in brackets; row %)

Rank

	1 (most important)	2	3	4	5 (least important)	Mean	Rank
Health care which **prolongs** life **and reduces** pain or disability in people who are severely ill or disabled	42% (128)	31% (94)	13% (40)	10% (30)	5% (14)	2.046	1
Health care which **prevents** illness amongst people who are currently well	35% (107)	18% (55)	23% (70)	15% (48)	9% (27)	2.456	2
Health care that **does not prolong** life but **does reduce** pain or disability in people who are severely ill or disabled	12% (37)	23% (71)	22% (67)	25% (75)	18% (56)	3.141	3
Health care which **improves** mental health in people who are severely mentally ill	6% (19)	23% (72)	27% (82)	31% (94)	13% (40)	3.208	4
Health care which prolongs life but **does not reduce** pain or disability in people who are severely ill or disabled	5% (15)	5% (16)	15% (45)	19% (59)	56% (171)	4.160	5

Number of respondents = 306-307

White Europeans, Turks/Kurds, Jewish people and those in 'other' ethnic groups were most likely to prioritise 'health care which improves mental health in people who are severely mentally ill' as most important/important.

Finally, **Asians and Black Caribbeans** were more likely than others to rate as most important/important 'health care that does not prolong life but does reduce pain or disability in people who are severely ill or disabled'.

Attitudes

Respondents were also asked an attitude question on the extent of their agreement or disagreement with a series of single-item statements. The responses are shown in Table 5 and indicate a consistency with earlier attitudes, although they also illustrate how question wording can substantially affect response to similar items. For example, 65% of respondents either strongly agreed or agreed that 'if someone is very ill, in pain and is going to die, it is better to let them die quickly than to keep them alive for as long as possible', although fewer, 37%, strongly disagreed or disagreed that 'the health service should keep people alive as long as possible even if they have a very low (poor) quality of life', and 33% strongly agreed or agreed that 'there is little point keeping someone alive if they have a very poor quality of life'.

Instead of curing it, prevent it. There's no guarantee that you can cure someone so it is better to prevent illness.

Table 5: Attitudes towards treatments (numbers in brackets; row %)

	1. Agree strongly	2. Agree	3. Don't know	4. Disagree	5. Disagree strongly
It is **more important** for people with physical illnesses to be treated than it is for people with mental illnesses	66% (227)	34% (115)	(*1)	—	—
Preventing illness is **at least** as important as curing it	52% (161)	38% (118)	3% (9)	4% (11)	3% (8)
Services which deal with mental illness are **at least** as important as those which deal with physical illness	34% (104)	44% (135)	10% (29)	10% (30)	2% (6)
The financial cost **should not** be considered when deciding whether to provide a treatment or not	44% (137)	36% (112)	4% (14)	11% (33)	5% (14)
If someone is very ill, in pain and is going to die it is **better** to let them die quickly than to keep them alive for as long as possible	35% (109)	30% (94)	11% (35)	12% (36)	12% (37)
The health service **should** keep people alive as long as possible even if they have a very low quality of life	20% (59)	20% (59)	19% (56)	29% (81)	12% (35)
There is **little point** in keeping someone alive if they have a very poor quality of life	11% (34)	22% (66)	17% (53)	27% (81)	23% (70)
It is **more important** to treat people who are ill than it is to prevent illness amongst healthy people	10% (32)	30% (93)	10% (31)	35% (106)	15% (46)
When deciding whether to treat someone **it is important** to consider the financial cost of the treatment	5% (15)	12% (36)	4% (12)	35% (108)	44% (135)

* Less than 1%
Number of respondents = 290-343

All but one person agreed that it is more important to treat physical illnesses than mental illnesses, although most, 78%, strongly agreed or agreed that mental health services are as important as physical health services. High priority was also given to prevention of illness being as important as cure, with 90% strongly agreeing or agreeing. Most, 79%, disagreed or strongly disagreed that cost should be considered in decisions about treatment. The replies to the two cost items were remarkably consistent.

Some differences with ethnicity were found with these items. **Jewish respondents, White Europeans** and those in 'other' ethnic groups were more likely to agree strongly that 'if someone is very ill, in pain and is going to die, it is better to let them die quickly than to keep them alive for as long as possible'

White Europeans and Jewish respondents were more likely to agree strongly or agree that 'it is more important to treat people who are ill than it is to prevent illness among healthy people'.

White Europeans were most likely to disagree or disagree strongly that 'the health service should keep people alive as long as possible even if they have a very low quality of life'. Consistent with this, the White Europeans were also least likely to disagree strongly that 'there is little point in keeping someone alive if they have a very poor quality of life'.

Black Caribbeans, followed by **Turks/Kurds**, were most likely to agree strongly that 'it is more important for people with physical illness to be treated than it is for people with mental illness'.

If the person is still alive and not in pain, then they've still got a good quality of life, whereas if you've got a person who could die without treatment you've got to give that person a chance to live. You haven't got the right, there's only one person who's got the right to say 'No, you don't live' and He's up there.

Financial priorities

We asked respondents a question developed in North-East Essex[46] on resource allocation. They were asked to assume that they had £1 million to spend on local health services: 'With the £1 million you could cure 10 people with very severe problems or cure 100 people with less severe problems. How much of the £1 million would you give to the 10 people with very severe problems and how much would you give to those with less severe problems?' The results are shown in Table 6. The largest groups of responses were divided between giving half to each group and giving a quarter to the 10 people with severe problems and three-quarters to the 100 people with less severe problems.

Table 6: Health care financial allocation priorities

	%	(no)
I would give all of the money to the 10 people with very severe problems	10	(32)
I would give half of the money to the 10 people with severe problems and half to the 100 with less severe problems	33	(104)
I would give three quarters of the money to the 10 people with severe problems and a quarter to the 100 with less severe problems	16	(51)
I would give a quarter of the money to the 10 people with severe problems and three quarters to the 100 with less severe problems	35	(107)
I would give all of the money to the 100 people with less severe problems	6	(18)
Number of respondents	100	312

White Europeans were more likely than other group to say they would 'give half of the money to the 10 people with severe problems and half to the 100 with less severe problems': 43%, in comparison with 32% of Jewish respondents, between 25% and 25% of Black African, Black Caribbean and Asian respondents, 16% of Turkish respondents and 39% of those in 'other' ethnic groups.

Community health values

The group discussions were essential for understanding people's rankings and emphasis on life-saving technologies even when effectiveness was unknown. The groups found the rankings and evaluations difficult but most appeared to enjoy the exercise, judging by the amount of fierce debate, argument, laughter and the noise of everyone trying to talk at once!

SECTION 3

THE POSTAL AND INTERVIEW SURVEY

Aims

To test the representativeness of the opinions expressed by the members of the community groups as well as to document the health service priorities of a random sample of the public in City and Hackney.

Methods

A postal survey followed by an interview survey of non-respondents. The questions used were those developed for the community group study.

Subjects and sampling

About four hundred people were judged to be manageable for the postal survey within the time period, and we anticipated a great deal of following-up by post and in person. Only adults aged over 18 were sampled. The necessary sampling fraction was calculated and entered into a random sampling programme on the FHSA computer by FHSA staff. The computer generated 454 names and addresses of patients registered with general practitioners in City and Hackney.

Response rates

The response rate to the postal survey, despite four mailings, was poor, although the follow-up of non-respondents by personal letter and then interview was good. Sample members of the survey received, initially: a letter about the study, making clear the fact that this was a research study and carrying the personal signature of the principal researcher; the questionnaire; and a stamped addressed envelope. We invited people who needed help in completing the questionnaire (for example, if their main language was not English) to contact the researchers (one elderly woman requested help and was personally interviewed). The study had been given publicity in the local press and all the community groups and tenants' associations were aware of it. Several of them put up posters about the study in their blocks of flats.

After four mailings, during the summer of 1992, just 45 completed questionnaires were returned, which confirmed our suspicions that the subject was too complex for a postal survey. The post office returned 51 envelopes marked 'undelivered': 30 envelopes containing questionnaires were returned during the postal survey and a further 21 envelopes containing letters by the post office to all final non-responders informing them that we would like to interview them were also returned. In addition, the interviewer, who followed up all the non-respondents personally to try to interview them, recorded a further five people who had moved from the listed address. Thus the total number of ineligible sample members was 56, creating an eligible sample size of 398 instead of 454.

We successfully interviewed 265 of the remaining 353 eligible non-responders. Some people denied receiving the postal questionnaires; most simply seemed indifferent to completing postal questionnaires, but had received the letter about the interviewer calling and were prepared to be interviewed personally. The interviews took about 20 minutes each and the interviewer took three months to complete them (calling at least three times at each address where respondents were out before recording a non-response). Most interviews took place in the late afternoons and evenings. The interviewer was a male resident of Hackney who was familiar with the area and, importantly, also felt confident about travelling (he cycled) around the district at night.

The final combined response rate to the postal and interview questionnaire was 78%, which we considered to be very good considering the complexity of the topic and the fact that response is usually lower in inner-city areas. The response rates and reasons for non-response are shown in Table 7.

No differences between responders and non-responders were found when comparing sex or area of residence from the FHSA lists. However, of the total sample of responders there were some differences with ethnic status and response type: 68% of the 45 people who responded to the postal questionnaire were White European, in comparison with 50% of the 265 responders (all previous non-responders to the postal questionnaire) to the interview questionnaire. The implication is that, as was expected, Black people were less likely to respond to postal questionnaires, but appeared to be willing to be interviewed in person. There were no differences with age, sex or socio-economic status between these types of responders (postal or interview). Due to the small number of postal returns, we have combined the results for the postal and interview approaches.

Table 7: Response rates - postal interview survey

Sample size	454
Ineligible cases: returned by PO (postal stage)	30
Returned by PO (pre-interview stage)	21
Interviewer reported building demolished/being renovated/empty	3
Interviewer reported address to be non-residential [factory (1), shop (1)]	2
Sub total	56
Responder to postal questionnaire	45
Responder to interview	265
Sub total	310
Non responder to interview due to:	
Refused	10
Never in	14
Address not traced	32
Building inaccessible	4
Other (eg respondent said had returned questionnaire; asked by respondent to return but never in)	27
Communication (language) difficulties	1
Sub total	88
Grand total	454

Results

CHARACTERISTICS OF RESPONDENTS

The respondents were very similar to members of the community groups (Table 8a and 8b), with the exception that they included more White Europeans and fewer people aged over 60. The average age of the sample was 38, in comparison with the average age of 46 for the community groups. The other variables were very similar to the community group.

There were almost no differences between the sampled respondents and the residents of City and Hackney according to census data in relation to sex and ethnic group, and there was only a slight difference with age, with slightly fewer people under 30 being included in the sample.

Most people rated their health, for their age, as 'excellent' or 'good' and relatively few reported a long-standing illness, disability or infirmity. The most commonly reported problem was arthritis, followed by asthma, back trouble, bowel problems, depression or panic attacks and effects of a stroke. As would be expected, poorer health was associated with age.

While there were no differences in the proportions of males and females who assessed their health as 'fair' or 'poor', males were more likely than females to assess their health as 'excellent' rather than 'good' (36 per cent in comparison with 20 per cent) and were also slightly less likely than females to report a long-standing illness, disability or infirmity (16 per cent in comparison with 25 per cent).

People who described themselves as Turkish/Kurdish, Black UK or Asian were least likely to report a longstanding illness:15%, 8% and 6% respectively, in comparison with between 24% and 29% of the other groups who did so.

Respondents were asked about their housing tenure as an index of socio-economic status. A total of 24% rented their accommodation privately, 36% rented from the council, 18% owned their house via a mortgage, 15% were owner-occupiers, 5% said they were lodgers in private households, two people lived in housing tied to their jobs, one person lived in a public house and two said they were registered squatters. Black people were more likely to rent their housing privately than from the council or other sources or to own it (31 per cent in comparison with 17 per cent).

Socio-economic status was not asked about in the postal survey in order to keep the questionnaire as short as possible, but a sample of the interview respondents were asked for details of their occupation. Of these, 41% reported that they were economically active.

Satisfaction with the NHS

We wanted to lead the respondents in to thinking about health service issues, so we first asked a standard satisfaction question (taken, with permission, from the British Social Attitudes Survey): 'All in all, how satisfied or dissatisfied would you say you are with the way in which the National Health Service runs nowadays?'

The response categories ranged from 'very satisfied' to 'very dissatisfied'. Four per cent said they were 'very satisfied', 18% were 'satisfied', 34% were 'neither satisfied nor dissatisfied', 26% said 'quite dissatisfied' and 18% 'very dissatisfied'. To summarise, 22% expressed satisfaction to some degree and 44% expressed dissatisfaction (see Appendix V for brief comparison with British Social Attitudes Survey).

There was a strong association with declining health status and dissatisfaction with the NHS: 38% of those who assessed their health, for their age, as 'excellent' or 'good', 53% of those who assessed it as 'fair' and 82% of those who assessed it as 'poor' expressed dissatisfaction with the NHS. It is possible that those in poorer health had more experience of using the NHS and were more aware of shortfalls in service provision.

Table 8a: Characteristics of interviewees

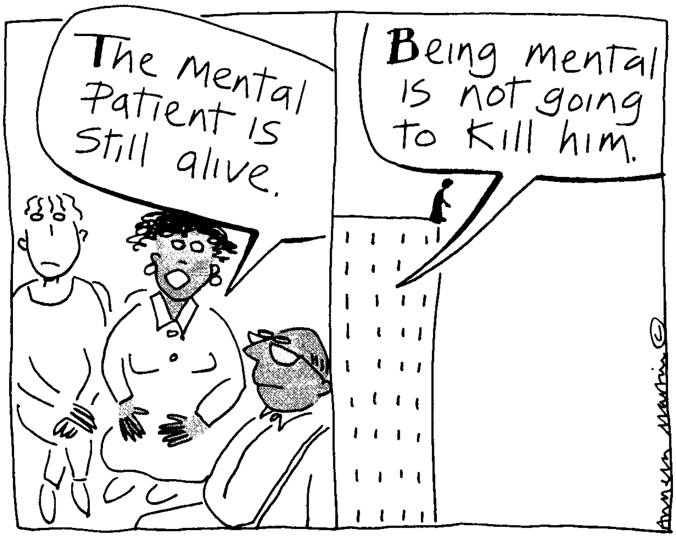
	%	(no)
Sex		
Males	44	(134)
Females	56	(171)
Age		
<30	30	(88)
30<40	30	(89)
40<50	18	(53)
50<60	10	(31)
60+	12	(37)
Ethnic group		
White European	50	(153)
Total Black:	50	(153)
Black African	7	(20)
Black Caribbean	8	(25)
Asian	11	(33)
Turkish/Kurdish	7	(21)
Jewish	5	(17)
Black UK	8	(24)
Chinese	3	(10)
Other	1	(3)
Self-assessed health status		
Excellent	27	(83)
Good	43	(130)
Fair	24	(71)
Poor	6	(17)
Longstanding illness		
Yes	21	(62)
No	79	(237)
Number of respondents + Age range 17-84 Mean: 38	298 - 306	

Table 8b: Characteristics of the random sample of the public in comparison with 1991 census data for Hackney

	Responders	Total population Hackney 1991 census estimates:
Sex	% (no)	%
Women	56 (171)	51
Men	44 (134)	49
Ethnic group+		
White UK/European	50 (153)	52
Total Black:	50 (153)	48
African	7 (20)	5
Caribbean	8 (25) > 23%	17 > 22%
Black UK	8 (24)	
Asian	11 (33)	7
Cypriot	— —	5
Turkish/Kurdish	7 (21)	1
Orthodox Jewish	5 (17)	7
Other	4 (13)	6
Age		
< 30	30 (88)	48
30 < 60	58 (173)	36
60+	12 (37)	16
Total	298-306	185,336

+ 1981 Census data due to incomplete coverage in 1991 Census

Those who expressed dissatisfaction were asked an open-ended question about what aspects of the NHS they were dissatisfied with. The most common ones mentioned were hospital waiting lists, reported by 20% of these respondents, and out-patient waiting times, also by 20%; 14% quoted inadequate funding of the NHS, 10% said staff attitudes needed improving, 10% quoted too many cuts in NHS funding and hospital closures and 10% said 'everything'. In addition, half of these respondents mentioned 18 other causes of dissatisfaction, ranging from privatisation of NHS services to overworked doctors, although these were mentioned only by 2-4% of respondents in each case (some respondents gave more than one reply).



Given the well-known insensitivity of most patient satisfaction questions, we then asked all the respondents 'Are there any aspects of the health service that you would like to see improved?' Respondents who replied 'yes' were asked an open-ended question about these (65% had said 'yes' to this question and 35% had said 'no').

Black respondents were more likely than others to say they wanted to see improvements (76 per cent in comparison with 54 per cent; $p<0.001$). Analysed separately, those who identified themselves as Black UK, White European and Black African were most likely to say they wanted to see improvements. Improvements most frequently mentioned were hospital waiting lists, outpatient waiting times, more financial resources, more nurses and/or doctors and hospital beds. Some respondents (9%) said 'everything' needed to be improved. Other improvements, mentioned by fewer people ranged from free dental care to cheaper NHS prescriptions to better primary care services.

Priority rankings: the random sample of respondents

Table 9 shows the priority ranks of the random sample of the public.

The four services which received highest priority were treatments for children with life-threatening illnesses, special care and pain relief for people who are dying, high-technology surgery and procedures which treat life-threatening conditions, and medical research for new treatments.

Those ranked as middle–high priority related to community services, surgery to help people with disabilities, therapy to help people with disabilities, and long-stay care.

Services which ranked as middle–low were preventive services, services for people with mental illnesses, intensive care for premature babies who weigh less than one and a half pounds and who are unlikely to survive, and family planning services. The four which were ranked as lowest priority were treatments for infertility, health education services, complementary therapy and cosmetic surgery.

In all but two cases the priority ranks of those who responded to the postal/ interview survey were the same as, or very similar to (for example, between 1 and 2 ranks' difference) to those of the community groups. In particular, the first two rankings (treatments for children with life-threatening illnesses and special care and pain relief for people who are dying) were identical among the two groups, as were the bottom two (complementary medicine and cosmetic surgery); items 6 and 7 were also ranked identically (surgery and therapy to help people with disabilities).

However, there were two statistically significant exceptions to the overall consistency – preventive services (for example, screening, immunisations) were ranked as 9th by the sampled respondents and as 5th (a 4-point difference; $p<0.05$) by the community groups; community services were ranked as 5th by the sampled respondents and as 11th (6-point difference; $p<0.001$) by the community groups.

AIDS

After respondents had completed this exercise, they were asked to look at the list of treatments and services again and rank treatment for AIDS within the list (this was not done with the community groups or the doctors). In order to ensure comparability with the community group exercise, this was not included in the list initially. However, it was felt, after the latter exercise, to be a major omission and was thus included at the survey stage in this way. Treatment for AIDS was given a very high mean priority rank of 1.5 (the mean was 1.632).

Table 9: Priority rankings of health services by the random sample of the public (n=293-305)

	1. Essential		2. Very important		3. Important		4. Less important		Mean	Rank*
	%	(no)	%	(no)	%	(no)	%	(no)		
Treatments for children with life threatening illnesses (eg leukaemia)	64	(195)	22	(68)	12	(36)	2	(5)	1.510	1 (1)
Special care and pain relief for people who are dying (eg hospice care)	38	(116)	32	(99)	22	(66)	8	(24)	1.993	2 (2)
High technology surgery and procedures which treat life threatening conditions (eg heart/liver transplants)	44	(135)	23	(70)	20	(60)	13	(40)	2.016	3 (4)
Medical research for new treatments	41	(122)	30	(89)	16	(47)	13	(40)	2.017	4 (3)
Community services/care at home (eg district nurses)	36	(110)	28	(84)	23	(69)	13	(39)	2.123	5 (11)
Surgery to help people with disabilities to carry out everyday tasks (eg hip replacements)	28	(84)	38	(114)	26	(80)	8	(24)	2.146	6 (6)
Therapy to help people with disabilities carry out everyday tasks (eg speech therapy physiotherapy, occupational therapy)	30	(90)	34	(102)	27	(82)	9	(28)	2.159	7 (7)
Long stay care (eg hospital and nursing homes for the elderly)	30	(90)	28	(83)	26	(76)	16	(49)	2.282	8 (10)
Preventive services (eg screening, immunisations)	32	(98)	24	(74)	24	(74)	20	(57)	2.297	9 (5)
Services for people with mental illness (eg psychiatric wards, community psychiatric nurses)	22	(65)	31	(95)	34	(104)	13	(39)	2.386	10 (8)
Intensive care for premature babies who weigh less than one and a half pounds and are unlikely to survive	28	(85)	21	(63)	24	(73)	27	(80)	2.492	11 (9)
Family planning services (eg contraception)	14	(43)	23	(71)	34	(102)	29	(86)	2.765	12 (13)
Treatments for infertility (eg test tube babies)	11	(33)	26	(79)	35	(106)	28	(84)	2.798	13 (14)
Health education services (eg campaigns encouraging people to lead healthy lifestyles)	15	(40)	21	(65)	31	(94)	33	(99)	2.809	14 (12)
Complementary/alternative medicine (eg acupuncture, homeopathy, herbalism)	6	(19)	10	(29)	17	(50)	67	(200)	3.446	15 (15)
Cosmetic surgery (eg tattoo removal, removal of disfiguring lumps and bumps)	36	(9)	28	(27)	23	(38)	13	(229)	3.607	16 (16)

* The community group ranks are shown in brackets for comparison

DIFFERENCES WITH ETHNICITY AND OTHER SOCIO-DEMOGRAPHIC VARIABLES

There were fewer statistically significant differences with ethnicity and priorities than with the community sample, possibly reflecting the smaller sample of those from Black populations. Alternatively, the earlier differences, although significant, may have occurred by chance. It is also possible that differences are due to intervening age–sex effects, but it is not possible to control for this with such small sub-groups of ethnic groups. The following associations should be viewed cautiously as a *possible* indicator of differences between ethnic groups only, especially in view of some inconsistencies with the results of the community groups study.

As with the community groups, respondents who described themselves as **Black African** were among those most likely to prioritise as essential 'medical research'.

In relation to 'therapy to help people with disabilities', **Black Africans** were most likely to prioritise this as essential.

In relation to 'surgery to help people with disabilities', **Turkish/Kurdish** people were most likely to prioritise this as essential. The proportion of **White European** respondents prioritising this as essential was very similar to the White European community group members, although there were inconsistencies among some of the other ethnic groups.

In relation to age, 64% of respondents aged 40 and over prioritised 'long-stay care (for example, hospital and nursing homes for the elderly)' as essential or very important, in comparison with 52% of respondents aged under 40.

Respondents who assessed their health as poor were more likely to prioritise as essential 'special care and pain relief for people who are dying (for example, hospice care)': 67%, in comparison with 31% of those who assessed their health as fair and 37% who assessed it as excellent or good.

Prioritisation of treatment for AIDS varied by age group, health status and reported long-standing illness. Younger people, and those in better health, were more likely to prioritise treatment of AIDS (actual figures available from the author). Presumably they were less likely to be competing for health resources and services.

Error 2

Health values should be listed as on page 38 in the Contents not page 37

HEALTH VALUES

To try to keep the questionnaire relatively short for most respondents, the interviewer asked a question on priority ranking of five treatment areas, to a sample of respondents only (shown in Table 10). They were asked to prioritise health care which:

- prolongs life and reduces pain or disability in people who are severely ill or disabled;
- prevents illness among people who are currently well;
- improves mental health in people who are severely mentally ill;
- does not prolong life but does reduce pain or disability in people who are severely ill or disabled;
- prolongs life but does not reduce pain or disability in people who are severely ill or disabled.

The priority ranks were identical to those of the community groups with the exception of mental health care and pain/disability reduction alone (see Tables 4 and 10). The results confirm the findings from the earlier community group survey that people prioritise prolongation of life coupled with pain/disability reduction as highest, followed by prevention, with prolongation of life without pain/disability reduction as lowest. There were no associations with socio-demographic variables.

Attitudes

At interview only (not postal questionnaire), respondents were asked about the extent of their agreement with nine statements about health treatments and priorities. Most responses were broadly similar to those of the community group members, although there was more 'sitting on the fence', with more of the randomly sampled respondents opting for a middle category (see Table 11). This is a well-known problem in survey research. The only solution is not to offer the middle category and to force people to make a choice one way or the other, although the danger is that this can result in false choices.

Mental health services are important. You've got to help these people. They're unfortunate. One never knows, it can happen to anybody.

Both the community groups and the sampled respondents agreed strongly/agreed for the most part that 'preventing illness is at least as important as curing it'. The distribution of responses to the item 'it is more important to treat people who are ill than it is to prevent illness among healthy people' also was similar, with most people either disagreeing or expressing uncertainty.

There were no significant differences between the sampled respondents and the group members on the questions relating to length and quality of life. For example, 68% of the sampled respondents and 65% of the group members agreed strongly/agreed that 'if someone is very ill, in pain and is going to die it is

Table 10: Priority ratings of treatments (number in brackets; row %)

	1 (most important)	2	3	4	5 (least important)	Mean	Rank
Health care which **prolongs life and reduces** pain or disability in people who are severely ill or disabled	36% (45)	31% (38)	15% (19)	14% (18)	4% (5)	2.200	1
Health care which **prevents** illness amongst people who are currently well	38% (48)	20% (25)	19% (24)	16% (21)	7% (9)	2.354	2
Health care which **improves** mental health in people who are severely mentally ill	13% (17)	19% (24)	32% (40)	26% (33)	10% (13)	3.008	3
Health care that does **not prolong life but does reduce** pain or disability in people who are severely ill or disabled	13% (16)	24% (30)	24% (31)	23% (29)	16% (20)	3.056	4
Health care which prolongs life but **does not reduce** pain or disability in people who are severely ill or disabled	2% (2)	7% (9)	10% (13)	19% (24)	62% (79)	4.331	5

Number of respondents = 125-127

Table 11: Attitudes towards treatments (number in brackets; row %)

	1. Agree strongly	2. Agree	3. Don't know	4. Disagree	5. Disagree strongly
It is **more important** for people with physical illnesses to be treated than it is for people with mental illnesses	2% (5)	19% (45)	29% (70)	39% (95)	11% (26)
Preventing illness is **at least** as important as curing it	32% (77)	45% (109)	10% (24)	13% (31)	* (2)
Services which deal with mental illness are **at least** as important as those which deal with physical illness	13% (32)	50% (119)	22% (53)	14% (34)	1% (3)
The financial cost **should not** be considered when deciding whether to provide a treatment or not	24% (57)	26% (63)	13% (32)	31% (75)	6% (6)
If someone is very ill, in pain and is going to die it is **better** to let them die quickly than to keep them alive for as long as possible	34% (79)	34% (79)	17% (40)	11% (26)	4% (11)
The health service **should** keep people alive as long as possible even if they have a very low quality of life	5% (12)	20% (47)	31% (73)	34% (79)	10% (23)
There is **little point in** keeping someone alive if they have a very poor quality of life	3% (8)	21% (48)	31% (72)	35% (81)	10% (23)
It is **more important** to treat people who are ill than it is to prevent illness amongst healthy people	4% (9)	32% (78)	23% (57)	35% (84)	6% (14)
When deciding whether to treat someone **it is important to** consider the financial cost of the treatment	2% (4)	27% (66)	14% (34)	33% (80)	24% (57)

* Less than 1%
Number of respondents = 232 - 243

better to let them die quickly than to keep them alive for as long as possible'. Forty-four per cent of the sampled respondents and 41% of the group members disagreed/strongly disagreed that 'the health service should keep people alive as long as possible even if they have a very low quality of life'. Twenty-four per cent of sampled members and 33% of group members strongly agreed/agreed that 'there is little point in keeping someone alive if they have a very poor quality of life'. As before, more of the interview respondents, at each item, opted for the 'don't know' category.

When combining the 'agree strongly' and 'agree' categories, there was a statistically significant difference with the first item shown in Table 11 between the sampled respondents and the community group members. Whereas almost all of the community group members agreed strongly/agreed with the statement that 'it is more important for people with physical illnesses to be treated than it is for people with mental illness', there was a greater spread of responses between the agree, don't know and disagree categories among the random sample of respondents.

Consistent with this, while 63% of the community group members agreed strongly/agreed that 'services which deal with mental illness are at least as important as those which deal with physical illness', more, 78%, of the sampled respondents did so.

The sampled respondents were slightly more likely than the community group members to agree that considerations of cost are important when making decisions about treatment. Fifty per cent of them agreed strongly/agreed that 'the financial cost should not be considered when deciding whether to provide a treatment or not', in comparison with 80% of the community group members. Similarly, 57% of the sampled respondents disagreed/disagreed strongly that 'when deciding whether to treat someone it is important to consider the financial cost of the treatment', in comparison with 79% of the community group members.

We all seem to be agreeing on the same sorts of things. People who are severely ill – the money should be spent on them. Because someone is ill, we shouldn't allow them to die.

There were some associations with attitudes and self-reported health status and reporting of a long-standing illness. Sixty-two per cent of respondents who assessed their health, for their age, as 'poor' said they agreed strongly that 'if someone is very ill, in pain and is going to die, it is better to let them die quickly than to keep them alive for as long as possible', in comparison with 27% who rated their health as 'fair' and 33% who assessed it as 'excellent' or 'good'.

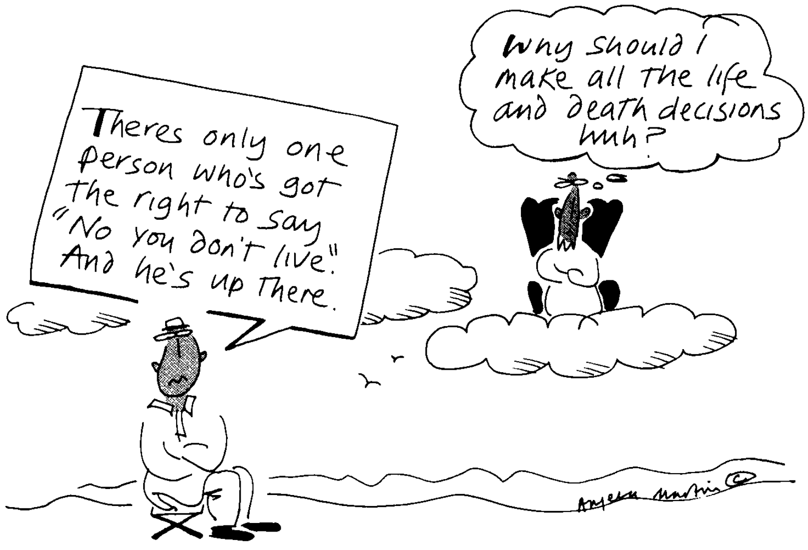
Thirty-nine per cent of respondents who rated their health as 'poor' said they agreed strongly or agreed that 'preventing illness is at least as important as curing it', in comparison with 77% of those who assessed their health as 'fair' and 79% of those who rated their health as 'good'. Consistent with this, respondents who reported a long-standing illness were less likely than those who did not to agree strongly that 'preventing illness is at least as important as curing it': 16% in comparison with 34% respectively. It appeared that iller respondents, then, valued prevention less.

Forty-six per cent of those who assessed their health as 'poor' said they disagreed strongly that 'when deciding whether to treat someone it is important to consider the financial cost of the treatment', in comparison with 23% of those who rated their health as 'fair' and 22% of those who said they were in 'excellent' or 'good' health.

Consistent with this, those who reported a long-standing illness were more likely to say they agreed strongly that 'the financial cost should not be considered when deciding whether to provide a treatment or not': 39% in comparison with 19% of those not reporting a long-standing illness. Their responses were undoubtedly influenced by their own needs and experiences, although everyone was asked to think about the needs of their community as a whole.

Financial priorities

Respondents were asked the question about how they would divide £1 million of health services expenditure between curing 10 people with very severe problems or 100 people with less severe problems. Table 12 shows that most would either equally divide the money between the two groups or give a quarter to the 10 people with severe problems and three-quarters to the 100 people with less severe problems. The distributions shown in Table 12 are almost identical to those of the group members. There were no significant associations with socio-demographic variables.



Attitudes to public consultation

Finally, we asked a sample of respondents a series of questions about how they felt about public consultation on the running of the health service. These questions were taken, with permission, from a priority survey conducted in Bath by the Bath Department of Public Health[23]. Their responses are shown in Table 13. The figures show that 67% of respondents either agreed strongly or agreed that 'the public should have more of a say in making the decisions'. Most of the remainder were uncertain rather than disagreeing. In response to the item 'I would like to have more of a say, but only when it affects me', there was a fairly even spread of responses in both directions, with 39% agreeing strongly/agreeing and 40% disagreeing/disagreeing strongly. While 32% agreed strongly/agreed that 'I would like to have more of a say, but I do not know enough about it', a further 44% disagreed/disagreed strongly. A sizeable minority in each case (21% and 24% respectively) chose a non-committal 'don't know'. Taken together with the first item, the implication is that most people did want more involvement in decision-making on health services generally rather than just when it affected them, and most people did not agree that they did not know enough about it to become involved.

We need more information, information about costs, before making these decisions . . . We're just not qualified to make these decisions.

Table 12: Health care financial allocation priorities

	%	(no)
I would give all of the money to the 10 people with very severe problems	4	(12)
I would give half of the money to the 10 people with severe problems and half to the 100 with less severe problems	35	(95)
I would give three quarters of the money to the 10 people with severe problems and a quarter to the 100 with less severe problems	16	(42)
I would give a quarter of the money to the 10 people with severe problems and three quarters to the 100 with less severe problems	36	(98)
I would give all of the money to the 100 people with less severe problems	9	(25)

Mean 3.107
Number of respondents 272

Table 13: Attitudes to having more of a say in running the health service in City and Hackney

	1. Agree strongly	2. Agree	3. Don't know	4. Disagree	5.Disagree strongly
The public should have more of a say in making the decisions	22% (48)	45% (96)	20% (42)	5% (10)	8% (17)
Decisions should be left to the doctors and other experts at the health authority	25% (54)	34% (73)	20% (43)	14% (29)	7% (14)
I would like to have more of a say, but only when it affects me	10% (20)	29% (60)	21% (43)	19% (39)	21% (44)
I would like to have more of a say, but I do not know enough about it	8% (16)	24% (51)	24% (50)	16% (33)	28% (59)

Number of respondents 206-213

However, 59% also agreed strongly or agreed that 'decisions should be left to the doctors and other experts at the health authority'. A similar discrepancy was reported by Richardson and his colleagues in the Bath survey[23], with almost identical results. This may be less of a discrepancy than is first apparent – people simply appear to feel that they should have 'more of a say in making the decisions', but that ultimately they should be made by 'doctors and other experts'. More sensitive wording of questions could elicit this.

Respondents who assessed their health, for their age, as 'poor' were more likely than others to strongly agree that 'the public should have more of a say in making the decisions' (53 per cent in comparison with 18 per cent of those who assessed their health as 'fair' and 20 per cent of those who assessed their health as 'excellent' or 'good').

Finally, in response to the question 'Do you think that surveys of the general public's opinions, like this one, should be used in the planning of health services?' 71 per cent said 'yes' and 29 per cent said 'no'. There were no associations with any of the socio-demographic variables.

I feel this is an immoral exercise and a complete waste of time. I feel by doing this we are encouraging the Government to run the NHS down. Your time and money would be much better spent encouraging people to join a mass campaign calling for more money for the NHS.

SECTION 4

THE SURVEY OF DOCTORS

Aims

To compare the priority ratings of members of local community groups and the random sample of the public with those of general practitioners (GPs), consultants and public health doctors in the same health district.

Methods

A postal survey of these groups of doctors. The questionnaire contained the long prioritisation question from the public's questionnaire. This requested doctors to prioritise the same 16 service areas that the public were asked about, again in relation to the needs of people in City and Hackney. In addition, some open ended questions were included, asking about priority areas for improvement in the NHS.

Subjects

All 197 hospital consultants, all 121 GPs and all seven public health doctors (registrars and specialists) were sent a postal questionnaire asking them to rank the priorities according to the needs of people in City and Hackney.

Response rates

The response rate after four mailings was 66% for the consultants, 68% for the GPs and six of the seven public health doctors. Of the total number of consultants mailed, 40% responded after the first mailing, 4% after the second and third mailings and the remainder after the fourth. Among the general practitioners, 37% of those mailed responded after the first mailing, 17% after the second and third and the rest after the fourth mailing. The crucial mailings were the first and fourth. Of the six public health doctors who responded, five did so after the first mailing and the sixth after the second.

Fifteen doctors wrote critical or negative comments about the exercise on their questionnaires:

> **'Doctors do not have enough information to decide priorities (e.g., costs.)'**
> **'Politicians and the government should decide priorities.'**
> **'All services are essential – there should not be any prioritising/cuts at all.'**
> **'Should take into account doctors' opinions, but should also include public's viewpoint.'**
> **'Doctors shouldn't be asked to ration health services.'**

Results

Table 14 shows the health service priorities of the public, the GPs, consultants and public health doctors and compares their mean ranks. The ranks for the public health doctors were often joint, partly reflecting the less divergent opinions among this group and probably also partly due to their small numbers (the adjusted ranks in brackets facilitate comparisons).

The table shows that in most cases the priority ranks of the GPs and consultants were very similar. Statistical testing was not carried out using the public health doctors' ranks because there were so few of them, but the table shows clearly that they differ from *both* groups of other doctors – in particular in their higher prioritisation of therapy to help people with disabilities, health education services, preventive services and family planning services. It is less valid to compare their lower priorities due to the confounding factor of their joint rankings.

All groups of doctors differed from the public in relation to services for mental illness, long-stay care and community services, which the doctors prioritised as higher. Table 14 shows that both the community groups and the random sample of the public prioritised community services as lower than each group of doctors; this was a statistically significant difference for the community groups and the random sample tested independently against the doctors. However, the members of the random sample of the public were significantly more likely than the community groups to prioritise community services as higher. On this their ranking was closer to the doctors' (although it was still given a rank of only 5 in comparison to the ranks of 1 and 3 allocated by the doctors). The random sample also prioritised preventive services significantly lower than the

Table 14: Mean priority ranks of the public and the doctors (in order of priority 1-16; 1=highest, 16=lowest)

	Public community groups	Public random sample	GPs	Consultants	Public health doctors+
Special care and pain relief for people who are dying (eg hospice care)	2	2	4	4	4 (8)
Treatments for infertility (eg test tube babies)	14	13	14	14	10#### (15)
Therapy to help people with disabilities carry out everyday tasks (eg speech therapy, physiotherapy, occupational therapy)	7	7	7	10	3## (5)
Treatments for children with life threatening illnesses (eg leukaemia)	1	1	5	2	5 (9)
Health education services (eg campaigns encouraging people to lead healthy lifestyles)	12	14	10	11	3## (5)
Services for people with mental illness (eg psychiatric wards, community psychiatric nurses)	8	10	2	1*****	1# (1)
Surgery to help people with disabilities to carry out everyday tasks (eg hip replacements)	6	6	8	5	3## (5)
Preventive services (eg screening, immunisations)++	5	9	6	7	2 (4)
Intensive care for premature babies who weigh less than one and a half pounds and are unlikely to survive	9	11	13	13	10#### (15)
Family planning services (eg contraception)	13	12	9	9	1# (1)
Complementary/Alternative medicine (eg acupuncture, homeopathy, herbalism)	15	15	15	16	9### (13)
Medical research for new treatments	3	4	11	8*****	7 (11)
Long stay care (eg hospital and nursing homes for the elderly)	10	8	3	6***	6 (10)
Cosmetic surgery (eg tattoo removal, removal of disfiguring lumps and bumps)	16	16	16	15	9### (13)
Community services/care at home (eg district nurses)+++	11	5	1	3****	
High technology surgery and procedures which treat life threatening conditions (eg heart/liver transplants	4	3	12	12****	8 (8)

Number of respondents 322-335/298-305/63-66/112-116/4-6
* P<0.05, ** P<0.01, *** P<0.001, **** P<0.0001, ***** P<0.00001 (public in comparison with GPs and consultants)
# joint 1, ## joint 3, ### joint 9, #### joint 10 (public health doctors)

\+ Alternate ranking method in brackets to facilitate comparisons
++ Difference between the community groups and the random sample of the public: P<0.05
+++ Difference between the community groups and the random sample of the public: P<0.001.

community groups, in line with the GPs and consultants, but not the public health doctors (the difference between public and doctors, excluding public health doctors, was not statistically significant).

The doctors prioritised as lower than did the public both medical research and high-technology surgery and procedures which treat life-threatening conditions (again, all significance testing was carried out excluding the public health doctors, due to small numbers). Appendix VI shows the detailed results for the GPs, consultants and public health doctors.

Priority rankings

The consultants

The four items which received highest priority by the consultants were services for mental illness, treatments for life-threatening illnesses in children, community services and care for people who are dying. Services ranked as middle–high were those relating to surgery for disabilities, long-stay care facilities, preventive medical services and medical research. Those ranked as middle–low were family planning, therapy for disabilities, health education services and high-technology services. Those ranked as lowest priority were intensive care for low-birthweight babies unlikely to survive, treatments for infertility, cosmetic surgery and complementary therapy.

The general practitioners

The highest priority ratings given by the GPs were for community services, services for mental illness, long-stay care facilities and care for people who are dying. Services ranked as middle–high priority were treatments for life-threatening illnesses in children, preventive medical services, therapy for disabilities and surgery for disabilities. Those ranked as middle–low were family planning, health education services, medical research and high-technology services. Those given lowest priority were intensive care for low-birthweight babies unlikely to survive, treatments for infertility, complementary therapy and cosmetic surgery.

The public health doctors

There was less divergence of opinion among the small number of public health doctors and this resulted in some joint rankings. The items they rated as highest priority were services for mental illness, family planning, community services; preventive medical services, surgery for disabilities, therapy for disabilities and health education services and care for people who are dying. Services they ranked as middle–high priority were those relating to treatments for life-threatening illnesses in children, long-stay care facilities, medical research and high-technology services. The services ranked as middle–low and low priority were complementary medicine and cosmetic surgery and treatments for infertility and intensive care for premature babies unlikely to survive.

Attitudes to public consultation

We asked doctors were asked whether they thought surveys of doctors' opinions and priority ratings like this one should be used in the planning of health services. A total of 77% of the GPs and 77% of the consultants and four of the six public health doctors said 'yes'. Similarly, most of the members of the public said they should be involved in decision-making.

Priority areas for improvement

In response to an open-ended question asking them to list in priority order up to five improvements they would like to see in health services in City and Hackney, the most commonly listed service was mental health/psychiatry. Of the GPs, 36% listed this as their first priority, 29% as their second and 15% as their third priority. Of the consultants, 16% listed mental health/psychiatry as their first priority and two of the public health doctors listed it as their first or second priority. This provided a validity check on their high prioritisation of mental health in the list of 16 services.

SECTION 5

SUMMARY, LESSONS LEARNT AND CONCLUSIONS

Attitudes and priorities of the public and the doctors

More than three-quarters of the doctors and 71% of the members of the public said that surveys of their opinion, such as this one, *should* be used in the planning of health services. The public also appeared to feel that doctors and other experts should be responsible for the *final* decision-making.

The responses to the priority listing exercises and the discussions held within the community groups consistently showed that the public valued life. The additional attitude responses about the value of *quality* of life among people who are terminally ill indicated that people value life when it is worth living (that is, with pain and disability controlled and of a tolerable level) rather than life at all costs (that is, poor quality). The quotations from the group discussions (see Appendix III), however, reveal the complexity of the issue, with respondents viewing the withholding of life-saving treatments as a result of prioritisation as undesirable. Life-saving treatments, including those for AIDS patients, and care of people who are dying were the main priorities as far as both the members of the community groups and the random sample of the public were concerned.

Among both the community group members and the people taking part in the random sample, the lowest priorities were health education, family planning, complementary medicine and cosmetic surgery. Services for people with chronic and mental illnesses ranked middle. Those in the random sample ranked preventive services as lower and community services as higher than the community group members.

The random sample's higher average ranking of community services does seem more consistent with the nature of the sample (one might expect people living in the community to be more concerned about community services) and warns against over-reliance on the values expressed by members of non-randomly selected community groups. The other priorities, and many of the attitudinal responses, were remarkably consistent between the two groups.

In most cases the priority ranks of the GPs and consultants were very similar (even where they differed it was within three ranks). The priority ranks for the public health doctors were often joint, partly reflecting the less divergent opinions among this group, and probably also due partly to their small numbers. Statistical testing was not carried out using the public health doctors' ranks because there were so few of them, but Table 14 showed clearly that they differed from *both* groups of other doctors, particularly in their higher prioritisation of therapy to help people with disabilities, health education, preventive services and family planning. It is less valid to compare lower priorities due to the confounding factor of their joint rankings.

All groups of doctors differed from the public in relation to services for mental illness, long-stay care and community services, which the doctors prioritised as higher. Table 14 shows that both the community groups and the random sample of the public prioritised community services as lower than each group of doctors; this was a statistically significant difference for the community groups and the random sample tested independently against the doctors. However, the participants in the random sample were significantly more likely than the community groups to prioritise community services as higher. On this their ranking was closer to the doctors' (although it was still given a rank of only 5 in comparison with the ranks of 1 and 3 allocated by the doctors). The random sample also prioritised preventive services significantly lower than did the community groups, in line with the GPs and consultants but not the public health doctors (the difference between public and doctors, excluding public health doctors, was not statistically significant).

Medical research, high-technology surgery and procedures which treat life-threatening conditions were given lower priority by all the doctors than by the public.

Consistency between item responses

The public rated mental health services as middle priority (8th by the community groups and 10th by the random sample of the public) in the list of 16 service areas (see Table 14). It is possible to check for the consistency of their responses by analysis of the additional attitude questions. The additional questions on health values confirmed that mental health was regarded as important, but not as important as physical health, and helped to confirm the reliability of the results of the priority rating.

Tables 4 and 10 showed that prolongation of life *with* reduction of pain/disability was the highest priority. Prevention was accorded second-highest priority. Mental health was ranked as middle-low as a treatment priority. This reflected well the higher public priorities for life-saving treatments, which were illustrated in Tables 2 and 9, and the lower ranking of such treatments where there was an indication of ineffectiveness (as in the case of intensive care for low-birthweight babies unlikely to survive). Tables 2 and 9 also confirmed the public's higher prioritisation of preventive services in comparison with mental health services.

The most important thing is to cure people who have life-threatening illnesses and then to help people lead a good life.

Tables 5 and 11 confirmed that few respondents disagreed that 'it is more important for people with physical illnesses to be treated than it is for people with mental illnesses', although there was more 'sitting on the fence' among the random sample. The community group discussions confirmed that people valued life itself and that mental health services, family planning and health education ranked lower.

Mental health was still regarded as important, as can be seen by the response of 78% of both the community group members and the random sample of the public who strongly agreed/agreed that 'services which deal with mental illness are at least as important as those which deal with physical illnesses'. The doctors' very high prioritisation of mental health services was similarly checked for consistency against the question enquiring about their views of services requiring improvement. Mental health/psychiatry was most frequently listed as having highest priority in this respect. This contrasted with the public's view, which placed a more middle priority on mental health.

Comparisons with other studies

The findings of this study in relation to public consultation – people feeling that they should be involved in health service decision-making, although doctors and other experts should be responsible for the final decisions – mirrors almost exactly the findings reported from a survey of the public in Bath[23]. This is reassuring, given the different socio-economic compositions of the two districts. In contrast to Bath, Hackney is the second most socially deprived district within North East Thames Regional Health Authority[48]. In addition, the attitude expressed by most of the community group members and by over half of the survey respondents that costs should not influence treatment decisions is consistent with findings from a survey of UK adults, commissioned by the *Health Service Journal*, that negative attitudes about rationing of treatments are more likely to be expressed by people in poorer areas and lower socio-economic groups[51].

The public's priorities reported here are also consistent with the public consultation survey carried out in Bath, described in the introduction. In both studies a high emphasis was placed on life-saving technologies and a lower value placed on health education and family planning[23]. Most of the findings presented here are also consistent with the values expressed by members of voluntary groups and random and non-random members of the public in the preliminary results circulated by researchers in Mid-Essex and North East Essex[45,46,52,53]. The findings from those districts also showed some differences from the opinions of the Hackney respondents, with a higher priority given to prevention, and there was less emphasis on high-technology procedures in Essex (possibly reflecting the absence of teaching and special hospitals). However, the low emphasis in Hackney given to IVF and rehabilitation services is consistent with the results from the public surveys in the two Essex districts. All studies reported middle or middle-high rankings given to care/treatment of chronic conditions. It is not possible to make specific comparisons due to the different questionnaire design used (the Essex districts questioned respondents about fewer procedures and asked them to rank each simply as high, medium or low).

With mental health sometimes there is no success at the end, is there? And I think it all boils down to success, spending all this money, ploughing it in, if there's nothing at the outcome in the end [it's wasted].

The question on treatment priorities (quality versus quantity of life, prevention and mental health), which was illustrated in Table 4, was developed by researchers in Oregon and Mid-Essex and further developed by the researchers in Hackney. Despite differences in ranking techniques, the results were almost identical, with priority being given in both districts to quality of life rather than length of life without an increase in quality (for example, pain/disability relief) and on prevention. A recent (unpublished) survey of doctors, health service managers and the public in England reported that health services priorities between these groups differed in a similar way to the results reported here between the public and the doctors, with the public valuing life saving treatments most, and health education services less[54]. A paper presenting the implications for public health and policy has been written by this author[55].

Methodological issues

THE QUESTIONNAIRE

The 16-item prioritisation question reflected existing local services. Each district may have its own unique services to include in such a list. For example, we included complementary medicine because the DHA funds complementary medical practitioners (for example, for acupuncture) at a local health centre. It is funded on a short-term contractual basis, which is often precarious when health service funding is short. The members of the public health department wanted to know, as with the other services, how much the public valued this service. While this was an academic and exploratory exercise, and while the DHA are not committed to using the findings in decision-making, it will inevitably be viewed with interest when health service spending decisions are being made (which justifies the concern expressed by the CHC about the study). All respondents were informed that this was a research exercise and that although the DHA would have access to the quantified results, the researchers could not guarantee that they would take any notice of them. The representativeness of the sample was therefore of importance.

If the money was there to provide all of these services then I'd say yes, they're all important, but looking at the financial situation and the running-down that's going on in the NHS then you know you're looking at priorities.

The pilot exercises and the consistency checks within the questionnaire did, however, reveal that responses were sensitive to question wording, as is well known in survey research. In the pilot studies the item relating to intensive care of premature babies was unqualified and thus was given a high priority by the public. However, when it was subsequently qualified by the addition of babies 'weighing less than one and a half pounds and unlikely to survive', its ranking dropped markedly.

The question illustrated in Table 4 also provided further evidence of the complexities surrounding valuations of quality versus length of life, and the influence of even slight variations in question wording on response. The responses of the random sample of the public to the attitude questions did reveal a greater tendency than among the community group members to 'sit on the fence' (for example, by responding 'don't know'). This is a well-known problem in surveys and leads some researchers not to offer a middle category and instead to force a choice of one opinion or another. It is apparent that this was more a problem in the interview survey than in the community group study and indicates that respondents felt constrained by the presence of an interviewer in a one-to-one situation. It may be preferable, in future exercises of this type, not to offer a middle (neutral or don't know) category and also to use a sealed envelope technique. With this method, the choices are shown on cards given to the respondent, who then selects the one reflecting her or his opinion and seals it in an envelope, unseen by the interviewer.

IVF – we don't want these. Most people's families have split up anyway.

Methodological issues

INFORMATION

Although it is useful to measure the attitudes of the public before they have been given any information about health services, for example in order to provide baseline data, a major problem with involving lay people in decision-making is that they do not have the complex information needed with which to make such judgements. Richardson, Charny and Hamner-Lloyd (1992) noted that a barrier to the democratisation of decision-making is the lack of information provided to the public[23]. This is not easy to rectify.

An information sheet including a simply-drawn pie chart illustrating the major preventable causes of death, for adults and children separately, in the district was designed for the postal survey. Half of the sample members contacted by mail received the sheet and the others did not but its inclusion made no difference to responses. The interviewer later reported that respondents generally said that they did not remember seeing it. While we accept that the public need information if they are to be involved in decision making, this proved extremely difficult to compile. It was difficult to extract information on costs, needs and effectiveness, especially given the general nature of many of the services included in the priority list (for example, community services). Moreover, information on cost-effectiveness and need is not available for the majority of even specific treatment areas. One argument presented by the Community Health Council against the survey concerned this lack of data on which people could base informed decisions. This is an acknowledged problem. The CHC also expressed the view that the public's views cannot be regarded as valid because they are influenced by the media, with their emphasis on glamorising high-technology medicine. This possibility cannot be disputed, although people do also have their own direct encounters with health services which may modify this image of medicine.

Moreover, it could be argued that people obtain their information about party politics mainly from the media and are entitled to vote on the basis of this in national elections, so why should they not be entitled to make decisions about health services on the basis of the same sources of information?

The transcripts of the group discussions also revealed that people did debate priorities from several angles, in a coherent manner, before making their decisions. It cannot be denied, however, that this was a difficult exercise and that ideally decision-making should be informed. The ultimate challenge in public consultation exercises is undeniably the provision of this kind of information – especially in view of the paucity of rigorously collected outcomes data[8].

Although districts have information on resource allocation, mortality and some morbidity data, information on cost-effectiveness and outcome of care is often lacking, and even when it does exist it can be fairly complex. A challenge for the future is how to present meaningful and relevant information, in an interesting and comprehensible format, to lay people with different levels of education and who speak different languages. This is an initiative being developed in Oregon with the use of mass-produced printed material and educational videotapes[56].

A simple information booklet along the lines of those which many social services departments are making available to the public on community care plans would seem desirable (some departments are mailing them to every household in their boroughs). These simply outline the philosophy of community care and include figures, presented in a 'user-friendly' format, on the socio-demographic composition of the local population, population needs for social services, main types of expenditure (for example, mental health services, elderly people) and main types of services provided for that expenditure. Local authorities have a great deal of experience in providing information about expenditure and services to local people (for example, booklets on local authority expenditure that used to accompany rates bills). Health authorities may benefit from consulting them on this.

CO-OPERATION OF KEY LOCAL ORGANISATIONS

Community health councils have traditionally been the voice for the public on health issues and may feel affronted by other organisations becoming involved in public consultations. Some may also be opposed to the concept of prioritisation: they see this as another word for rationing, which they do not accept.

The researchers working on this study developed a good relationship with members of local consumer groups at the outset. Members of the CHC and the local umbrella organisation for all the community groups were involved either by representation on the study's advisory group or in the piloting of the questionnaire.

Unfortunately, after the survey got under way, the CHC expressed the fear that the study was an instrument of the district health authority in its attempts to impose health service cuts. These fears were not dispelled, despite several assurances that this was not the case and that the study was an independent research exercise.

We had the support of the local press, the regional health authority, the district health authority and the King's Fund Grants Administrator, but did not obtain the co-operation of the CHC, which protested about the ethics of the study and boycotted it. There have been pleas to CHCs in the literature to take up the challenge of consulting the public on health service priorities[21]. It remains to be seen how many do so.

Implications for other DHAs

City and Hackney is an extremely difficult area in which to conduct research. The high level of social deprivation leads inevitably to participation in surveys being low priority on people's agendas. The racially mixed character of the district also means that many people speak languages other than English as their first language, and extra efforts must be made to ensure that samples are representative and that translators are available.

We feel that this exercise was a success in so far as the community groups and their members were extremely co-operative and willing to be involved and most participants in the random sample were also willing to be interviewed (if not fill in a postal questionnaire). The study took a tremendous amount of energy, persistence and determination on the part of the researchers and was inevitably a difficult exercise for the members of the public. Contacting community groups, attending meetings (often late in the evening) and tracking down householders is no easy task in a run-down inner-city district with a poor public transport service. If this exercise can be successfully carried out in this district, then it can be carried out in other areas of the United Kingdom.

The respondents found the exercise extremely difficult and it is clear that the questionnaire wording requires further simplification. However, the respondents were willing to try to complete the questions and discuss the issue of prioritisation. The willingness of members of the public to 'have a go', if the right approach is made to them, should not be under-estimated. The only part of the study which was a failure was the specially called public meeting which was attended by few members of the public. The message from this study is that, in socially deprived areas, researchers have to go out to find the public rather than sit back and expect them to be motivated enough to come and find us.

Taken together with the results of priority surveys from other areas of England, the assumption can reasonably be stated that the public value life above all else and consequently life-saving treatments. Services such as health education, infertility treatments, family planning and cosmetic surgery are valued least. The members of the public in City and Hackney also prioritised complementary medicine as low. It should be pointed out that this is not the same as not valuing these services – they are simply prioritised as low in relation to services which the NHS should provide (that is, fund).

The representativeness of the community groups

The question remains as to whether people who attend meetings can be regarded as representative of the wider community. They are probably going to be different in some way from people who do not attend meetings. Crawshaw in Oregon argued that such attenders are legitimate spokespeople simply because they make the effort to involve themselves – in the same way that voters at a national election are also regarded as representatives of that community for political purposes[56]. The most valid approach to such an important issue as health service priorities is to try to ensure that, as far as possible, the views of a representative sample of the population have been collected.

It is known by market researchers that people who attend groups are different from a random sample of the public – for example, they are more likely to have university degrees[57]. There were differences between the composition of community group members and a random sample of the adult population in City and Hackney. The members of the random sample were more likely to reflect the characteristics of the population of the district in relation to census data. The community groups were over-represented by Black people, older people and those who had received further education (twice as many of the community group members, in comparison with the random sample of the public, reported that they had received some further education).

Researchers should also be cautious about setting up panels (whether of lay people alone or professionals and lay people) because the lay member can soon become an 'expert' and no longer representative of the public (the so-called Hawthorne effect: people become interested in the subject of study, may seek information about it, and may thus become unrepresentative).

On the whole, despite some differences in the composition of the random sample in comparison with the community groups, the distribution of responses to the items in the questionnaire was generally remarkably similar. The main difference was with the ranking of community services and preventive services in the main priority question. The higher ranking of community services by the random sample, along with their slightly greater willingness to consider that the cost of treatments should be taken into account in treatment decisions, does caution against over-reliance on findings from non-randomly selected members of the public. Overall, however, the consistency of opinions expressed by the group members and the random sample of the public lends credibility to the community groups exercise. The implication is that most members of the public do share a similar set of values about most types of health services.

Which method? Group consultations or postal or interview surveys?

While in the past the method of choice would have been a postal or interview survey, there has been a recent interest in other, less 'scientific' methods of tapping the public's views. The NHS Management Team's paper *Local Voices*[18] encourages experimentation and a diversity of approaches ranging from surveys to public meetings. The widespread publicity from Oregon has popularised community group meetings as market-research-style focus groups. Postal surveys are still popular, due to their relatively low cost, although they are not suitable for use with lay people when complex issues are being explored.

One lesson to be learnt from this study which is consistent with the experiences of researchers in Bath[23] is that a postal survey is *not* the method of choice when aiming to target a random sample of the public: response is likely to be poor. Moreover, this exercise showed that members of Black popluations were less likely to respond to the postal questionnaire than to the interview. The issue of health service priorities is also too complex for a postal questionnaire, as was confirmed by the low response rate to this part of the study in comparison with the good response rate achieved with personal interviews.

A good response rate using a postal questionnaire was obtained with the consultants, the general practitioners and the public health doctors. This was higher than was expected on such a contentious issue in a district already undergoing mergers with other health districts and changes due to contracting and rationalisation of services. This survey also indicated that a fourth mailing was worthwhile in terms of enhancing response. A good response rate locally does not mean that a good response rate for a national survey would have been achieved, but it is encouraging to discover that controversial issues can be investigated among medical professionals using a postal questionnaire.

The interview survey of the non-responders to the postal survey achieved a very good response rate. Most people were willing to be interviewed, although they found the exercise difficult. The questionnaire used for this study was reported by the interviewer to be too long – it was difficult to maintain the impetus to complete it in a one-to-one situation. A simpler questionnaire with the omission of many of the consistency checks is recommended. Attempts were made at the postal and interview stage to shorten the questionnaire by omitting the less salient question on quality-of-life priorities and by asking some less salient questions (for example, the standard but long question on socio-economic status–occupation) to sub-samples only.

The method of choice, in terms of obtaining a representative sample of the community and achieving a good response rate, is an interview survey of a random sample of adults, perhaps with extra sampling (booster samples), where necessary, of groups thought to be unrepresented (for example, those from

Black populations). Samples can be taken from the postcode directory, the electoral roll or FHSA lists of patients. The method of choice will depend on the area of the study.

In the inner city, with high population turnover, the electoral roll and FHSA lists may not be updated quickly as people move or die. This delay can result in wasted (and costly) interviewer visits. Also, although most people register with an NHS general practitioner, not everyone eligible to vote registers on the electoral roll. The Office of Population Censuses and Surveys uses the postcode directory to sample dwellings in order to overcome these problems, and adults who live within the sampled household are included in their surveys.

A well-trained, determined and persistent interviewer will also be an essential component of the success of the study – recalls will have to be made at different times of day and on different days of the week to respondents who are out, and good social skills will be needed to present the aims of the study and to encourage people to take part. Some people will be politically opposed to participating in a survey about priorities on the grounds that it is 'really about cuts'. The interviewer will require the confidence to portray honestly the aims of the study as well as to respect people's opposing views without getting upset.

While an interview survey is undoubtedly the method of choice, this should be supplemented with group meetings in order to canvass the depth and range of discussion about health issues. This can be achieved only when groups of people come together and discuss varying ideas and opinions. In addition, our experience is that community group consultation is an extremely good public relations exercise and achieves a high profile for a health service issue.

The lesson from this exercise is that it is extremely time-consuming to consult a wide range of community groups, and there is no guarantee that they will represent the wider community (attendance at the community meetings took five months), so such a method should be supplemented with a survey of a random sample. A series of focus groups held by market researchers in the local high street would be quicker, although a large number of groups (for example, 20) would be needed and this method usually involves giving people some financial remuneration for participating. A market research company would typically charge £2,000 per focus group, comprising about six people. The focus group technique is widely used by market researchers for testing ideas and testing initial reactions to new products. However, it is eventually supplemented by large-scale surveys[58].

A mixed methodological approach to health care prioritisation is essential. It is necessary to have data on health needs, the evaluation of service effectiveness, local practice and the monitoring of costs and outcomes alongside public consultation. Hard epidemiological data reviews, combined with interviews with key people and community group members who act as representatives of the community, population surveys and booster samples appear to be the way forward.

Financial aspects of the study

OVERALL COSTS

The study took 12 months to complete and the research costs were £24,000. This excluded College overheads and also the extensive amount of time spent by the principal researcher (the author) on supervising the project, data analysis, report writing and verbal presentations of the findings. The real costs were easily twice this figure.

COMMUNITY GROUPS

A research assistant was employed for six months to carry out the community groups study. Attendance at meetings (including those of the tenants' associations) took five months and often required evening attendance. Setting this up was also time-consuming. A community group umbrella organisation provided the researchers with a list of all groups in the district and the local council supplied a list of tenants' and residents' associations. All the community groups listed were contacted by telephone with a request to attend the next routine meeting in the case of those which held meetings with their members. Most leaders required this request in writing and some wanted to discuss the project with the researcher in person before attendance at a meeting was permitted. The organisation of translations also took time and was an additional expense. As with the interview study, the success of this part of the study depended on having a persistent, determined and confident research assistant.

During this six-month period, the research assistant completed the pilot studies, helped to develop the questionnaire, completed the community group study and coded and entered the data on to computer. The cost of £13,000 included the research assistant's time, the printing of the questionnaires, translation and travel expenses.

THE POSTAL SURVEY

The postal questionnaire was the cheapest part of the study. The author conducted it with the help of an administrator to collate and post the sample of 454 questionnaires and the reminders. As so few were returned, very little time was spent checking them back in! The cost of printing and postage was just under £2,000. Each mailing took a week of administrative time (conducted alongside other office duties).

THE INTERVIEW SURVEY

The interviewing was inevitably more expensive than the postal questionnaire. However, this was completed more quickly than most (within three months) due to the willingness of the interviewer to work mainly in the evenings, when people are most likely to be at home. The interviewer was male and a local resident. It is usually difficult to find interviewers who are willing to work in the evenings in such socially deprived areas, due to fear of personal attack. The cost of the interviewing was about £4,000. No travel expenses were involved as the interviewer used a bicycle. Before the interviewer approached householders, the researcher mailed out a letter to each of the remaining 379 addresses of non-responders to the postal questionnaire to inform them that he would be calling. The printing, paper and postage, coding, data entry and analysis cost about £3,000.

THE SURVEY OF DOCTORS

The postal survey of consultants, general practitioners and public health doctors was conducted fairly economically. A total of 325 were sent a postal questionnaire, and this first mailing was followed by three more to non-responders. No stamps were required as the health district mail van covered all doctors. The mailing-out was carried out by the author with the help of an administrator. Each mailing-out took about a week (alongside other office duties). The printing costs, checking in, coding and data entry costs totalled about £3,000. The analysis and writing-up of all parts of the study were carried out by the author and were therefore not directly costed.

Use of the results in planning and purchasing

Although this was a research exercise, it is always rewarding when research is used in planning exercises. Valid information on the public's views of health service priorities could be used by planners as just *one* source of information among many. Information on costs, effectiveness and need are essential for planning decisions, although it is often lacking. It should be remembered that the research on the public's views reported here, and information from other studies (for example, Bath), indicates that while the public feel that they should be involved in decision-making, the final decisions should be made by experts.

Information on what people feel is important should be considered only if the information is valid. It can be valid only if rigorous research methodology is used to ensure that all groups of interest, or a random sample of the population of interest, are included. The debate also needs to be raised about the amount and complexity of information required by the public to make their decisions.

Within this framework of consulting the public, if planners feel that services for a particular condition that the public have prioritised as low are actually important in terms of funding, for example because a large number of people suffer from a condition for which an effective treatment/service exists, then the onus is on the planners to feed information back to the public about why they disagree with their priorities. Similarly, the public may prioritise a group of services as high, but there may be information available that the service is not cost-effective and therefore the planners do not wish to purchase it for their local population. The results leave members of the local public health department faced with some awkward dilemmas: they are willing to be responsive to public demands, but their main priorities differ from those of the public, particularly in relation to services for mental illness, which the public prioritised as middle but which the doctors prioritised as high; the public also prioritised community services as lower than did all the groups of doctors. In both these instances, the priorities of the public health doctors were supported by the consultants and GPs. The public health doctors‘ priorities differed from those of the public *and* the other doctors particularly in relation to family planning services, health education and preventive services, and therapy for disability.

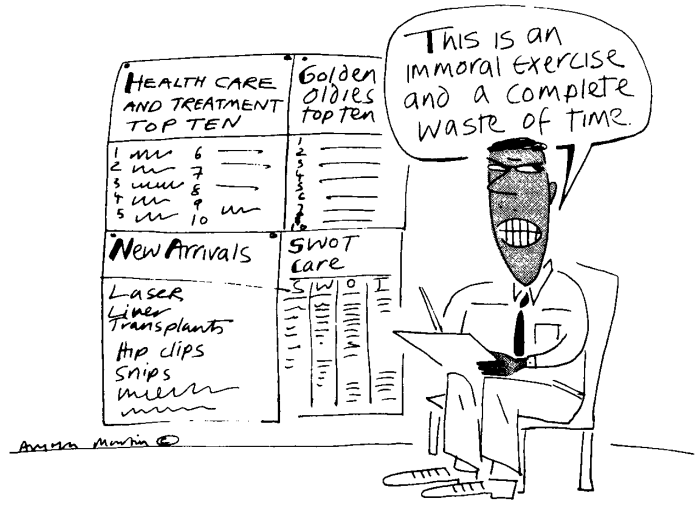
Thus, what do a DHA and public health department do when, having consulted the public and added doctors' views, they find disagreement over some priorities? Some members of the public health department have argued that they have to 'educate the public and the doctors' about certain priority areas (for example, services for mental illness and community services – the public; family planning and health education – the public, the consultants and general practitioners). If they are not going to act on the views of the people consulted, then they need to tell these people why they are not going to prioritise the services they wanted prioritised and must justify their decisions with information on population need and cost-effectiveness. Any actions taken require justifying to the public if a spirit of healthy democracy and mutual education and feedback is to ensue.

It is possible that the groups consulted might change their priorities when presented with some 'hard' information. These processes may need to take part within a public debate.

Conclusions: some ethical concerns

It is likely that there will be an emphasis in the United Kingdom in the future on systematic attempts to obtain information about societal preferences for medical treatments and care. The lesson to be learnt from the Oregon experiment is that priority setting is extremely complex and that the information on medical outcomes that is currently available does not facilitate such exercises. Even in Oregon, the attempt to use cost-benefit and effectiveness criteria was abandoned because of inadequate data, and the decision-making process became reliant on public values and inexplicit professional values[59,60]. However, if it is accepted that one cannot reasonably expect lay people or professionals to rate specific medical conditions and their treatments in priority order without the necessary information to justify this, public values can certainly be explored in a similar way to Oregon's public health forum mechanisms.

The purpose of the Oregon public meetings was to develop information on why members of the community judge certain health services to be particularly important for the community: in other words, whether people share a set of values about health care that can help to define a set of health services as constituting some common good[29]. An example of this can be seen in the excerpts from transcripts of the audio recordings from the City and Hackney community group meetings in Appendix III. The implication of the research presented here, and the comparisons with other studies, is that people do, on the whole, share a set of common values, the most important value being the treatment of life-threatening conditions, qualified where the quality of life is poor. How these values are formed and influenced is a subject worthy of further debate and investigation.



It is insufficient to conclude the debate by reporting, without caution, on public priorities for health care. We hope that the presentation here of data on public values can stimulate responsible debate about the ethical issues, value judgements and provision of information to people about health services.

Debate in the future is likely to focus on the interpretation and use of public ratings for planning purposes. Ethical issues are raised by these and some other survey results which show that higher values are placed on acute high-technology services as opposed to treatments for chronic conditions and on life-saving treatments and care for children and young adults rather than for elderly people[23,40,41]. Despite such complexities, such studies have been judged to be of

I think life-saving treatments for children are most important. We've had our lives now.

value, as they are reported to have raised local planners' and doctors' awareness of the importance local people attach to specific services[45].

Further ethical issues are posed by the previously reported findings from the national survey commissioned by the *Health Services Journal* that agreement with the statement that 'the NHS should restrict some non-essential treatments' varies by socio-economic group and type of area, with people in higher socio-economic groups and people in Greater London and the South-East of England being more ready to agree with restriction of non-essential treatments on the NHS than people living in the rest of England, Wales, and Scotland[51]. Large proportions of the respondents in the study presented here were unwilling for considerations of cost to enter into the process of decision-making.

If people don't lead healthy lives why should the health authority waste money on making them aware?

What other criteria could be used in priority setting decisions, in addition to epidemiological data about need, data on cost-effectiveness and the public's view? The philosophical concerns about equity focus on the principle of just deserts (for example, people should get what they deserve, so that those who do not take responsibility for their own health do not get priority over resources), satisfaction of needs (but this is difficult to define) and utility (for example, the number of lives saved, or the quality of life achieved). These issues have been clearly outlined by Heginbotham and Ham (1992)[61] and the inevitable semantics of rationing illustrated by Hudson, Ham, Warner *et al* (1992)[62]. Readers wishing to pursue these lines of thought further are referred to these publications.

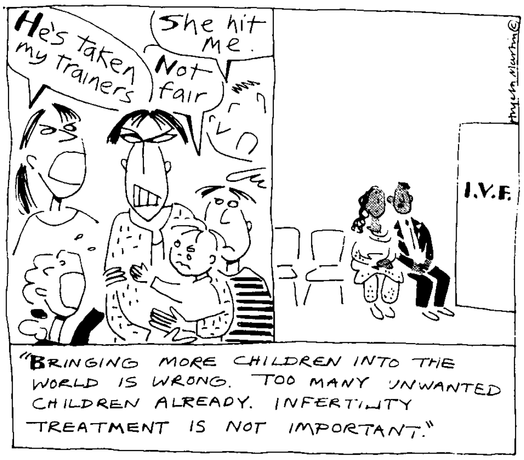
Consistent with the views of the public expressed here and in the other studies reviewed, a report by the King's Fund in 1988 concluded that NHS funds should be allocated to ensure that appropriate and proven life-saving treatment is provided and not withheld. It is also argued that appropriate and proven therapies which reduce morbidity should be available within a reasonable period from the onset of symptoms[63].

The report also argued, in line with Griffiths (1988)[64], that the Department of Health should publish a statement of objectives and priorities, specifying service standards, and ensure a match between policy objectives and the resources provided to meet them, in the same way as insurers. It is argued that for a government to admit that there is a lack of resources for certain treatments is not unjust, but it is dishonest to pretend to finance comprehensive health care when health authorities cannot meet expectations. While the NHS reforms have gone some way towards greater accountability, the government prefers to delegate to districts the responsibility for explicitly setting priorities and targets for care[3].

Clinicians are now accepting the need for explicit rationing rather than shirking the issue with reference to clinical decision-making[65]. This inevitably conflicts with the commonly held ideal or philosophy in Europe that a basic human right in a developed, industrial society is equity of access to high-quality medical and social care when needed and for whatever length of time it is needed[66]. Nowhere in the world is this ideal achieved, given the speed of medical advance and the high cost of medical technology. This does lead, however, to another ethical concern over rationing or prioritising health care: prioritisation of health services may be judged to be grossly unfair until Britain spends more on health care, given that it spends far less of its gross national product on health care than the United States and the rest of Europe.

There is no easy solution. Philosophical debates do not help DHAs who are forced to make spending choices in the present and immediate future. If it is accepted that there is to be prioritisation, or a hierarchy of entitlement, the question still remains about the criteria to use. The attempts at public consultations, along with the spirit of 'consumerism' of the 1990s, will inevitably have to raise the issue of values and have to face the challenge of eliciting genuine, non-professional, human values rather than misinformed prejudices. Hard data reviews and evaluations of services, combined with interviews with key people who act as representatives of the community and population surveys, with booster samples where necessary, appear to be one way forward in this respect[67,68].

To date only 12 of 114 health authorities surveyed have been reported to have made any policy decisions to ration treatments (for example, tattoo removal, in-vitro fertilisation, cosmetic surgery), instead preferring to reflect the status quo with their purchasing patterns[69]. Prioritisation will inevitably become a feature of the future in the United Kingdom; 1992 and 1993 saw four major conferences on prioritisation of health services and rationing[54,70,71]. While prioritisation within the NHS has always occurred, the current debate about prioritisation has been stimulated by the NHS reforms and by the pioneering attempts to draw up a plan for rationing state health care in Oregon. Although the out-going Bush government rejected the Oregon plan the Clinton government has accepted it. The debate on priorities is set to continue. The findings presented here are not intended to be used in health service planning, but as a stimulus for the further debate of a very complex topic.



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APPENDICES

APPENDIX I

Details of the Oregon experiment and the priority ranking methods used

The Oregon Health Services Commission (HSC) is composed of a group of 11 consumers and health care professionals (three family doctors, an obstetrician, a paediatrician, a public health nurse, a social worker and four lay persons). It was appointed as required by the Oregon Basic Health services Act 'to report ... a list of health services ranked by priority from the most important to the least important, representing the comparative benefits of each service to the entire population to be served.' Prioritisation would be finally decided by the legislature, which would determine the extent to which the list of services could be funded to provide health care for Medicaid recipients.

In Oregon, health outcomes sub-committees were formed (one for physical and one for mental health) with the purpose of developing an approach to the evaluation of the relative importance of each service to be considered[29]. Kaplan's Quality of Well-Being (QWB) Scale was selected as the most appropriate measure. The method assigns a score of 1.0 to a perfectly healthy person and a score of 0 for death. Oregon residents, via a telephone survey, were involved in the derivation of the weightings for disability states (about 1000 people were asked to assign numeric scores to various sets of health symptoms and functional impairments as they related to Kaplan's scale of perfect health = 100 and death = 0). The disadvantage of the telephone survey was that women were slightly over-sampled and households below the poverty line were slightly under-sampled. The results of the survey provided the commission with a set of weighted functional categories and symptoms which were then used by health care providers to describe the probable outcomes of treatments for specific conditions.

The HSC solicited outcome of treatment information from 54 panels of specialist health care providers. Providers were asked for: median age at onset of diagnosis; probability that the designated treatment would be used; expected duration of benefits from the treatment; outcome probabilities with and without treatment: death/residual effects (for example, major symptom or physical, social activity or personal mobility impairment) and asymptomatic cure (for example, the probability of a return to the former state of health as a consequence of either treatment or no treatment for a specified condition). This acted as a probability estimate of that particular outcome occurring; cost to payer with and without treatment[27].

The survey information and the information from these provider panels was combined into a cost-benefit ratio formula, which provided a single index for each condition-treatment pair. The index values were used to establish a rank order among the items. The net benefit of a service or intervention for a particular condition or group of conditions was defined as the difference between the expected QWB score resulting from the condition and that following either definitive or palliative treatment (net QWB). This measure was applied to a large number of treatments used for the majority of conditions coded according to the World Health Organisation's International Classification of Diseases (9th edition) (ICD9). Calculation was further refined by the addition of duration of time with QWB status. The cost-benefit formula was (simplified):

$$\frac{\text{Cost \$}}{\text{net benefit X duration, years}} =$$

$$\frac{\text{Cost \$}}{\text{(QWB2-QWB1) X duration, years}}$$

QWB1=QWB resulting from untreated condition

QWB2=QWB following treatment

The expected outcome results are measured at five-year intervals, which was agreed to be the customary norm for treatment success or for the lifetime of the treatment if longer (for example, hip replacements)[28]. A computerised database is available for actuarial analyses.

For each service category, each commissioner rated (on a 0-10 scale) the service in terms of value to society, value to the individual and whether it was essential to basic health care. These are taken into account by the legislature along with the cost-benefit analyses. The legislature is not authorised to change the list. The low-priority items will be provided only if the more 'effective' items are also included. Interim decisions are being made on the basis of a consensus on outcomes obtained from 'knowledgeable experienced practitioners'[28].

Thus, prioritisation is based on a cost-benefit formula applied to over a thousand treatment/condition pairs and assignment of each of these to a general category which has been ranked on the basis of 'public value' and according to cost, effectiveness and improvement in quality of life (assessed on the basis of Kaplan's scale, incorporating public values for the weightings from a telephone survey). The condition-treatment pairs were derived from ICD9 and current procedural terminology. Information on effectiveness came from published studies or consultations with experts[73]. The bill required active solicitation of public involvement to build a consensus on the values to be used to guide resource allocation decisions and implementation of the results through contracting with managed health care systems[28].

Controversy was generated when organ transplantation was initially ranked by the commission near the bottom in terms of priority, near cosmetic surgery, and cosmetic breast surgery was ranked higher than treatment for an open thigh fracture. The resulting disquiet led to the formation of two sub-committees to work separately to create new priority lists[20]; this aims to incorporate information on outcomes into decision-making, together with information from public forums (for example, to elicit the weighting given by citizens to preventive rather than curative treatment). The aim is to update the lists every two years.

Currently, the list consists of 709 condition-treatment items; the commissioners used a system of 17 disease and health-oriented categories to organise the list, based on values derived from the public meetings – for example, ranked 1-17 respectively:

- fatal conditions: treatment prevents death (full recovery/residual problems/maternity/preventive care for children) (ranks 1-4)
- treatment extends quality of life/reproductive services (5-6)
- comfort care/preventive dental care/adult preventive care (7-9)
- non-fatal conditions: acute conditions (treatment provides full cure) (10)
- chronic condition (single treatment improves quality of life) (11)
- acute condition (treatment achieves partial recovery (12)
- chronic condition (repeated treatments improve quality of life) (13)
- acute, self-limiting condition (treatment speeds recovery)/infertility/adult preventive care (other) (14-16)

- fatal or non-fatal conditions (treatments provide minimal or no improvement in length or quality of life) (17).

The commissioners recommended that ranks 1-9 should be 'essential components of basic health care'; 10-13 were 'very important – fund to greatest extent possible'; 14-17 'valuable to individuals but significantly less likely to be cost-effective or to produce substantial long-term gain'[27,35].

The top 10 conditions currently accorded priority are: pneumococcal pneumonia, other bacterial pneumonia, bronchopneumonia, influenza with pneumonia; tuberculosis; peritonitis; foreign body in pharynx, larynx, trachea, bronchus, oesophagus; appendicitis; ruptured intestine; hernia with obstruction or gangrene or both; the croup syndrome, acute laryngotracheitis; acute orbital cellulitis; ectopic pregnancy.

The bottom 10 currently are: gynaecomastia; kidney cyst; treatments for (as opposed to palliative care) terminal HIV disease with less than 10% survival rate at five years; chronic pancreatitis; superficial wounds without infection and contusions; constitutional aplastic anaemia; prolapsed urethral mucosa; central retinal artery occlusion; extremely low-birthweight babies (under 1.3 lbs) and under 23 weeks' gestation; anencephaly and similar conditions in which a child is born without a brain[73].

APPENDIX II

Priority rankings: two pilot studies

It was not possible to combine the pre-pilot and pilot findings because the list of services and the ranking procedure had been altered and anomalies and ambiguities in wording had been resolved in order to improve reliability. These changes inevitably affected rankings.

The services which achieved the highest ranks in the first pilot study were interventionist services aimed at preventing ill health and death (for example, screening, immunisation), high-technology procedures (for example, heart and liver transplants) and intensive care for premature babies (all jointly ranked highest).

Care for people with mental illness, chronic conditions and those who are dying achieved high to medium rankings (4-6), followed by community care, medical research for new treatments and long-stay care (7-9). Non-emergency treatments (for example, physiotherapy, hip replacements) were ranked lower at 10 and 11 respectively and 'occasional very expensive drug treatments for individuals' was ranked joint 11th.

Services which often appeared less specific, or not focusing on a specific disease group, were given the lowest rankings, for example, those concerned with day surgery (14) and alternative medicine (15). The lowest ranking of all (16) was given to infertility treatments (IVF, 'test-tube' babies). Day surgery was too vague to be useful on the list and was subsequently removed. A second pilot study was carried out with further refinements to wording and scoring and the addition of more items, as previously explained.

The results of the second, much smaller-scale, pilot study showed very similar distributions, even with the addition of new categories of services. Treatments for life-threatening conditions were ranked highest at 1 (for example, children with leukaemia; organ transplants); care and pain relief for people who are dying achieved higher scores (2) in the second pilot study. Care for other chronic conditions ranked joint 2; medical research for new treatments, high-technology surgery, preventive service and long-stay care were next in priority, ranked from 4 to 6.

Mental health (hospital and community, ranked separately), community services and rehabilitation received middle-high and middle-low rankings respectively (7-8, 11-12); health education received a lower rank of 13; family planning, complementary medicine, IVF and cosmetic surgery were ranked lowest (14-17 respectively).

The only marked difference between the first and second pilot studies was with intensive care for premature babies. It is of interest that when the item in the pilot study 'intensive care for premature babies' was changed to 'intensive care for premature babies weighing less than one and a half pounds and unlikely to survive', the rating decreased markedly from 1 to 10.

APPENDIX III

The community group discussions

'WE'RE JUST NOT QUALIFIED'

'We need more information, information about costs, before making these decisions . . . We're just not qualified to make these decisions.'

'I found this really difficult because I think that all these services are essential.'

'You've got to think . . . you've got to sit down and study this . . . It clicks differently in your mind after reading it again.'

'This big form would put a lot of people off.'

'It needs a lot more time . . . and discussion.'

'I'd like to have this on my own indoors and fill it in quietly.'

'THEN YOU KNOW YOU'RE LOOKING AT PRIORITES'

The study was controversial, although only a few people expressed dissent and most accepted that some form of prioritisation was inevitable:

'I feel this is an immoral exercise and a complete waste of time. I feel by doing this we are encouraging the Government to run the NHS down. Your time and money would be much better spent encouraging people to join a mass campaign calling for more money for the NHS.'

'I don't think that priorities should have to be set but I can see things are gearing up that way.'

'If the money was there to provide all of these services then I'd say yes, they're all important, but looking at the financial situation and the running-down that's going on in the NHS then you know you're looking at priorities.'

'THEY'RE NOT LIFE-SAVING, THEY'RE A WASTE OF MONEY'

Although the exercise was difficult, it demonstrated that the public does have strong views about health priorities, even in the absence of information of disease prevalence, costs and outcome:

ILLNESS

'Illness comes first and foremost. Illness comes first and foremost, doesn't it?. . . because they need immediate care.'

'The ones like cosmetic surgery, infertility and health education, I put them as low because they're not really illnesses.'

LIFE-SAVING TREATMENTS

'The most important thing is to cure people who have life-threatening illnesses and then to help people lead a good life.'

'[Infertility treatments and cosmetic surgery] aren't important because they're not life-saving, they're a waste of money.'

'In severe cases cosmetic surgery may be important, but usually it's not.'

'Severe cases aren't classed as cosmetic, though. I mean hare lips and things like that aren't cosmetic.'

'It's [cosmetic surgery] not as important as other things because it's not a life and death situation.'

'There may be a one in a million chance, a one in a million chance, but they deserve that.'

CHILDREN

'I put "life-saving treatments for children" as essential because it's really important for children to be treated.'

'Oh yes [life-saving treatment for children], it is important because they are the future, the backbone of the country.'

EFFECTIVENESS

'With mental health sometimes there is no success at the end, is there? And I think it all boils down to success, spending all this money, ploughing it in, if there's nothing at the outcome in the end [it's wasted].'

FUNCTIONING

'People with disabilities should be enabled to lead as normal lives as possible.'

'Someone who is alive should be given the best possible chance of leading a normal life.'

PREVENTION

'Prevention is better than cure. It makes more sense and, in the long run, it's cheaper to prevent people from becoming ill than treating people when they become ill. It sounds really stupid to put health education services as high until you realise that this is the thing that can stop people becoming ill in the first place.'

'Instead of curing it, prevent it. There's no guarantee that you can cure someone so it is better to prevent illness.'

INDIVIDUAL RESPONSIBILITY

'I put cosmetic surgery as low because for instance, with tattoo removal, if someone's chosen and paid to have one they should pay to get rid of it.'

'If people don't lead healthy lives why should the health authority waste money on making them aware?'

'It's up to the individual to find out about family planning; it's people's personal responsibility.'

'THEY SHOULD BE GIVEN THAT CHANCE'

The following group discussions illustrate the extent of the debate which took place in the groups and the values expressed.

GROUP A

Respondent 2: If there is a hundred-to-one chance that they may survive, they should be given that chance.

R 3: You give them that chance.

R 4: Whilst there's a life. . . .

R 3: That mental patient is still alive. Him being mental

is not going to kill him. That unit for that baby will help it.

R 5: But it says here they are unlikely to survive.

R 3: Yes, but without it, it's not going to, you've made the decision. . . If the person is still alive and not in pain, then they've still got a good quality of life, whereas if you've got a person who could die without treatment you've got to give that person a chance to live. You haven't got the right, there's only one person who's got the right to say 'No, you don't live' and He's up there.

R 2: If a child is really unlikely to survive it really does seem a bit naive to plough a lot of money into it.

GROUP B

Respondents discuss their reasons for ranking care as 'essential', 'very important', 'important' and 'less important'.

Respondent 1: Special care for people who are dying is essential, definitely essential. . . and treatment for children with life-threatening illnesses. I think that's essential. . . and heart and lung transplants, that's essential as well. . . Preventive services are very important and immunisations for children are important, it's the start of their lives.'

R 2: High-technology care, heart and liver transplants are essential. It gives people an extra chance of life, doesn't it? Even if it's only five-ten years, that's a long time for someone at death's door.

R 1: Intensive care for premature babies unlikely to survive is less important. If they're unlikely to survive, what's the point of doing anything. . . if they're one and a half pounds and not fully developed anyway?

R 3: Cosmetic surgery (laughs) [is less important] and I don't believe in this alternative medicine.

R 4: How would you feel if. . . [hospital] said: 'We're stopping X'?

R 1: You'd feel guilty.

R 2: Cosmetic surgery should be wiped out completely.

R 1: Lumps and bumps are not the same as tattoo removal.

GROUP C

R 1: Health education is least important.

R 2: It is important, but it's the money situation. . . I had a heart attack and I was smoking eighty a day – it's wrong, but it's an individual thing.

R 3: I've ranked health education as middle as it's going to save the NHS money in the years to come. If you can educate 50 people to give up smoking that's 50 people in the future. . .

R 4: But a lot of people don't take any notice of health education.

R 3: But a lot of people have given up. What were you smoking ten years ago?

R 5: Cigars, pipe. . . .

R 4: And you?

R 6: Pipe.

R 4: There you are, so you've been educated.

R 7. Alternative medicine is marvellous. . . but no NHS money should be spent on it.

R 8: Family planning clinics are less important – sex education and prevention [of pregnancy]. So much more is known about it now. They teach it at 7 or 8 in schools. Now there aren't enough babies for adoption. . .

R2: Yes, we've all got arthritis.

R1: Arthritis affects the majority of people.

R3: Yes, that's very important.

R1: Heart and liver transplants are essential – it's their life.

R 5: Heart conditions are prevalent now.

R 8: We all seem to be agreeing on the same sorts of things. People who are severely ill – the money should be spent on them. Because someone is ill, we shouldn't allow them to die.

R 5: Also pain relief and special care for the dying. It's a high priority on my list that people should die with their dignity. Same with community care: there should be more money ploughed into care at home so hospitals can stick to operations and so on rather than caring for people who could be at home.

R 2: The younger generation won't follow the NHS anyway. If they can afford it they'll pay for it. They want a better service than what we've had. It's [the NHS] only going to affect older people.

GROUP D

R 1: Once you're in pain and you're dying then they should let you die.

R 2: IVF is 'less important' – test-tube babies aren't even here [yet], are they?

R 3: It's like going to the moon.

R 4: There are plenty of children waiting to be adopted.

R 5: I think life-saving treatments for children are most important. We've had our lives now.

R 6: I don't think there should be a choice anyway. (ie between treatments – rationing)

R 7: Intensive care for premature babies – I've seen a lot of them on TV. Their brains are not fully formed, they're 'less important.'

GROUP E

R 1: Care of the dying – why should people suffer? – is most important.

R 2: Bringing more children into the world willy-nilly is wrong in my opinion. There's too many unwanted children already. Infertility treatment is not important.

R 3: Every one of these is important.

R 4: Mental health services are important. You've got to help these people. They're unfortunate. One never knows, it can happen to anybody.

R 1: IVF – we don't want these. Most people's families have split up anyway.

R 2: Intensive care for premature babies – it's not as important as other things. They're so tiny, they may be in such poor health that it's going to affect them and their parents.

R 5: It's important to its mother.

R 6: Family planning – oh, that's not very important. That's 'less important'.

R 1: It's my opinion that it's ridiculous when people have eight, ten children. Family planning is very important.

R 7: What about their religion?

GROUP F

R 1: High-tech [treatments] – they can help people keep on living; they're important. . . .

R 3: Mental health is important but there are other things that are more important. With mental health, sometimes there is no success at the end, is there? They spend all this money on them and there's nothing to show for it.

R 4: People who are ill mentally need help, why should they be less important?

R 1: Which is most important – mental health or intensive care for premature babies?

R 2: Well, mental health.

R 3: So you'd allow the babies to die?

R 2: Low birth-weight babies of one and a half pounds are unlikely to survive.

R 3: If there's one chance they may survive they should be given that chance.

R 3: Someone who's mentally ill – they go into hospital and then they come out and they get depressed again or whatever, or they go back in again.

R 2: The babies are less important.

GROUP G

R 1: Premature babies. It's essential we should look after the young.

R 2: Treatment for children with life-threatening illnesses is very important. I've got a grandson with leukaemia and they've been treating him for over a year and haven't helped him.

R 1: Infertility treatment isn't important to me.

R 3: There are too many children – here and in the Third World.

R 1: Most of us think it's [infertility treatment] not very important.

R 2: It is to young people who want a child.

R 1: Yes, but they can adopt a child. It's a minority issue, it's not important.

R 4: Young married couples who can't have children are very unhappy.

R 2: I would have liked a second and I would have loved the doctors to tell me why I couldn't at that time of life. But now there are other things that are more important.

R 4: Mental health services are very important. This Government just puts them out on the streets – you see a lot of them wandering about in this area.

APPENDIX IV

Validity and reliability correlations

HEALTH PRIORITIES

The face validity of the questions was tested in the two pilot studies and questions were re-formulated until the meaning of each item was evident to respondents and appeared sensible in relation to the dimension being measured.

The questionnaire was too short to test for split half reliability. Two tenants' associations agreed to participate twice in the study and the questionnaires were re-administered to members in order to test for test–retest reliability. Almost identical rankings of items were obtained on the two test periods.

Other aspects of validity were difficult to test for in the absence of a 'gold standard'. However, similar items on health priorities were contained in three separate questions and these were correlated, although strong correlations were not necessarily expected as respondents had to rank treatments and conditions in relation to a different set of other treatments and conditions at each question. Pearsons product moment coefficient of correlations were carried out on similar items in the priorities questions. Examples of the correlations obtained, which were statistically significant at least at the 0.05 level, are shown below.

COMMUNITY GROUPS

The correlation was 0.302 between the item from the 16-item priority list: 'services for people with mental illnesses (for example, psychiatric wards, community psychiatric nurses)' and the from the 5-item priority list: 'health care which improves mental health among people who are severely mentally ill'.

The 16-item priority list also contained an item on 'preventive services (for example, screening, immunisations)', and the 5-item priority list contained an item on 'health care which prevents illness among people who are currently well'. The Pearsons product moment coefficient of correlation between these items was 0.211.

Question 5, which asked for respondents' level of agreement with 9 statements, contained items on 'if someone is very ill, in pain and is going to die, it is better to let them die quickly than to keep them alive for as long as possible' and 'the health service should keep people alive for as long as possible, even if they have a very low quality of life'. The Pearsons product moment coefficient of correlation between these items was -0.157 (inverse as the items were opposing).

Good overlap between questions and items was not necessarily expected, as different question wording and the inclusion of a different number and type of items in a priority list can affect response.

THE RANDOM SAMPLE OF THE PUBLIC

The same correlations were carried out with the random sample of the public (question numbers varied according to whether it was the postal or interview questionnaire).

The correlation was 0.149 between the item from the 5-item priority list: 'health care which improves mental health in people who are severely mentally ill' and the 16-item priority list: 'services for people with mental illnesses (for example, psychiatric wards, community psychiatric nurses)'.

The correlation was 0.178 between the item from the 5-item priority list: 'health care which prevents illness among people who are currently well' and the item from the 16-item priority list: 'preventive services (for example, screening, immunisations)'.

The attitude question which asked for respondents' level of agreement with 9 statements contained items on 'if someone is very ill, in pain and is going to die, it is better to let them die quickly than to keep them alive for as long as possible' and 'the health service should keep people alive for as long as possible, even if they have a very low quality of life'. The Pearsons product moment coefficient of correlation between these items was -0.206 (inverse as the items were opposing).

APPENDIX V

Comparison of satisfaction with the NHS with British Social Attitudes Survey

The 1990 British Social Attitudes Survey shows that satisfaction with the NHS among adults in the United Kingdom had declined from earlier surveys, with 37% of adults expressing some degree of satisfaction (very or quite) in 1990 in contrast with 55% in 1983; conversely, 47% expressed some degree of dissatisfaction (very or quite) in 1990, in comparison with 25% in 1983.

Comparing these national results with those of the responses to the same question in City and Hackney, it is evident that although the proportions expressing dissatisfaction are almost identical (44% in City and Hackney and 47% nationally), the proportion of City and Hackney residents who expressed some degree of satisfaction is much lower at 22%, in comparison with 37% nationally[75,76]. This confirms the reported trend of less satisfaction with health services in London[77]. More of the City and Hackney residents than the national sample said they were 'neither satisfied nor dissatisfied', 34% in comparison with 15% in the 1990 British Social Attitudes Survey.

A greater proportion of respondents said they wanted to see improvements to the NHS than admitted dissatisfaction. This also confirms other research which distinguishes between 'satisfaction' and 'quality' questions[57].

Appendix VI Detailed priority ranks of doctors

Table 15: Hospital consultants' priority rankings of health services in Hackney (n=112-116)

	1. Essential % (no)	2. Very important % (no)	3. Important % (no)	4. Less important % (no)	Mean	Rank
Services for people with mental illness (eg psychiatric wards, community psychiatric nurses)	47 (53)	36 (40)	14 (16)	3 (3)	1.723	1
Treatments for children with life threatening illnesses (eg leukaemia)	45 (51)	32 (36)	23 (26)	* (1)	1.798	2
Community services/care at home (eg district nurses)	40 (46)	37 (42)	22 (25)	1 (1)	1.833	3
Special care and pain relief for people who are dying (eg hospice care)	40 (45)	37 (42)	22 (25)	1 (1)	1.841	4
Surgery to help people with disabilities to carry out everyday tasks (eg hip replacements)	31 (36)	46 (53)	20 (23)	3 (3)	1.939	5
Long stay care (eg hospital and nursing homes for the elderly)	32 (36)	35 (39)	27 (30)	5 (6)	2.054	6
Preventive services (eg screening, immunisations)	33 (37)	31 (35)	31 (35)	5 (6)	2.088	7
Medical research for new treatments	30 (34)	29 (33)	30 (34)	11 (12)	2.212	8
Family planning services (eg contraception)	30 (34)	23 (27)	31 (35)	16 (18)	2.325	9
Therapy to help people with disabilities carry out everyday tasks (eg speech therapy, physiotherapy, occupational therapy)	13 (15)	40 (46)	41 (48)	6 (7)	2.405	10
Health education services (eg campaigns encouraging people to lead healthy lifestyles)	20 (23)	15 (17)	42 (48)	23 (27)	2.687	11
High technology surgery and procedures which treat life threatening conditions (eg heart/liver transplants)	17 (19)	17 (20)	37 (43)	29 (33)	2.783	12
Intensive care for premature babies who weigh less than one and a half pounds and are unlikely to survive	4 (4)	8 (9)	19 (21)	69 (77)	3.541	13
Treatments for infertility (eg test tube babies)	1 (1)	6 (7)	31 (36)	62 (72)	3.543	14
Cosmetic surgery (eg tattoo removal, removal of disfiguring lumps and bumps)	——	——	16 (18)	84 (96)	3.842	15
Complementary/alternative medicine (eg acupuncture, homeopathy, herbalism)	2 (2)	2 (2)	7 (8)	89 (104)	3.845	16

Table 16: General practitioners' priority rankings of health services in Hackney (n=63-66)

	1. Essential	2. Very important	3. Important	4. Less important	Mean	Rank
Community services/care at home (eg district nurses)	65 (43)	20 (13)	14 (9)	1 (1)	1.515	1
Services for people with mental illness (eg psychiatric wards, community psychiatric nurses)	53 (35)	36 (24)	9 (6)	2 (1)	1.591	2
Long stay care (eg hospital and nursing homes for the elderly)	43 (28)	40 (26)	12 (8)	5 (3)	1.785	3
Special care and pain relief for people who are dying (eg hospice care)	41 (27)	38 (25)	20 (13)	1 (1)	1.818	4
Treatments for children with life threatening illnesses (eg leukaemia)	42 (27)	27 (17)	27 (17)	4 (3)	1.938	5
Preventive services (eg screening, immunisations)	38 (25)	34 (22)	22 (14)	6 (4)	1.954	6
Therapy to help people with disabilities carry out everyday tasks (eg speech therapy, physiotherapy, occupational therapy)	26 (17)	44 (29)	27 (17)	4 (3)	2.076	7
Surgery to help people with disabilities to carry out everyday tasks (eg hip replacements)	25 (16)	45 (29)	29 (19)	1 (1)	2.077	8
Family planning services (eg contraception)	18 (12)	28 (18)	42 (27)	12 (8)	2.477	9
Health education services (eg campaigns encouraging people to lead healthy lifestyles)	21 (14)	26 (17)	36 (24)	17 (11)	2.485	10
Medical research for new treatments	6 (4)	12 (8)	46 (30)	36 (24)	3.121	11
High technology surgery and procedures which treat life threatening conditions (eg heart/liver transplants)	11 (7)	8 (5)	33 (22)	48 (32)	3.197	12
Intensive care for premature babies who weigh less than one and a half pounds and are unlikely to survive	8 (5)	11 (7)	25 (16)	56 (35)	3.286	13
Treatments for infertility (eg test tube babies)	5 (30)	6 (4)	32 (21)	57 (38)	3.424	14
Complementary/alternative medicine (eg acupuncture, homeopathy, herbalism)	6 (4)	3 (2)	24 (15)	67 (42)	3.508	15
Cosmetic surgery (eg tattoo removal, removal of disfiguring lumps and bumps)	1 (1)	— —	11 (7)	88 (57)	3.846	16

Table 17: Public health doctors' priority rankings of health services (n=4-6)

	1. Essential	2. Very important	3. Important	4. Less important	Mean	Rank
Community services/care at home (eg district nurses)	5	—	1	—	1.333	1+
Services for people with mental illness (eg psychiatric wards, community psychiatric nurses)	4	2	—	—	1.333	1+
Family planning services (eg contraception)	4	2	—	—	1.333	1+
Preventive services (eg screening, immunisations)	5	1	—	—	1.167	2
Therapy to help people with disabilities carry out everyday tasks (eg speech therapy, physiotherapy, occupational therapy)	2	4	—	—	1.667	3++
Health education services (eg campaigns encouraging people to lead healthy lifestyles)	3	2	1	—	1.667	3++
Surgery to help people with disabilities to carry out everyday tasks (eg hip replacements)	3	2	1	—	1.667	3++
Special care and pain relief for people who are dying (eg hospice care)	1	4	1	—	2.000	4
Treatments for children with life threatening illnesses (eg leukaemia)	2	1	3	—	2.167	5
Long stay care (eg hospital and nursing homes for the elderly)	1	1	4	—	2.500	6
Medical research for new treatments	1	—	4	1	2.833	7
High technology surgery and procedures which treat life threatening conditions (eg heart/liver transplants)	—	2	2	2	3.000	8
Complementary/alternative medicine (eg acupuncture, homeopathy, herbalism)	—	—	1	5	3.833	9+++
Cosmetic surgery (eg tattoo removal, removal of disfiguring lumps and bumps)	—	—	1	5	3.833	9+++
Intensive care for premature babies who weigh less than one and a half pounds and are unlikely to survive	—	—	—	4	4.000	10++++
Treatments for infertility (eg test tube babies)	—	—	—	6	4.000	10++++

+ Joint rank of 1
++ Joint rank of 3
+++ Joint rank of 9
++++ Joint rank of 10

What people say about
PRIORITISING
health services

The changes in the NHS mean that clinicians will have to accept the need for explicit rationing, rather than shirking the issue with reference to clinical decision-making. The current system of implicit rationing will be replaced by one which bases resource allocation on explicit criteria. But how are those criteria to be prioritised? And who should be involved in making those decisions?

In the first study of its scale in the United Kingdom, Dr Ann Bowling and her colleagues set out to discover what 'ordinary' people think by conducting detailed surveys of residents of the City and Hackney Health Authority area and the doctors who serve them.

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