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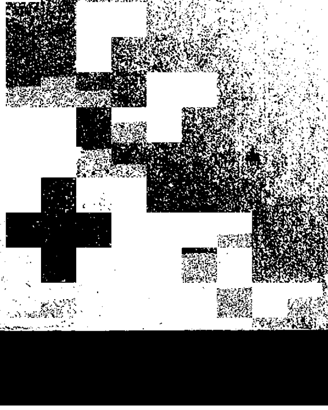
LONDONERS' VIEWS ON THE FUTURE OF HEALTH CARE



Londoners' Views on the Future of Health Care

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With the assistance of Tina Posner and John Philo

King's Fund Institute

for the King's Fund Commission
on the Future of Acute Services in London

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EXECUTIVE SUMMARY

The object of this study was to collect information which embraced the richness and complexity of people's views on London's health care services to contribute to the King's Fund's work on London's acute services. Discussion groups were selected as the most useful means of collecting such data and a total of 17 groups were held with a purposeful sample of London's population. This report provides a detailed picture of the ways in which respondents would like to see their health care services develop in the future.

In broad outline, respondents would like to see:

- London's future health care services continuing to be provided for most people by the NHS.
- Closer co-operation between primary and secondary care, between health and social care, and between various specialist health services, so that patients receive a 'seamless' and more 'holistic' service.
- Well resourced central hospitals as 'centres of excellence' to provide services for medical conditions and emergencies requiring a high degree of specialist equipment and/or medical expertise.
- An expanded form of primary health care, offering facilities for minor surgery, specialist clinics, social care and community support.
- Resources increased to reduce waiting times for admission to hospital.
- The 'care' element injected back into health services, and, especially, the increased technology of specialist nursing counterbalanced by more emphasis on the care and comfort of the patient.
- Patients given more information about their specific illnesses and treatment. Also, patients to be kept informed about reasons for delays in being called for treatment or for extended waiting times at out-patient clinics.
- Enhancement in the quality and status of care in what are often described as the 'cinderella services' (such as geriatric and mental health services).
- Recognition of the importance that patients place on developing a good relationship with their doctor. Realisation that consistency in seeing the same doctor is an important factor in building up confidence and satisfaction with health care.

- More attention given to patients' and relatives' anxieties and emotional needs. The provision of counselling services through the NHS and with access in the primary care setting.
- A recognition by health care professionals that users of health services are from diverse religious and ethnic backgrounds and may, therefore, differ in their health care and information needs.
- A consideration of how complementary treatment can be provided within the NHS.
- Medical staff developing contacts with and increasing their knowledge of self-help groups to facilitate patient access to their services and support networks.
- Health promotion programmes taking account of the effect on people's lives of poverty, poor housing and limited access to those services which contribute to people's sense of well-being, e.g. leisure and educational activities.
- Health education for children and young people introduced at a sufficiently early age to inform their decisions on lifestyle choices. Health professionals being involved in providing information and guidance in schools on sexual health issues.
- Recognition that health care users and professionals have equally valid and valuable contributions to make to the debate on health care policy and priorities.
- The establishment of an independent and impartial body to investigate complaints, which includes a facility for receiving complaints verbally as well as in writing.

CHAPTER 1 Introduction

Origins and aims of the project

In June 1991 the King's Fund London Acute Services Initiative invited the London Research Centre (LRC) to conduct a qualitative research study of Londoners' views on the future of health care in the capital. This invitation followed a widely held opinion in the Fund that the work of the Initiative needed to be informed by insight into the views of London residents (Beardshaw and Judge, 1991).

The aims of the study were:

- to explore in depth Londoners' views on the future of health care in the capital;
- to identify differences in these views between various population groups;
- to explore how views might affect current and future use of London's health services.

Project development

The research study began in September 1991. A preliminary report outlining some of the key findings emerging from the fieldwork up to that date was presented to the King's Fund in January 1992.

This final report incorporates and expands on those preliminary findings and presents the full results and conclusions of the completed fieldwork.

Drawing on a literature review, this report also provides a research context for the study and discusses the merits and limitations of the chosen qualitative research method.

When commissioned, the LRC study was planned to complement the work of two other studies on Londoners' views commissioned by the King's Fund at around the same time – the Greater London Association of Community Health Councils' (GLACHC) report on London's acute health services from a user perspective (GLACHC, 1992) and a quantitative opinion survey carried out by OPCS and co-ordinated and analysed by the King's Fund Institute (Solomon, 1991; Judge *et al.*, 1992; Solomon, 1992; Judge and Solomon, 1993). Where appropriate, reference has been made in this report to the findings and conclusions of these two studies.

A note on terminology

When funding this study, the King's Fund's primary interest was in obtaining views on acute services. Acute services have been defined as comprising 'those processes of diagnosis and forms of care which respond to acute episodes of illness and injury', and so include most hospital-based specialities and many aspects of primary care (SETRHA, 1991). Furthermore, the King's Fund sees its role as considering acute services within the broader context of health and social care, including provision for chronic illness and disability (Beardshaw, 1991).

It is clear that people do not categorise their experiences of illness or their views of services according to professionally and administratively defined service boundaries. So while care was taken in the setting up of this study to ensure that respondents had experience of a range of acute services according to the above definition, the fieldwork discussions have allowed and followed participants' self-definitions of service boundaries and categories.

Terms such as 'Londoners', 'people', 'the public', 'respondent' and 'participant' are primarily used in this report to refer to those individuals whose views are being sought rather than 'user', 'patient', 'citizens', 'customers' or 'consumers'. The terms 'customer' and 'consumer' have been avoided because they tend to suggest a particular (essentially market-led) relationship between those who provide and manage services and those who receive them (see pages 20–21) (Winkler, 1991). This study is interested in people's views beyond their direct experience as 'patients' or 'users' of health services – it is interested in their views as carers or relatives, and as citizens with wider concerns about public expenditure and the role of public services in achieving a balance between differing interests (McIver, 1992; Stewart, 1990).

We also decided to use the term 'complementary' rather than 'alternative' medicine to describe services such as homeopathy and acupunture, as this more adequately describes how these services were viewed by many of those participating in the group discussions.

The relevance and limitations of exploring public views

There are a number of important reasons for studying public views on the future of health care in London.

As a counterbalance to professional views

Lay views can provide a useful counterbalance to professional views and help to minimise the dangers of what Berger has described as 'cognitive imperialism' (Berger, 1977). Through its work on London's acute services, the King's Fund has gathered a mass of professional views on how London's health services should develop into the next century. While not wishing to underplay the crucial contribution of professional views to policy and service development, professional definitions of problems and need may well be very different from the concepts and views of those actually experiencing health services as recipients of care.

Wilding argues that all too often in the social welfare field it is professional definitions 'which determine the pattern and direction of services and, as gate-keepers to those services, the professions are able to impose particular constructions of social reality on those who seek to use them' (Wilding, 1982).

Researching public views enables policy makers and service providers to find out what people want from health services in the future, rather than simply relying on professional definitions of need. This is not to argue that public opinion should be the sole basis for service and policy development, but rather that it should form a significant component within the decision making process.

Public services and consumerism as a central policy issue

A second reason for studying Londoners' views is that Government health policy in the UK has increasingly placed 'the consumer' of services at the forefront of debate, most recently in the publications 'Working for Patients' and 'Caring for People' (Department of Health, 1990a and 1990b; see also DHSS, 1979; Griffiths, 1983; Cumberlege, 1986) and in the 'Patient's Charter'. More generally, consumerism within the public sector has become a major preoccupation of governments throughout Europe (Epstein, 1990).

A growing number of commentators are concerned that this emphasis is more to do with advancing a rhetoric of consumerism than with significant change in the way health services are planned, managed and delivered so as to take public views into account (Williamson, 1988; Winkler, 1987). These criticisms are outlined on pages 19–20.

Exploring ways of improving public participation

Thirdly, research into Londoners' views is important because indirectly it may contribute to a process of greater public participation in health service development. It can contribute by exploring people's views on participation and by identifying possible strategies for greater participation in the future. Greater public participation in health service development is a key objective of the World Health Organisation's Health for All Strategy (which the UK has officially endorsed). The World Health Organisation states that: 'the people have the right and duty to participate individually and collectively in the planning and implementation of their health care' (WHO and United Nations Children's Fund, 1978).

The effect of public perceptions on the use of services

Finally, public perceptions of health services and related health beliefs are likely to influence levels of use of those services. Research on lay views can therefore contribute useful insights into what medical sociologists refer to as 'illness behaviour' (although care has to be taken not to assume that present attitudes and beliefs are predictors of future behaviour (Judge and Solomon, 1993)).

This report aims to address such questions as: how might people's views about complementary therapies affect their use of orthodox NHS services? Is there increasing support for private health care provision, and what might be the implications for use of NHS services? Is it possible to detect shifts in the size and shape of the 'clinical iceberg' (the amount of ill health that is brought forward for treatment relative to the amount of ill health in the population), and what might be the implications for levels of demand upon services?

Limitations of exploring public views

As well as the benefits outlined above, there are also a number of conceptual and practical difficulties associated with exploring people's views on the future of health services. Recognition of these difficulties underlines the need for an appropriate and sensitive interpretation of the research findings.

The conservatism of public views

Some commentators have suggested that people's views are liable to take existing patterns of life as given and thus the findings on public attitudes tend to exhibit an inbuilt conservatism (Shaw, 1978). However, this is a limitation which can apply equally to professional as to public views and conceptions. Also, the rate of change within society and the impact of the media (particularly television) have meant that people's awareness of other experiences and patterns of life has tended to erode this perceived conservatism.

The influence of professional views on public views

Given the pervasiveness of professional ideologies in society, it has been argued that lay views are likely to be shaped to a considerable extent by dominant professional definitions. For example, Cornwell's research of accounts of health and illness from East London residents suggested that in absorbing the ideas and values of the dominant sections of the medical profession, lay people have learned to undervalue preventive and community services which are exactly the parts of the health services that official health policy is now attempting to promote (Cornwell, 1984).

Research as a diversion from other channels for feedback

Although research into people's views may be able to contribute to public participation in health as indicated above, there is a danger of it having the opposite effect. If the research process is perceived by respondents as being an end in itself rather than a means of effecting user-oriented change, then it may be perceived as exploitative and risk pushing people further from, instead of nearer to, an active involvement in health service and policy development.

It has been suggested that health authorities' current reliance on market research into patient satisfaction, combined with their increasing reluctance to involve and develop community health councils, may result paradoxically in services becoming less accessible to locally initiated public pressure and change (Saunders and Pinder, quoted in Shearer, 1991).

Thus, it is important that research into the views of individuals is placed and promoted in the context of the full range of available political and organisational channels for feedback and representation (for example, through complaints procedures, representation by community health councils, media reports and campaigns, pressure group activities, and voting in general elections (Jones *et al.*, 1987)).

As well as seeking views on health care services, this study explored people's views of and demands for user involvement in policy development and service management and the channels for representation and complaint. In order for the study to be participative, rather than concerned solely with the collection and analysis of public views, as far as possible, those participating in the discussion groups received feedback on the research findings.

A 'gratitude barrier'?

Finally, some commentators have argued that a 'gratitude barrier' exists in users' assessment of their health care services, and that this creates an impediment to using opinion data to measure satisfaction with quality of services (Winkler, 1991). However, others believe that users (and, particularly, those in the younger age groups) are no longer inclined to be as grateful or as accepting of public services as they were in the past (Shearer, 1991), and argue that research into public views need not see the 'gratitude barrier' as the problem that it perhaps once was. This issue is discussed in the context of our findings on pages 64–65 and in Chapter 5.

CHAPTER 2

Research methodology

Qualitative techniques

An important premise of this study was that qualitative research techniques have an important contribution to make in eliciting valid data on public views about the future of London's health services. The term 'valid' is used here to refer to how closely information gathered represents a 'slice of reality' (McIver, 1991a). Within medicine and health care research, the dominance of a biomedical model of science has meant that qualitative methods are still under-utilised (Dingwall, 1989). However, there is growing recognition that quantitative data on its own often produces a limited understanding of how people think, feel and decide about health care matters, and there is increasing acceptance that qualitative data is authentic data in its own right.

In the context of this study, qualitative methods have the following main advantages:

They are *naturalistic*. Qualitative methods record user views as they are and do not set the parameters within which respondents must reply (as is intrinsic to quantitative instruments such as precoded questionnaires). They enable respondents to define for themselves a range of issues and attach their own sense of relative importance to them. They do not preset the range of possible responses or results. The naturalistic feature of qualitative methods is particularly important in examining the views of minority groups of users; given that differences between lay and professional views are likely to be compounded by differences in class, ethnicity and gender (see pages 64–66).

They are *inductive*. Qualitative methods begin by exploring open questions rather than testing theoretically derived (deductive) hypotheses. Thus, they build up a picture of people's views based upon specific experiences in a particular situation and classification only takes place after the data are recorded. This allows new issues to emerge through the research.

They are *holistic*, i.e. they look at views expressed as a whole and in the context of people's lives. The relationships between different strands of opinion and how they may interact can be elucidated. Qualitative techniques aim to uncover factors that illuminate the 'why' of what is being revealed.

Finally, it has been observed that qualitative material is likely to be more persuasive to policy makers and has a greater prospect of producing action (Patton, 1990).

Offsetting these benefits, there are limitations. The main one is that qualitative methods are generally not appropriate for measuring the scale of phenomena; they cannot show the precise extent to which a particular view may be held. Thus, there are limits to the extent to which qualitative findings can serve as a basis for generalisation. However, even this is not an absolute limitation. In the current research, 146 people took part in 17 discussion groups and it is likely that any views that they may share will be common to a much wider range of people.

The advantages of discussion groups

The discussion group, led by an experienced facilitator, was chosen as the most appropriate qualitative research instrument for eliciting people's views on health service issues. There are a number of advantages in the discussion group format.

Participants can develop ideas through interaction with others

In this study, the issues being explored were complex and the research attempted to tease out frequently unformulated patterns of thought. For example, the development of the health service over the next 20 to 30 years is not a topic on which participants are likely to hold readily articulated views. The discussion group format, however, enables participants to develop their views through interaction with others. In a group, participants may 'find their experiences given shape and form in the words of others, and so be better able to express their own views' (McIver, 1991b).

Discussion facilitates the generation of new ideas

Discussion groups are creative and lead to the generation of new ideas. The participants are given the opportunity to discuss the 'ins and outs' of a situation and to describe their own specific experiences. This process can result in respondents suggesting ideas which are taken up and explored by the rest of the group and, subsequently, may be developed into recommendations for policy or action. Likewise, various service scenarios can be discussed and preferred options identified by participants.

Enables the discussion of sensitive issues

Through the approach of the facilitator and the form of the discussion, the groups should provide a 'safe' and supportive environment in which people can express their views about extreme experiences or on sensitive or potentially embarrassing topics. At the beginning of the discussion, the participants may be reluctant to describe their very personal experiences or opinions. However, as the discussion progresses, participants discover that many of their experiences are shared by others and they gain the confidence to describe how ill-health, bereavement and other intensely personal issues have affected them.

Encourages 'private and public' accounts

For similar reasons to those described above, discussion groups are of value in enabling participants to express views which they may not consider to be strictly compatible with the views of health care professionals. Cornwell's research into lay health beliefs among people in East London (Cornwell, 1984), as mentioned in chapter 1, discovered that there were differences between what she called people's 'public and private' accounts of health and illness. 'Public' accounts, in general, drew attention to aspects of respondents' experiences and ideas which they believed would be acceptable to doctors and compatible with a medical perspective. 'Private' accounts, on the other hand, included what might be thought by respondents to be medically unacceptable and incompatible with medical opinions and values. Cornwell concluded that a fuller picture of views on health can be obtained by exploring both types of accounts.

Our previous experience with discussion groups suggests that participants feel more confident about expressing views which they think the medical profession would consider unacceptable when they hear others expressing similar views. In a one-to-one interview, respondents may be less willing to express such views as they are alone with the interviewer, whom they perceive as a 'professional' rather than a 'lay' person.

The selection of discussion groups

The objective of this research was to collect information that reflected the richness and complexity of people's views and opinions on London's health care services. This objective, and the advantages of discussion groups identified above, were more likely to be achieved by collecting data from groups which already had some established identity (i.e. comprised individuals who shared a common interest or concern and had usually met previously as a group).

In selecting discussion groups, therefore, it was considered most appropriate to adopt a process which Patton refers to as 'purposeful sampling' (Patton, 1990) whereby 'information-rich' cases are selected on the basis of identified areas of interest. For this study, the sampled cases are groups rather than individuals.

In consultation with a King's Fund advisory group, the following categories were selected as identified areas of interest for the study: general users of the NHS (including young people); frequent or 'expert' users of specific services (for example, people with diabetes); frequent users of a diverse range of services (for example, elderly people); those using services on behalf of others (for example, carers), and users of 'complementary' health services. With regard to the 'expert' users of services, a wide range of different medical specialities was identified (see Appendix 1).

There was also a concern to select groups that would include people from a range of population groups in terms of age, social class, gender, ethnicity and area of residence (within London).

As a common feature of this kind of research method, the process of selecting and setting up individual discussion groups was complex and time consuming. Within the framework of the categories described above, a large number of organisations and individuals were contacted and asked whether they would be interested in taking part in the research. These included many of the voluntary organisations listed in the 'Health Directory' (Macdonald, 1990); health centres; educational establishments; social services departments; and organisations working with lesbians and gay men. In some cases, meetings were arranged with staff or committee members to discuss the project in greater detail.

Where organisations held a regular monthly or quarterly meeting, it was often possible to arrange for one such meeting to be allocated to our discussion. In other cases, a special meeting was called and interested members, patients or clients etc. were asked whether they would like to attend. Some organisations asked that a short talk about the research be given at a meeting, already timetabled, and this talk was concluded with a request by the researchers for possible discussion group participants. Other organisations placed an advertisement in their newsletter or on a notice board in their club or clinic suggesting that interested participants contact us.

In addition, discussions with the National Community Health Resource (NCHR) resulted in a leaflet, circulated with their newsletter, which described the purpose of the project and gave recipients the opportunity to contact the research team and arrange to participate in one of the discussion groups. This leaflet was circulated to all community health initiatives in and around London on NCHR's mailing list, including women's groups and those groups working with black and ethnic minorities. Many of the organisations contacted through the NCHR newsletter expressed an interest in assisting with the study and the research team provided more information and details on how a discussion group could be set up or attended.

Although every effort was made to include as wide a cross section of people in the group discussions as possible, the process for selecting the groups, and the fact that attendance was voluntary, meant that the majority of participants were people who join voluntary organisations, belong to patients' groups or had responded to written requests to take part in consultations. Thus, the groups which were finally formed should not be considered as 'typical' of the population as a whole nor should it be assumed that the views they expressed will necessarily be shared by others in similar situations or locations. Nevertheless, in keeping with the aims of the research, the groups provided information-rich cases according to the identified areas of interest. Given the qualitative nature of this research, it is important that the findings are considered alongside, and in the context of, other relevant studies. Where possible, such studies have been identified thoughout this report.

For a number of reasons, some of the group discussions we attempted to arrange did not take place. In the first place, our initial approach for setting up the group could be received enthusiastically by one member of an organisation but rejected or less favourably considered by others. For example, one general practitioner agreed, if his partners approved, to write to all his patients asking if they would be interested in taking part in the research. His partners, however, felt that this was an invasion of their patients' privacy and that it would place them under undue pressure to take part. As a consequence, this discussion group did not go ahead. Secondly, people who were seriously ill and/or disabled found it very difficult to attend a group discussion or even to reply to a request to take part in the research. For example, the HIV/Aids group and one of the mental health groups could not be held because the ill health of the potential participants prevented their attendance, despite the strong wish of some members to take part. Thirdly, provisional arrangements to hold a discussion group were made with some organisations whose membership was very scattered and seldom met. Despite the offer of a financial contribution towards travelling expenses, it proved difficult for some of these organisations to persuade a sufficient number of people to participate and for the discussion group to take place within the timescale of the study.

Despite the difficulties outlined above, a total of 17 discussion groups were held, at which 146 people attended. A descriptive list of the discussion groups is provided in Appendix 1 with the distinguishing feature of each category of user and the rationale for their selection.

Discussion group attendance

To provide basic statistics of group attendance, each participant was asked to complete a short questionnaire covering personal details, such as age, ethnic origin, gender, socio-economic and health status. In addition, participants with carers' responsibilities were asked to provide details of the cared for person. The statistics and descriptive analysis on those attending the group discussions and, where relevant, those they cared for is provided in Appendix 2.

Discussion approach and format

The discussion groups lasted between one and a half and two hours. Each group met only once because previous experience has shown that properly facilitated, this is often the most effective way of obtaining information, stimulating ideas and maintaining the active interest of participants.

The format for each session was set by a structured schedule which was used to introduce topics for discussion. This schedule was pretested through a specially convened pilot group. The aim throughout was to stimulate discussion and generate ideas rather than just to obtain answers to specific questions.

The schedule included the following topics: hospital services, primary care, complementary therapies, health promotion and education and self-care, access to information, consultation processes, complaints procedures, private health care, and participants' priorities for future health care services in London.

The discussions were led by an experienced facilitator from the research team and attended by another of the researchers who noted the main points of the discussion. In addition, all the discussions were recorded and transcribed as necessary to enable analysis.

Each of the groups participating in the study was provided with a summary of the research findings.

CHAPTER 3

Approaches to analysing views on the future of health care

A review of relevant literature suggests that it is possible to identify three main theoretical approaches to analysing views on the future of health care: a consumerist approach; a social context approach; and an organisational/political process approach. Previous conceptual and empirical work has tended to follow one or other of these approaches.

Consumerist model

There is an approach that primarily sees the public as 'consumers' of health care or 'customers' of the health service. This approach has dominated the majority of those patient satisfaction surveys which have become increasingly popular in the last decade as exercises in quality assurance, audit and the marketing of health care (Carr-Hill *et al.*, 1989; Jones *et al.*, 1987).

The surveys have tended to focus on user satisfaction rather than preferences. The approach is useful for looking at immediate reactions to services. Also, satisfaction surveys have provided some valuable material on which aspects of service provision are most in need of improvement and have raised crucial issues about the accessibility of services (Jones *et al.*, 1987).

However, the consumerist approach has been heavily criticised for offering a limited, and some would say an inappropriate, vision of the relationship between the public and the NHS: 'The NHS is now encouraged to see its users in the same way as supermarkets ... The supermarket vision of customer relations extends to reducing the waits at the check-out counter and exchanging faulty goods with the minimum of questions asked. It does not extend to inviting the customers on to the board nor to consulting them about investment or even about what should be on the shelves, let alone in their products' (Winkler, 1991).

These criticisms draw attention to the crucial distinction between 'consultation' and 'opportunity to influence' (McIver, 1992)(see page 56). On the whole, the consumerist approach has failed to provide data on people's views concerning the broader role of the NHS in public service provision. It tends to ask questions of people as individual consumers of goods rather than as citizens with views about collective needs and equity of provision.

The introduction of market principles to the provision of health services and the emphasis on the need for consumer advice in government policies carry with them the assumption that consumers have the information with which to make a choice and will look around for the 'best buy'. The relevance of an economic cost-benefit calculus to the individual's decision-making process about health care has been shown by studies within the social context to be limited (Cant and Calnan, 1992).

Social context model

This approach is more common in sociological studies of public views. It looks not only at what people's views are but also at why they hold particular views and explores the reasons for differences in attitudes, use and experience of services; and how these differences are affected by class, ethnicity and gender. Some studies are based upon anthropological methods with an emphasis on social processes. They attempt to grasp how the different elements in people's lives are integrated (Cornwell, 1984; Davison *et al.*, 1991).

In this approach, views on health services are seen as one part of more general views and beliefs about health which, in turn, are one aspect of people's views about life in general. It has produced illuminating material on various health belief models (Herzlich, 1973; Blaxter, 1979; Pill and Stott, 1980); on the relationship between lay and formal health care systems (Friedson, 1970); and how these factors and others determine health and illness behaviour (Scambler, 1991).

Organisational/Political Process Model

This approach explores people's views within the context of organisational structures and processes and can be found particularly within the social policy literature relating to health care. For example, studies of professional power are useful in exploring the negotiation of doctor-patient relationships (Wilding, 1982); while studies of organisational and political demands within health care have contributed to an understanding of issues such as 'gatekeeping' as a form of rationing, and problems in discharge planning (Russell and Brenton, 1989). The distribution of health care between social groups, health care client groups and geographical regions has also been an important focus of such studies.

User involvement can be analysed at different organisational levels: at the level of the individual participant; at the collective level, for example involving self-help groups; and at the representative level involving the health authority or the community health council.

CHAPTER

4

Findings

This major section explores the findings from the discussion group data presented in the context of data from secondary sources drawn from relevant literature. We have grouped the findings under key themes as they emerged from the discussion data. These are: overall impressions of London's health services, the organisational structure of London's health services and the process of care, inter-personal communication and information needs, complementary health care, health promotion and education, user involvement in health care planning and delivery, the funding of London's health services, and Londoners' health care priorities. The implications of the findings for the future development of London's health services are also explored. In the main, we have focussed on general patterns to emerge from the discussion group data. However, where possible, we have drawn attention to differences between groups, and between individuals within groups, and have attempted to identify possible factors contributing to these differences. Furthermore, at the end of this chapter we draw together our findings on age, gender, class and ethnic differences.

Overall impressions of London's health services

Over the last ten years, many surveys of public opinion of the NHS have shown that feelings of dissatisfaction with the running of the NHS as a political institution are far more widespread than discontent with specific services. However, the work of Judge and Solomon (1993) has shown that public opinion survey data requires careful interpretation as there are many factors influencing the expression of satisfaction levels. The specific wording of the questions and the context in which questions are asked will have a bearing on the results and appears to account for differences between surveys in terms of the proportions of respondents expressing dissatisfaction.

Coverage of relevant issues in the media can also influence the expression of public concern, and may help to explain differences recorded for levels of overall satisfaction with the NHS (Solomon, 1991; Judge *et al.*, 1992).

The British Social Attitudes Survey (BSAS) regularly asks people about their levels of satisfaction with the NHS in general and with specific services. Between 1983 and 1990, the proportion of BSAS respondents reporting dissatisfaction with the running of the NHS nearly doubled from 25% to 47% (Jowell *et al.*, 1987-1990). The National Association of Health Authorities and Trusts (NAHAT) and the Health Service Journal (HSJ) annual surveys have also found increasing levels of dissatisfaction with the NHS as an institution during the 1980s. However, the proportions of respondents expressing dissatisfaction in the NAHAT/HSJ surveys have been lower (between 10% and 17%), perhaps because they were asked specifically about health services in their area.

In 1991 and 1992 the King's Fund commissioned the OPCS to include questions about aspects of the NHS in their Omnibus surveys. These questions focussed on those aspects of the health service with which people were most dissatisfied and particular services felt to be most in need of improvement. Identical questions about satisfaction with the NHS to those used in the BSAS were included in the OPCS surveys conducted in August and November 1991 and February and May 1992. A fluctuating level of dissatisfaction was found, with the average level being about a fifth of respondents, compared to 47% in the BSAS 1990 survey. According to Solomon (1991), the lower level of dissatisfaction in the OPCS surveys is a result of questions being asked in a health care context and immediately after references to respondents' own state of health and use of services.

Other opinion polls seem to show that overall dissatisfaction with the health service is rising. The *Health Service Journal* (reporting on the annual NAHAT/HSJ surveys) suggests that 'fewer people now have a good opinion of the NHS than at any time in the past five years' (Davies, 1990). A Gallup poll for the *Daily Telegraph* carried out in November 1991 found that 'people believe that the quality of the service has deteriorated, is deteriorating and will continue to deteriorate if the [government] stay in power' (*Daily Telegraph,* 11 November 1991).

Various demographic, health status and regional characteristics have been demonstrated to be significant predictors of satisfaction with health services. For instance, younger people, people classified as 'non-white' and people in higher social classes are more likely to express dissatisfaction. Moreover, of particular relevance here is the finding that people living in London and the south-east of England are, other things being equal, more likely to report dissatisfaction with health services (Judge and Solomon, 1993).

Although the levels of satisfaction expressed for the NHS as a whole have varied between surveys, the pattern of dissatisfaction with individual services has been consistent. Most dissatisfaction has been expressed in relation to hospital services and, particularly, out-patients. Between 1986 and 1990, BSAS found between 28% and 30% of respondents dissatisfied with hospital out-patient services (Judge *et al.*, 1992). The most satisfaction was expressed about the quality of care received from general practitioners and hospital medical personnel (Solomon, 1991; 1992).

The findings from our research support the conclusions of Judge and Solomon in arguing for cautious interpretation of satisfaction data. From our discussion groups it appears that people's views are specific to each experience/contact they have. So while individual participants were satisfied with some parts of the health service, they were dissatisfied with others; also they were satisfied with some episodes of treatment, and not with others:

> *People have very different experiences, I know, but mine was very good. I had a heart attack about five years ago and I can't fault the service at all – but I know that hasn't been how some people have felt. Even at the same hospital – on the same ward, they vary. And I know they vary over a period of years.*
>
> (participant with diabetes)

> *My experience is that things have not gone from bad to worse ... but people's experiences are very personal – different people can have good or bad experiences of the same hospital, ward or clinic ... perceptions can depend to some extent on what you are expecting.*
>
> (participant in complementary users' group)

> *... I think it all depends – which hospital you are attending, which department, which ward – the attitude of the doctors – when it comes down to it, it's all our individual experiences.*
>
> (participant in elderly group)

Although many of the views recorded in the group discussions were critical of services, these criticisms were made in the context of support for NHS-provided services. Without exception, the participants endorsed their commitment to London's future health care services being provided for most people by the NHS:

> *The NHS is the most valuable thing we can ever have and we should fight for it tooth and nail ... and the money should be made available to improve it – that should be a top priority.*
>
> (participant in mastectomy group)

Participants expressed strong views that they did not want the NHS of the future to provide only a 'safety net' service for a minority unable to take advantage of private health care. These views were expressed by all types of users, irrespective of their economic and family circumstances, and whether they had direct experience of private health care. A full discussion of participants' views on the future provision of health services by the NHS and the role of private health care is covered on pages 56–62.

The organisational structure of London's health services and the process of care

A number of key themes emerged from the discussions concerning the organisational structure of health services and the process of care.

A seamless, holistic service

Participants want policy-makers and service providers to give greater recognition to the inter-relationship between primary care and secondary care, between health and social care and between various specialist health services, so that patients can receive a 'seamless' or 'holistic' service.

Participants commented on the need for closer liaison and better co-operation between hospital specialists, general practitioners and support services. In particular, discharge from hospital was identified as a particular instance where co-ordination of services needs to be improved significantly. One discussion group identified that co-operation is weakest between social services departments and general practitioners' practices.

In recognition of this need, the GLACHC report on Londoners' views commissioned by the King's Fund argued for improved communication between health authorities, local authorities and Family Health Services Authorities (FHSAs) (GLACHC, 1992). It recommended systems of joint planning and liaison, and the allocation of responsibilities between sectors 'in order to prevent the further fragmentation of services and to ensure the close integration of primary, secondary and social care'. The report's foreword suggests that its studies of acute care for older and single homeless people illustrate the interlinking between physical, emotional and psychological well-being. It stated: 'while it may be administratively convenient to approach acute services as if they were clearly delineated, in fact users know that acute services must be seen as part of a continuum of care which includes primary and community services and continuing care. Users also know that it is futile to try and understand their needs by looking only at health services in isolation from social services and domestic support'.

The identification of shortfalls in the provision of satisfactory care on discharge from hospital for frail elderly people led Russell and Brenton (1989) to argue that policy-makers had avoided the 'fundamental task of tackling the institutional and professional blockages that impede a smooth transition from hospital to home'. A co-ordinated policy for frail elderly people encompassing social care, health and housing has never been developed and responsibilities remain fragmented and disjointed. Marks (1992) recently concluded that this lack of co-ordination manifested itself in 'ambiguities over the transfer of responsibility from hospital to home care'.

The group discussions with elderly people and those caring for elderly relatives emphasised the importance of a continuum of care and support (see the findings in the sub-section below on 'greater community support and care'). There was criticism of the lack of recognition that there are many people living alone and without a wide network of informal care and support to meet short-term or long-term needs. The problems people identified through the group discussions were to do with the levels of care and support available within the community and also, at a very practical level, with the physical transition from hospital to home. Some participants identified that the problems for them had begun with trying to secure adequate and appropriate transport to reach their home, either on discharge as an in-patient or after attending an out-patient clinic:

> *There doesn't seem to be any proper co-operation or liaison between the hospital and the transport service. We were waiting for an ambulance to take us home from quarter to three to five o'clock and then we were told that we wouldn't get one because the service had finished. In the end, we*

> *had to get an ambulance car but my wife was very ill and it was very upsetting and quite unsuitable.*
>
> (participant in elderly group)

> *All you get from the staff is – are you still here ? – are you still here ? – what do they expect you to do – fly home!*
>
> (participant in carers' group)

Commenting on the current practice of early discharge from hospital, many participants felt neglected because 'it was no one's responsibility to ensure that care would be provided':

> *My daughter's just had an operation in hospital on her thyroids – and they just sent her home, there was no aftercare at all – all they said was see you in six weeks. The scar was weeping and all that. She went to her own doctor and he said I can't do anything – you'll have to go back to the hospital. What they should have said at the hospital is – we'd like to see you in a week to see that everything is OK.*
>
> (participant in elderly group)

> *The attention I got in the hospital I couldn't fault, but the lack of information and help afterwards when I was at home – that's when you really need it because in hospital you are cushioned – but when you come out and you get home and it's all terribly quiet, that's when you need the support.*
>
> (participant in mastectomy group)

> *My friend was amazed about the lack of support and continuing care to convalesce after she had left hospital. She got in touch with an alternative practitioner and, if it wasn't for her, she does not think she would be strong enough yet to walk around her own house.*
>
> (participant in complementary users' group)

Participants also questioned 'whatever happened to convalescence?' In general, participants expressed a strong desire to see a return to a health service that 'really cares for patients', and providing access to adequate convalescence was identified as an important ingredient of such care:

> *after [my] operation ... I went for convalescence – but that's another thing they [the NHS] don't do now – I had to find and pay for my own. I couldn't go home – I couldn't rest at home ... I was still emotionally drained.*
>
> (participant in colitis/Crohn's group)

Not all the experiences were negative, however, and some participants praised the excellent care and attention they or their relatives had received from medical staff both in hospital and on discharge:

> *My mother-in-law recently went into hospital to have a mastectomy and the attention she got was absolutely extraordinary – she got regular visits from the breast care nurse, before the surgery and right the way through and all the exercises she should be doing. And when she was discharged a list of telephone numbers to contact. So it can be done.*
>
> (participant in mastectomy group)

Centres of excellence

Many participants emphasised their preference for expert, specialist services, based on the latest research developments. For this reason, many liked the idea of attending a London teaching hospital, where they felt that they had access to the 'best possible service'. These views were expressed particularly by those participants with specific long-term illnesses:

> *In London there are centres of excellence, like Great Ormond Street, Guys, where you do get the best attention but as you go further out, smaller hospitals ... they don't know what is the latest in a particular treatment. I just feel very worried that with all the changes now we'll have to go to more local hospitals and these specialist hospitals could lose their 'excellence' – and what would happen then?*
>
> (parent of child with cleft lip and palate)

> *If the GP is going to have a special clinic for diabetes – I'd be loath to go to it. Once a year you need to go to a proper hospital for your annual tests – it's your MoT – at the hospital you get the proper equipment and your expert and someone who is a specialist – but I suppose you could go back to your local clinic in between hospital appointments.*
>
> (participant with diabetes)

However, there were also concerns that the size and complexity of large hospitals create an impersonal service and there can be a lack of attention to the individual:

> *You are just a number at the hospital – you are not even looked upon as a person – having feelings should count for something but it doesn't.*
>
> (participant in mental health group)

> *... it's horrific – the sheer scale of it – it's just so impersonal and you feel you are being processed.*
>
> (participant with diabetes)

Expanded primary care and greater community support and care

There was considerable support, particularly among those people who had experience of using a health centre, for an expanded form of primary health care centre which was easily accessible, offered facilities for minor surgery, and various specialist clinics (such as asthma and diabetes clinics):

> *I've had a cyst removed at the doctor's, he had a minor surgery day. It was marvellous not to have all the inconvenience of going to the hospital.*
>
> (participant in elderly group)

> *It would be much more convenient to have some hospital services in the community rather than all this waiting to see a doctor at the hospital ... I think that anything local would have to be better and especially for things like maternity care – it would be a very practical compromise.*
>
> (participant in complementary users' group)

Participants also felt that such centres could benefit from the inclusion of emergency services:

> *My son fell off his bicycle and the doctor stitched him up at the surgery – he didn't have to go to hospital at all. It was marvellous – not having to go to casualty and go through hours of waiting.*
>
> (participant in elderly group)

There were concerns, however, whether the expertise available at the health centre or surgery would be appropriate for the level of treatment:

> *I don't think that services for MS have to be provided in a specialist hospital – it doesn't matter to me what the size of the hospital is – it's what goes on in it that counts – but I wouldn't be very happy going to a local doctor to have a cyst out of my foot. I'd want to be sure that it was someone with good training who was going to do it. Staff doing day-to-day surgery have to be qualified and good.*
>
> (participant with multiple sclerosis)

Some participants felt that having more services in the primary care setting would still mean that 'you would have to wait for treatment' unless much greater resources were made available to deal with the demand. There was concern too about the effect on medical staff of an expanded role for primary care:

> *So long as all the responsibility doesn't come down on our doctors or health centres – that would be very unfair because they would not have the resources to cope.*
>
> (participant in elderly group)

Participants in our group discussions also stressed the need for more support at home – they wanted more and better community support services such as nurses, meals-on-wheels, home-helps and day care:

> *When you are on your own, you become very isolated and when you need help – you can't get help. And that's when you become ill. I know people become ill because they can't get any help at home.*
>
> (participant in carers' group)

> *Surgery at the health centre is fine in principle with as few people staying in hospital ... but what if you are living on your own and you take a turn for the worse and there is no one to do anything for you ... there has to be a supportive environment available ... it's wrong to assume that there are friends and relatives there just waiting to help – it just isn't true for everyone.*
>
> (participant in NCHR group)

> *... and it can be worse, if you are black – the stereotype is about the extended families and communities ... often it's just not there.*
>
> (participant in NCHR group)

Several participants also wanted access to social care through the health centre, stating a preference for 'going to the GP rather than social services':

> *It was only through the doctor that I got any help at all – I saw him one day and he said that I looked terrible and asked what the problem was. I explained that I'd been on my own – looking after my wife who had been very ill for more than a year. He said – what you need is some care – some back-up. I'll get in touch with the welfare people – she isn't just your responsibility. Someone came to the house and assessed us and the situation and from then on they were very helpful – but I wouldn't have known that I could get help without the doctor – I just didn't know what to do.*
>
> (participant in patients' group)

The appropriate setting for medical intervention

The preferred scenario for secondary and primary care appears, therefore, to be well-resourced central hospitals acting as 'centres of excellence', together with local health centres offering an expanded range of acute and social services, in addition to existing primary care services:

> *We need two tiers for medical treatment. The hospital which can give you more intensive or semi-intensive care. They have got the equipment and the trained staff and can do that much better than a health centre. The hospital is for the really sick and very ill, and to do the surgery that health centres could not possibly cope with. The simpler things and the more usual surgery – that could be done at the health centre.*
>
> (participant with multiple sclerosis)

This picture has recently been reflected in a programme for future health services development suggested by the King's Fund (1992). The programme's proposed goals are: to address London's present deficit in primary and community services; to encourage primary health care practitioners to undertake aspects of treatment that currently take place in acute hospitals; and to involve Londoners in designing services to meet needs which they have helped to identify.

The GLACHC (1992) investigation into London's acute services from a user perspective found support for a two-pronged approach to service development: the further specialisation of medical services for people who are heavily dependent on particular technologies or intensive care; and the provision of services by the primary care team in the community rather than in a highly medicalised setting. As the GLACHC report points out, these views highlight a central theme concerning the organisation of services and, particularly, the appropriate level of medical and technological intervention for a particular health problem.

Problems of waiting times

The problem of waiting times has long been an area of dissatisfaction with the NHS. Long delays with general practitioner appointments and long out-patient waiting times with 'unsatisfactory amenities' were included in Jones, Leneman and Maclean's list of perennial problem areas in their review of consumer feedback on the NHS (Jones *et al.*, 1987).

The BSAS (1987 to 1990) (Jowell *et al.*, 1987-90) and the OPCS

Omnibus survey (1991 to 1992) (Solomon, 1992) have produced consistent evidence of a widespread view that waiting lists for non-emergency operations and waiting times before getting an appointment with a hospital consultant are unsatisfactory. Over 80% of respondents in the BSAS thought that these waiting times were 'in need of a lot of improvement'. In the OPCS Omnibus survey, 75% thought this about non-emergency operation waiting lists and 71% thought the waiting time before coming to an out-patient clinic was too long.

Additionally, 41% of respondents in the 1990 BSAS and 47% in the OPCS Omnibus survey thought general practitioner appointment systems were in need of improvement. A survey conducted on behalf of the National Consumer Council (NCC, 1989) found that 'waiting times for general practitioners, out-patients and casualty departments presented more problems in 1989 than ten years earlier'.

Hospital waiting times

In our study, there was a general consensus that more resources were needed to reduce waiting times for in-patient services. It was felt that waiting for admission to hospital can mean that the patient's condition deteriorates further and this increases anxiety:

> *My husband had to go in for an operation and we were told to get there at 8 am – someone else who was waiting to go in had been there since 7.30 am and then three others came. Then at 10.30 a nurse came along and said the surgeon can only take two of you today but you'll have to wait until he's finished operating so he can tell me which two he wants. It was well past 11.30 before the doctor came along and told us who he wanted and the rest of us had to go home.*
>
> (participant in elderly group)

There was criticism of the length of time spent waiting for tests to be carried out and for the results to be known:

> *Why does it take months and months to do the tests and get any information? At the end, you get to thinking that surely something could have been done if it was diagnosed earlier. My husband was having tests for eighteen months before they diagnosed cancer and by then there was nothing they could do.*
>
> (participant in counselling group)

There was also concern that many people have to wait too long before attending out-patient clinics:

> *About a year ago, I was paralysed in one leg which meant that I couldn't get up or down stairs at home or get out much. My doctor was ringing the hospital every day to get me there because they didn't know how to treat me without an x-ray. I still had to wait nearly six months for the appointment.*
>
> (participant in carers' group)

Whilst waiting for an out-patient appointment, the condition could worsen:

> *Why do you have to wait so long for an appointment? ... my wife has*

> *been waiting six months to go to the clinic and she's deteriorated since she first went to see the doctor.*
>
> (participant in elderly group)

There was criticism of an appointment system which did not appear to take notice of the date for the next appointment specified by the doctor or consultant:

> *You go to the out-patient clinic and are told to make another appointment in four weeks but the computer won't let them make it – so you're told that you can't be seen for eight weeks – does the consultant know about this?*
>
> (participant in patients' group)

Participants were most critical of waiting times at accident and emergency departments. The experience of waiting in casualty was 'unpleasant and frightening' and the 'squalid' surroundings did nothing to ease participants' anxiety. One participant felt:

> *Casualty is just like a cattle market.*
>
> (participant with asthma)

Participants also identified the paucity of information available to explain the system to people waiting for treatment:

> *One of the things that bothers and irritates me most about casualty is that nobody informs you – you are left entirely in ignorance. You don't know who this bloke is in the white coat or why he's wandering about or what is happening. They just call you out and you don't know if there is a proper queuing system – you don't even know where to sit.*
>
> (participant in counselling group)

Opinions on waiting times when visiting out-patient clinics were less clear-cut. The main criticisms were not about the time kept waiting, but about the absence of information and the attitude of staff.

In general, participants were less critical of having to wait if they were supplied with information about what was happening:

> *On occasions, people can be kept waiting a long time to be seen at a clinic – and that's unavoidable – but I don't think people would mind if they were given a reason. If someone came out and said 'such and such has happened and there will be a delay'.*
>
> (participant in patients' group)

Participants seemed prepared to wait longer in order to see the doctor they wanted to see:

> *I don't mind waiting for three hours to see the specialist – if I don't see the specialist I usually only wait for an hour – but I'm quite happy to wait longer to see the top man.*
>
> (participant with diabetes)

It was suggested that the time people were kept waiting at clinics could be used more productively:

> *In clinics where you are sitting around for two to three hours, this could be an ideal opportunity for some kind of counselling – someone could be*

> *there to pull up a chair and ask you how are you – you as a whole person.*
> (participant with diabetes)

A minority of participants, however, did describe positive experiences in the time waiting at hospital:

> *I've been going to hospital out-patients for the last thirteen years and if I have an appointment for 9 am, I'm seen by 5 minutes past – they always apologise, if I have to wait any longer.*
> (participant in elderly group)

Waiting times in primary care

Generally there was less severe criticism of waiting times in primary care settings, although the responses varied considerably according to the type and organisation of the practice. Participants had experience of surgeries, health centres and clinics operating an appointment system and those seeing patients on a 'first come, first served' basis.

The main advantage of having an appointment system was to 'cut down on the waiting time'. However, it was recognised that, for the appointment system to work efficiently, there would have to be a time allotted for each consultation and, as far as possible, this time should not be exceeded:

> *You need to tell the doctor how long you need to see him for – most people have an allotted time of ten minutes and, if that's not going to be long enough, then you should tell the doctor in advance.*
> (participant in sixth form centre)

One participant described the technique used by her general practitioner to keep the consultations to time and maintain the appointment schedule:

> *I don't know if the allotted time is five or ten minutes but you can tell when your time is up – it's the technique doctors have of gradually walking towards the door … and you've got to follow and you're still talking – but your time is up!*
> (participant in colitis/Crohn's group)

The experience of participants at a busy health centre was, however, that the appointment system worked well and could be combined with giving individual patients sufficient time with their doctor:

> *The system works well here. You are able to make an appointment fairly quickly but in that case, it may not be with the doctor you regularly see but with one of the other doctors at the practice … the way it is organised means that you are not 'in and out' but they [the doctors] always give the patient time.*
> (participant in patients' group)

In contrast, other people described the difficulty they experienced in obtaining an appointment in the first place and how this deterred their use of the service:

> *I don't tend to use my local health centre simply because I can't make an*

> *appointment and by the time you have got to them – you are better!*
> (participant in complementary users' group)

> *Last Thursday, I fainted twice but the surgery could only give me an appointment for this Thursday – what's the point in that, I'd fainted twice and still had to wait a week.*
> (participant in school sixth form)

Some practice receptionists were criticised for an over-zealous attitude and giving the impression that 'their job is to guard the doctors from the patients':

> *I used to belong to a health clinic where you couldn't get to see the doctor in less than ten days – that was simply because of the receptionist – she just wouldn't give you an appointment!*
> (participant with diabetes)

A survey carried out by the Northumberland Community Health Council and Family Health Services Authority (1991) among patients of general practitioners found that only 50% thought the standard of help which receptionists gave patients was good and 54% thought the level of privacy when dealing with them was poor.

The difficulties in obtaining appointments, the experience that 'even with an appointment you have to wait anyway', and the restrictions which that system could impose on the time available to see the doctor led many participants to favour a less rigid and 'first come, first served' process:

> *When I was young, there wasn't an appointment system – we just queued up and took our turn going in. I'm trying to remember how I feel now and how I felt then – I think I felt better then, you knew when you were going to be the next one in and it seemed fairer somehow.*
> (participant in elderly group)

Although participants identified benefits with a well-organised appointment system, they did not want the shorter waiting times which might result to be at the expense of restricted consultations. Their main concern was to ensure that, whatever system was in operation, the consultation was not rushed and there was an opportunity to talk fully to the doctor:

> *You know when you're waiting to go in that he's with someone and taking the time to listen to them – I'd rather wait and know that, when my turn comes, I'll be given the time as well. I don't particularly like it but you accept the fact that you'll have to wait.*
> (participant with asthma)

The need to inject 'care' into health care

A common perception expressed in the group discussions was that the 'care' has gone out of health care, especially in the hospital setting, and this adversely affects the dignity of the patient:

> *An elderly lady with MS needed to go to the toilet immediately she needed to go – the nurse would take her along to the toilet and leave her outside*

> *the door and say I'll be back in a minute – but they'd be much longer and she'd wet the floor and then get into trouble with them for wetting it. She was treated as though she was a 4-year-old – not like an adult at all. She was very depressed and spent most of her time crying ...*
>
> (participant with multiple sclerosis)

One participant encapsulated the views of many by describing the process of receiving medical treatment as 'an invasion without dignity':

> *It's a completely depersonising experience – takes all your power away and it can make you ill just being there ...*
>
> (participant in complementary users' group)

The changes in the quality and depth of care were seen to be partly the result of increasing pressures on health care staff due to limited resources.

Also, the perceived deterioration in the quality of care was attributed to changes in the responsibilities and structure of the nursing profession. Nursing had changed from being 'a caring to a technological profession'. Participants felt that nurses are now required to be so technical that they have little time left for the basic caring tasks of feeding and washing and, above all, talking to patients:

> *It seems to me that the care has gone out of nursing and out of hospitals, they [nurses] do not seem to learn the basics of nursing care. They know how to read monitors but not how to make you comfortable in bed ...*
>
> (participant with multiple sclerosis)

Participants were critical of nursing staff who tended to cut themselves off from patients and spent insufficient time being with and talking to them. As an extension of the perceived lack of care from hospital staff, there were descriptions of nurses 'shutting themselves away from patients in their nursing stations'.

Some comments referred specifically to the attitude of staff in the accident and emergency departments:

> *I waited four hours in casualty with my daughter and that was absolute agony. What I think was wrong there ... is that the nurses and doctors are shut up in a box – you can't see them – and there is no one attending to the great suffering that is going on in the waiting area. Because of their need for security they shut you out as firmly as they can. Then, the nurse sees you to ask what the problem is and tells you – you will be seen – but you're not told anything – and no one is caring or seeing anyone there and then.*
>
> (participant with diabetes)

> *It was 3 o'clock in the morning the day after Christmas ... I had to take my neighbour to hospital because she was in terrible, terrible pain. I took her to casualty and there were five or six nurses just standing there chatting and laughing. My neighbour was crying and occasionally screaming with pain but no one came near her ... then someone came over and put a thermometer in her mouth but without taking the plastic cover off – so it was a complete waste of time – and then they left and she was screaming again with pain.*
>
> (participant in complementary users' group)

In the primary care setting, the attitude of the general practitioner was the main determinant of participants' assessment of the level of care in the service. There was criticism of the disinterested attitude of some GPs:

> *He [the GP] asks all the questions you would expect, but he seems to knock off and stop listening as soon as you start to answer them; he always seems to be in a rush and withdrawn.*
>
> (participant in sixth form centre)

> *My GP has already got my name on the prescription as I walk into the surgery – that's all wrong – it's a lack of interest – I know it's all just routine to him and he's not listening.*
>
> (participant in colitis/Crohn's group)

> *You don't get enough encouragement from your doctor – you go in and tell him your problem and he gives you pills. There is no time for him to encourage and support you. I'm sure that they get fed up with seeing the same people all the time.*
>
> (participant in Community Health Foundation group)

In contrast, other providers of primary care services (e.g. district nurses, health visitors) were described generally as 'caring' and 'helpful' but their resources were 'too few and overstretched'.

Inequalities in the quality of care

Our findings indicate that participants are very aware of inequalities in the quality of health care for different groups in the population. The group discussions have highlighted particularly the poorer quality service that elderly people, black people, and people with chronic illnesses and disabilities, and mental health problems feel they receive.

Those using the mental health services felt at a particular disadvantage and described situations where treatment had been refused, their needs ignored or unrequested medication had been given:

> *I think the mental health services are much worse than the physical. A physical illness you can see and I think with physical illnesses ... there's more understanding. Where – with mental illness, you can't see that, but you actually do need help ... in casualty it's waiting and waiting for a good many hours – then the psychiatrist comes along – and there's no beds, so you're just sent home.*
>
> (participant in mental health group)

> *The doctors just keep giving you drugs which make you very slow and your speech slurred ... they don't talk to you and explain what they are doing – just pump you full of drugs and it's too long before they reduce them and I can get back to my own state of mind.*
>
> (participant in mental health group)

A participant with multiple sclerosis described how the perceived attitude of medical staff towards her chronic condition had a negative effect on the type and quality of care she received:

> *I think MS is such a dull boring disease anyway – they [doctors and*

> *hospital staff] are only interested in something that is quite unusual – and the older you get – the less interesting you are ... as you get older you are just one of the elderly disabled.*
>
> (participant with multiple sclerosis)

Elderly participants in the group discussions described many incidents where the standard of hospital and community care fell far short of good health care:

> *My wife was in hospital four times with a heart attack. The nurses had a great deal of difficulty lifting her – she was dropped twice on the floor. Also the incontinent pads were put on inside out.*
>
> (participant in carers' group)

> *I gave the hospital staff details about my mother when she went into hospital – I explained that she was almost blind. I'd looked after her for nearly seventeen years and she had been fine, but the first night she was in hospital, they let her wander and I was told later that she had broken her leg.*
>
> (participant in carers' group)

> *... look at the breakdown in community care – we had an elderly woman who was homeless – she was discharged three times from hospital before finally she died in the street of hypothermia.*
>
> (participant in NCHR group)

> *Let's face it – do they really care what happens to us 'old uns' – after all their attitude is that we're going to die soon anyway.*
>
> (participant in elderly group)

The discussion with representatives from black health users' groups highlighted the prevalence of institutionalised racism within the NHS. One participant commented:

> *My mother's experience as a black woman was that at the beginning she was able to benefit from the NHS ... but what has happened now is that because of the cuts, we have become alienated from the service; there are groups that get ignored. I am black and the health literature does not represent the needs or the presence of black women and black men working in and as users of the health service. We can have health problems which really create problems for us but we will only get something done when we take these concerns on board as an issue for ourselves – that's the only way in which we will get anything done ... if you think different or look different or want to question your diagnosis – then you are a problem for the NHS.*
>
> (participant in NCHR group)

Inter-personal communication and information needs

The need for consistency

The key to satisfaction with health services appears to be the relationship between health care staff and patients. Several dimensions of this relationship were identified. First, great importance was attached to consistency of contact – seeing the same doctor, both in the hospital and the primary care setting.

> *In thirty years, I have not established a relationship with any doctor in the practice which I use ... partners come and go, practitioners come and go ... there is always the notion that you should have a good relationship with your GP but is it really achievable?*
>
> (participant in NCHR group)

Constant changes of staff were felt to undermine people's confidence and their trust in the health care provided. The need to repeat case histories and personal information was seen as frustrating and time consuming:

> *Every time you get used to a doctor – a doctor changes and it's another one – and it's difficult you know to repeat everything, your history and try to get to trust them.*
>
> (participant in mental health group)

> *There's a real sense of security in going on seeing the first doctor you've seen – although another doctor may have your file, he might not really know what is going on.*
>
> (participant in school sixth form)

Participants also identified, as a separate difficulty, that prescribed or recommended treatment could differ between practitioners and this would undermine consistency:

> *Every doctor has their own views about this [glue ear] and the required treatment ... and if you do not have the same doctor this can lead to a lack of consistency in the treatment.*
>
> (participant in complementary users' group)

Another participant, however, suggested that the opportunity to see a different doctor could, in effect, provide the patient with a second opinion:

> *One doctor tells you one thing but you may want to go to another at the practice for a second opinion.*
>
> (participant with diabetes)

For some participants, reliance on agency staff meant longer-stay patients in hospitals did not feel they had the opportunity to develop any relationship with the ward's nursing staff. Also, the lack of consistency in nursing personnel was perceived to affect treatment and their knowledge and understanding of individual cases:

> *My bad feeling about hospitals is agency nurses – I know they do a good job and they are necessary but as a patient it's useless. It's the lack of continuity. You just get used to a face and it's gone. Someone else comes along, they don't know who you are and don't want to know. So you haven't got that bonding that you need with mastectomy.*
>
> (participant in mastectomy group)

> *... there are so many agency nurses and this means very little follow-through as far as nursing care is concerned – ever-changing groups of nurses*

> *– they don't know your case, they don't know anything about you – they just begin to find out and they are off to another ward.*
>
> (participant with multiple sclerosis)

The need for an improved quality of relationship

A research programme in the South East Thames Region (Calnan and Williams, 1991), looking at consumer satisfaction with primary, dental and in-patient hospital care, found that: 'the highest associations with overall general practitioner satisfaction scores have less to do with access, availability and type of service provision and much more with the quality of the doctor-patient relationship and the GP's professional skills'.

The quality of the relationship between health care staff and patients constituted a key area of discussion in this study. Participants wanted to feel that someone really cared what happened to them, rather than feeling like a number in the system. They wanted to be courteously treated, and asked for their opinion 'as equals' in their own health care. They wanted to be treated with dignity, as individuals with rights and intelligence. All these qualities in the relationship were identified as the advantages of complementary and private health care systems.

A large-scale survey of discharged patients in Canada (Heffring *et al.*, 1986) investigated the dimensions of patient satisfaction and found that 'being treated as an individual' was by a considerable margin more important to patient satisfaction than 'getting better'. Many of the participants in our study agreed:

> *You might not need a prescription – but to talk. That's an important point about medicine and healing. The relationship, if it is good, can be healing in itself. If you think the man is listening to you, that's the healing aspect. As you are talking to the doctor, you are feeling more relaxed and you feel better as you leave the surgery.*
>
> (participant in colitis/Crohn's group)

In the discussions, many participants described from their experiences serious inadequacies in the doctor-patient relationship:

> *My experience was with my partner ... he was very ill in hospital and we felt very worried and insecure ... it was the experience of seeing him lying in the hospital bed and occasionally being swooped on by men in white coats – they don't say anything to you and they don't introduce themselves ... everything is just said in a matter of fact and impersonal way.*
>
> (participant in complementary users' group)

> *I think I'm about average intelligence but the attitude of doctors is – how dare you imply that you know something – how dare you question what I'm doing.*
>
> (participant with diabetes)

> *You feel there should be courses in how to deal with doctors – how to tell them things which don't offend them or close off their minds, how to be terribly tactful and make sure that their professional dignity isn't affronted*

> *– we shouldn't need to feel like that.*
>
> (participant in complementary users' group)

Although seeing the same health care professional on each visit will allow the development of a relationship, rushed consultations can undermine the quality of that relationship. The South East Thames RHA survey mentioned earlier (Calnan and Williams, 1991) found that the time available for consultations was an area of concern for a quarter of all survey respondents.

Calnan and Williams (1991) also point out that, if the new general practitioner contract means that GPs are able to spend less time with their patients in individual consultations, this could result in a deterioration in the quality of the doctor-patient relationship. This point was taken up by several participants in the discussion groups.

Unmet information needs

Research has shown that people coming to terms with illness and medical intervention need to know what is happening to them and that a great deal of anxiety and distress is caused by a lack of information. The GLACHC (1992) report on London's acute services from a user perspective stated simply : 'the failure to keep patients informed about their illness and treatment is a major shortcoming. Much greater effort needs to be made to improve communication with users and to provide comprehensive information in an easily accessible form'.

People's desires and expectations in relation to health care information have grown in the last two decades. The concept of patient choice, the individual's responsibility in their own care, and consumer feedback are based on the assumption that people using services will have enough information with which to make choices, take greater responsibility for their own health and provide feedback to service providers.

In a review of consumer involvement in health care for Swindon Health Authority, Taylor (1990) reported that people 'constantly complain that they are not given enough information about the treatment they receive or enough advice on how to manage their illness'.

A report on user-consultations with people living with cancer in Dyfed (East Dyfed Health Authority *et al.*, 1991) concluded that 'the main issue to emerge is the importance of giving individual service users choice'. Such choice included the opportunity for the individual to be given as much or as little information as required, the opportunity to make informed choices about treatment, and the offer of professional or peer group support. The report also emphasised 'the need for clear, personalised information for patients which is to be given at the right time'.

Participants in our group discussions described their unmet information needs which they wanted addressed in their contact with health services:

> *Some people haven't any idea at all what is going on – there are some people who will ask questions and other people will take what the doctor says to them as gospel truth and they won't argue or ask anything. It*

> *happens particularly with older women – sometimes it's because people don't want to know but if they are given written information they can choose whether to read it or not – it would be their choice.*
>
> (participant in mastectomy group)

> *... doctors are far too busy and never available to talk to you, if you are worried ... when you come out from seeing the doctor, you think – what did he mean by that? – it's all rushed and very confusing – even if you are familiar with the terminology. People need someone to sit with them and explain it to you – there's nothing at all like that in an out-patient clinic.*
>
> (participant with multiple sclerosis)

Some participants, with illnesses or conditions which were relatively uncommon, had the experience of providing the doctor with information but getting very little back in return:

> *You often feel when you go to hospital that your child is being used as a guinea pig by someone who has never seen it [the complaint] before. The doctor asks you lots of questions but doesn't come up with anything useful at the end of it. I'm giving a lot of information and, at the end of the day, I haven't got anything that is helpful to me and I'm the one that has to cope with the problem.*
>
> (parent of child with cleft lip and palate)

Also, there were particular difficulties faced by participants given conflicting advice or information:

> *There is no one pool of knowledge, you go here and you read or hear this and get told the opposite somewhere else and this can be very unnerving, especially with something serious.*
>
> (participant in mastectomy group)

A minority of participants felt that health care staff, particularly doctors, were getting better at providing patients with information:

> *They make more information available now – it's a growing thing – they didn't use to tell you things ten years ago – it is improving.*
>
> (participant in colitis/Crohn's group)

> *Doctors are more open now about the limits of medicine and are prepared to talk about it. That's an improvement – when I was young their attitude was much more – we know everything and you know nothing.*
>
> (participant in complementary users' group)

Providing patients with information primarily involves a member of staff, not necessarily the doctor or nurse, taking time to talk and listen to patients:

> *This could go for all illnesses – alongside the doctor ... someone outside in another room who will put you at ease and explain – it gives the doctor a way out because he hasn't got time to talk to you for hours.*
>
> (participant in colitis/Crohn's group)

Some participants in the discussions identified a role for self-help groups in providing information, advice and support through clinics and primary care practices:

> *It would be good to have a volunteer from the self-help group at the breast care clinic – they could explain and reassure women. But there is still some professional resistance to that sort of help.*
>
> (participant in mastectomy group)

Access to medical records

Participants were asked whether they welcomed access to their medical records, and to what extent, having access to these records had fulfilled their need for information. Although many participants welcomed the right of access, there were mixed views on how useful or informative the records would prove:

> *Yes, it's a very good idea to be able to look at your medical records and see what they say about you – also sometimes they get it wrong. On those occasions, I've been down to them and told them that they have got it all wrong. That's very important with children – it could be very serious, if they have made mistakes with their records.*
>
> (participant in parents with toddlers group)

> *You can comprehend so much better when you see things written down – you may not have grasped what the doctor or the hospital has said until you sit down quietly and read it.*
>
> (participant with diabetes)

> *If you are not allowed to read them – it conjures up in your mind that there is something in them that they don't want you to read and then you worry about it.*
>
> (participant in colitis/Crohn's group)

> *It is very important to have the right to read them – if you want to and not everyone will. If you have a lot of confidence in your doctor, being able to read your records will be far less important.*
>
> (participant in patients' group)

> *But would you understand them? – if it's all written in jargon, how would you know what it means? It could make someone very worried or frightened, when they have nothing to be nervous about.*
>
> (participant with asthma)

Unmet emotional needs

On the whole, people felt that the anxiety, worry and confusion that many patients feel on learning of an illness is not addressed by the health service, and that this aspect of care needs to be given much greater priority in the future:

> *They don't take into account worry – and worry is the worst thing – I was quite unbearable to live with at the time – that's all you want to talk about (diabetes) – but there's no one to talk to – it makes or breaks you in the end.*
>
> (participant with diabetes)

> *If a person is under the weather, they become anxious about everything – even whether the milkman is going to call in the morning ... the worry builds up and up and makes them worse – doctors don't seem to realise*

this – people need someone to talk to to make them feel more confident – better about the future.

(participant in elderly group)

The report on a series of consultations with users of services for people living with cancer in Dyfed (East Dyfed Health Authority *et al.*, 1991), found there was 'almost universal complaint about the lack of counselling and support for both patients and carers/families throughout the whole episode of care'. The study identified that 'what cancer patients need first and foremost is someone to listen to them on an individual basis ... or within a group'.

In the South East Thames research (Calnan and Williams, 1991), referred to earlier, the overall levels of satisfaction with hospital care were correlated most strongly with 'the more diffuse interpersonal aspects of care, and the communication of information'.

The need for emotional support, similar to that for information, relates to the quality of the relationship with health care professionals. It appears from our discussion group data that good communication is seen as fundamental to such relationships and may be as important a component of 'getting better' as any technical intervention.

Our research has suggested that one aspect of communication between health care professionals and users which could be better developed is the recognition and facilitation of people's capacity to take care of themselves and each other, rather than solely being the recipients of services. Mutual aid groups and the voluntary sector in general make a substantial contribution, with limited resources, to try to deal with shortfalls in unmet emotional and information needs. However, information on how to contact such groups and access their services and support is seldom systematically or readily provided by the statutory services (see pages 49–56).

Counselling

There was widespread recognition in the group discussions of the value of counselling and strong support for this to be an integral part of the health service of the future as a basic element of preventive health care.

Participants described how the distress and fear associated with health care problems could be eased through access to counselling facilities in the primary care and hospital setting:

Counselling is very important – because I'd never seen anything like it before in my life [cleft lip and palate]. When the nurse showed my baby boy I was very shocked ...

(parent of child with cleft lip and palate)

I had counselling – she came just a couple of times – I've got family, but I could talk to her. I could cry – if I'd cried in front of them they would have got very upset.

(participant in colitis/Crohn's group)

I think you need the counselling when you get home afterwards – you are on your own and people can feel very apprehensive – that's when you need to be able to talk to someone.

(participant in mastectomy group)

One of the groups convened was formed exclusively of participants who had been or were in receipt of counselling provided within an NHS group practice. In common with participants in other discussion groups, they emphasised the value of having a holistic approach to health care, with the mind and body seen as one and treated together. Counselling was identified as an important part of that process:

> *I don't think counselling can be overestimated. It helps to bring everything together – you can't really separate who you are and the workings of your mind from your body.*
>
> (participant in counselling group)

Individuals in the group described the value of counselling in helping them to cope with stress, depression and anxiety without medication or with a reduced dependency:

> *I think one of the important values of counselling is that it probably makes medication unnecessary – I've had a long history of depression from way back and I've had lots of medication. If I had had counselling earlier, I wouldn't have needed the medication for so long.*
>
> (participant in counselling group)

A number of the counselling group's participants described events and experiences which had left them with feelings of 'powerlessness' and a sense that their life was 'out of control' or 'falling apart'. In some instances, illness or a traumatic experience of hospital treatment had been at the root of these feelings. The benefits of counselling had enabled the participants to take control again of their lives and had prevented illness and dependency.

Participants identified considerable advantages in having access to counselling located in the primary care setting. Most expressed a reluctance to use comparable hospital out-patient services which they felt had 'a stigma':

> *Knowing I could see a counsellor at the practice has got over my prejudice – I never thought I'd need to see a counsellor but having it at the health centre has made it all right.*
>
> (participant in counselling group)

The benefits of having a counselling service accessed through a health centre or GP practice were more than those of convenience:

> *It's so important that it should be seen as part of your normal treatment – you call in to see your doctor and you can be talking about how you feel, what your problems are and then it's just natural that he recommends the counsellor.*
>
> (participant in counselling group)

> *There are times when you just couldn't cope with being referred somewhere else. You've already plucked up the courage to go down and see your GP and you feel like hell – it's so important when you are feeling low like that to get that counselling help at the practice.*
>
> (participant in counselling group)

Participants in another group identified another important reason for locating 'psychological services' in a primary care setting:

> *One thing that could work within a GP surgery is the attachment of psychological services ... we find that many people in the Asian communities and I suspect in other communities go to the GP with physical problems that have an emotional underpinning. The GP does not often have the knowledge or access to psychological services but it would be very effective, if placed there. It would mean that people who only use GP services would benefit from them as well.*
>
> (participant in NCHR group)

In their conclusions for improving the quality of acute services in London, the GLACHC (1992) report emphasised that ensuring social and emotional support for patients is an important and often neglected part of hospital care: 'counselling services need to be made much more widely available, giving patients the choice of multilingual and black counsellors, where appropriate. Everyone should be carefully assessed to make sure they receive practical help with benefits and with their domestic responsibilities, if necessary'.

Complementary health care

In 1988, the Association of Community Health Councils of England and Wales published a report on 'The State of Non-Conventional Medicine: The Consumer View' (ACHCEW, 1988). This report argued that the consumer should have a right to choose and that there should be properly enforced standards of training, examination and qualification for professionals in complementary medicine. A recent survey of over 2,000 qualified non-medical practitioners (Thomas *et al.*, 1991) working in complementary health care in Britain and about 2,500 of their patients concluded that non-orthodox treatment was sought for a limited range of problems and used most frequently as a supplement to, rather than instead of, orthodox medicine. Most patients (75%) in the survey had a musculo-skeletal problem, two-thirds were women and only 15% were aged 65 years or older. An investigation by Sharma (1991) into how people use complementary health care also found that many patients seek help from both their general practitioner and the complementary therapist. Many of these patients reported chronic conditions such as back pain, migraine, arthritis and allergies which had not responded satisfactorily to orthodox medicine.

The experiences of complementary health care described in the group discussions showed similar patterns, with many participants seeking help from both complementary and orthodox medicine and, often, for chronic conditions:

> *When I was young, I used to get a succession of sore throats – but the doctor never tried to find out why – they just kept pumping me full of medicines ... but since I've been using natural health care, I've never had any problems.*
>
> (participant in Community Health Foundation group)

> *Down at the health project we've had acupuncture and osteopathy for five or six years now – it doesn't cost people anything. I've been having acupuncture for two years. Before, I'd been walking like a ruptured duck with terrible pains in my legs and hip – I'd been to hospital but the treatment never lasted. Now I can walk and get around fine.*
>
> (participant in elderly group)

In our discussions, participants described the benefits which they felt were inherent in complementary medicine. Complementary practitioners were seen as 'really taking care of the whole quality of people's lives' and the holistic aspects of complementary health care philosophy meant the treatment had a wider beneficial effect on well-being and happiness:

> *You need to look into balance and the environment – behind natural health care – there is light, sound and philosophy to be in harmony with life.*
>
> (participant in Community Health Foundation Group)

A second perceived benefit of complementary medicine was that it encourages people to take responsibility for their health and to feel more in control of the treatment process:

> *You don't have to rely on anyone else – it's taking charge and responsibility for your own health ... people will advise you but then it's up to you.*
>
> (participant in Community Health Foundation group)

> *My life is how I make it and if I'm ill then I look at what is causing me to be ill – that makes me in charge of my life.*
>
> (participant in Community Health Foundation group)

As an important element of complementary medicine, participants stressed the value of a healthy lifestyle and diet:

> *People are much more aware nowadays than they used to be that health is not necessarily a matter for doctors – it's more about sensible living and healthy living than illness.*
>
> (participant in complementary users' group)

> *We don't want prepackaged and junk food ... everyone wants things that are fast today and that's why we are getting fast developing diseases.*
>
> (participant in Community Health Foundation group)

For some participants, their reason for using complementary medicine was similar to that ascribed to private health care in the way it provided more immediate access to treatment:

> *I've had to wait so long to see my GP and that is even with an appointment system and that is one of the reasons why I have gone to an alternative practice and, in that sense, I suppose it is similar to going private. It's been a combination of wanting to see someone who will offer an alternative solution and the knowledge that ... I will be seen straightaway, that's very important for me.*
>
> (participant in complementary users' group)

Another participant described how modern medicine and technology had saved a woman's life but the quality of after-care was lacking and she had turned to complementary medicine to supplement orthodox treatment. Her experience had led her to the view that there was a role for both types of health care:

> *A friend of mine has just recovered from meningitis – she was in intensive care for about a week and three weeks in hospital. She is someone who is generally very sympathetic to alternative therapies. She said this experience has rekindled her support for hi-tec ordinary medicine because she wouldn't be alive if it wasn't for antibiotics. But, although the conventional care was fantastic while she was in hospital, when they discharged her she was in a very weak and frail state but they didn't take account of that – she needed to build her body up again – but there was no continuing care for that. So she turned to an alternative practitioner – she feels very strongly now that both conventional and alternative have their place.*
> (participant in complementary users' group)

Many participants also felt that complementary medicine should be available through the NHS and located in the surgery or health centre:

> *It shouldn't be something for the elite and what you can afford – it should be there for everyone as part of the NHS.*
> (participant in Community Health Foundation group)

> *If alternative practitioners were available within the NHS, it would be so much easier – with the co-operation of doctors – to refer people back and forth between different types of treatment.*
> (participant in complementary users' group)

In the discussions, there were differing views on the importance and impact of training for complementary practitioners. Some participants stressed the importance of training and recognised professional qualifications:

> *If people are ill, they are so desperate to have something but I'd be worried if I could not be sure that the person is qualified. For me that's a lot about having confidence in the person.*
> (participant in complementary users' group)

However, others made the point that the flexibility and naturalness of complementary medicine could be undermined through greater control on training and practice:

> *There is a danger that the naturalness of the whole approach will be lost – it will be formalised and those practising complementary therapies will have to become 'paramedical'.*
> (participant in NCHR group)

Health promotion and education

The government's first health strategy for England was published in a White Paper in July 1992 and gave a central role to health promotion and education in health policy (Department of Health, 1992). 'The

Health of the Nation' aims to reduce death and disease over the next two to eighteen years and sets targets for five key areas: heart disease and strokes; cancers; mental illness; sexual health and HIV; and accidents. In addition, targets were also set for 'risk factors' and were aimed at changing behaviour in relation to smoking, drinking, diet and nutrition, HIV and Aids, and at lowering blood pressure in adults.

In providing clear directions for improving the health of the population, the strategy established greater priority for disease prevention and health promotion. However, there is concern from health policy analysts that the strategy failed to give adequate attention to the importance of health inequalities and the uneven distribution of illnesses between socio-economic groups. Professor Ham, commenting on the White Paper, argued that 'unless all citizens have secure employment, adequate housing and access to education, then the health divide will not only persist but it will widen' and he called for 'healthy policies in areas such as housing, education, social security and the economy' (quoted in *The Independent* and *The Guardian,* 9 July, 1992). Although the White Paper (Department of Health, 1992) acknowledged the need for 'healthy homes', it also commented further that 'good housing is important to health, although the interdependence between factors such as occupational class, income, unemployment, housing and lifestyle makes it difficult to assess which health effects are specifically attributable to it'.

Although there was insufficient time in the group discussions for a full debate on health education and promotion, strong differences of opinion on its effectiveness and its priority in the allocation of health care resources were identified.

Tones (1991) has concluded that health promotion should seek to ensure 'the most efficient delivery of health and medical services, facilitate choice of a healthy lifestyle and be concerned with the creation of a physical and socio-economic environment which fosters health and reduces the likelihood of illness'. He has also argued that the 'single most important feature of health promotion is empowerment'. This was a theme explored by some participants in our discussions and, in particular, by those who identified a similar role for complementary medicine:

> *But the most important thing for me is that [health education] empowers people and gives them back control over their lives.*
> (participant in NCHR group)

> *Health education should be about giving people control and the information to make decisions over their own lives and treatment.*
> (participant in Community Health Foundation group)

The beneficial effects of health promotion were described by some respondents and, particularly, in relation to perceived reductions in smoking and improved attitudes to diet and alcohol consumption:

> *Nowadays it's cool not to smoke – healthy living and all that is seen as important. Education has helped a lot to bring all that about.*
> (participant in school sixth form)

> *People are so much more aware now than they used to be – look how attitudes have changed to alcohol – everyone used to be encouraged to 'knock it back' but now people know so much more about the harm it can do.*
>
> (participant in complementary users' group)

However, some respondents expressed their doubts about the effectiveness of health promotion and education when people's lives were affected by poverty, poor housing and restricted access to health-enhancing services and facilities:

> *Health promotion can increase inequalities and not reduce them. A lot of health promotion is about blaming people when so little is provided for many people. When they have to live with the problems of poverty what does it mean that you have to look after your heart?*
>
> (participant in NCHR group)

> *Why don't they make 'meals on wheels' a healthier diet? Why isn't it a priority?*
>
> (participant in elderly group)

> *It [health promotion] is also about the provision of public services: things like access to properly heated swimming pools – people must be aware of the wider considerations of health promotion and it has to be about access to public goods.*
>
> (participant in NCHR group)

Some discussion groups felt that health promotion should either have a lower priority for resources or that its current role should not be developed further. Generally, these were groups where participants were predominantly elderly or working-class or had experience of a serious chronic or life-threatening illness:

> *... I think they should spend money on more important things – like hospitals, looking after sick people. People know they shouldn't do things like smoke and if they do, that's up to them – if people want to smoke or drink heavily or whatever, nothing is going to stop them.*
>
> (participant in parents with toddlers group)

> *There's too much money spent on 'thou shalt not do this and thou shalt not do that' – all that money should go into care and not advertising.*
>
> (participant in elderly group)

Some participants' assessment of the effectiveness or benefit of health promotion had been undermined by a negative experience, for example, where they had been told or received conflicting messages:

> *When I was pregnant, the doctors asked me how many cigarettes I smoked a day – I said just six or seven. They told me that's OK – you're not really a smoker and so I kept on smoking.*
>
> (participant in parents with toddlers group)

> *A lot of information you get told about diet is misinformation – also people are fed up with hearing about diets – losing weight – doing this, doing that.*
>
> (participant in Community Health Foundation group)

> *This 'stop smoking' campaign is really two-faced – on the one hand, the Government is telling tobacco companies to write on the packets that it's detrimental to health – but it's a big source of money to the Government and that's why they let the companies go on advertising.*
>
> (participant in elderly group)

Some participants' perception of health promotion was that it was about 'negative messages' and blaming people. It failed to take sufficient account of the pressure or stress present in many people's everyday lives:

> *Different vices make different people happy – if you're looking after kids all day, you will smoke or something or you'd go mad. If people don't drink, don't smoke and don't have sex – what kind of life do they have – nothing!*
>
> (participant in parents with toddlers group)

> *People haven't got the time to worry much about healthy eating – today everything has to be so quick – and fast food is the quickest thing to get and eat.*
>
> (participant in school sixth form)

Attitudes towards health promotion were also affected by people's perception that it would either not be effective or the aim of making people healthier was of limited real benefit:

> *I have tried eating healthier foods but I don't know – I expect it's the way that you are brought up – it just doesn't work for me.*
>
> (participant in parents with toddlers group)

> *You can take a horse to water but you can't make it drink – health education is like that. You can put as much bumf about as you like but you can't make people read it or take notice of it – and if they don't, then the money is wasted.*
>
> (participant in elderly group)

> *Why not do things like smoke – what's the point in living so long – it's not worth it, when you see how miserable life is for lots of old people.*
>
> (participant in carers' group)

That many people are aware of the risks of an unhealthy lifestyle but some choose to ignore it was borne out by a Health Education Authority survey published in 1989. This survey showed that, although most people are aware of the risks to their health of heavy drinking, for example, very few believe that the dangers apply to them or monitor their own drinking levels (HEA, 1989).

Recent research has confirmed the comparatively early age at which children and young people regularly smoke cigarettes and drink alcohol. A study by Exeter University Schools Health Education Unit (1992) found from a survey of children aged 12 to 16 years that 30% of boys drink to ease their anxieties and 20% of fifth form girls smoke. A survey of school children carried out for the Health Education Authority found that 60% of children had tried smoking by the age of 15 and 20% were regular smokers (HEA, 1990). In our discussions (particularly with those with children and the school sixth form groups) emphasis was placed on the importance of health education for young people. Participants identified the need to inform children at a sufficiently young age to influence their lifestyle:

> *There should be a specific class on health promotion for children in secondary schools and for younger children too – to make them aware. But, by the time they tell you, you know things already or you think you do. Often it's too late by the time they tell you – they should tell you about things much earlier.*
>
> (participant in sixth form centre)

In addition, some participants identified the need for professionals to be used for health education at schools and, especially, for 'sensitive issues':

> *Health authorities should go into the schools with properly trained staff – a teacher would often find it very difficult to get the right message across about HIV and it needs a properly trained person.*
>
> (parent of child with cleft lip and palate)

An inquiry into sex education published by the National Children's Bureau (1992) identified teacher anxiety and embarrassment, time pressures on an overcrowded school curriculum and unease about how to handle sensitive issues as the most common barriers to sex education. Another study carried out in secondary schools in the South East Thames Regional Health Authority Area (1990) found that only a third of teachers had received any specific training in HIV/Aids and recommended the involvement of specifically trained personnel and school nurses.

User involvement in health care planning and delivery

In their review of 'Consumer Feedback for the NHS', Jones, Leneman and Maclean (1987) categorised feedback channels along a spectrum from 'direct' at one end to 'indirect' – that is, from personal contact through channels such as patient surveys and Community Health Councils to national pressure groups and general elections. Individual service providers are likely to be involved with direct feedback whilst health service managers are more concerned with feedback channels in the middle of the range. The review looked at the contribution of consumer surveys and other kinds of 'consumer-related' initiatives which the authors suggested fell into three overlapping groups. There were those which were aimed at informing consumers and enabling them to articulate and communicate their opinions, such as patient advocates and community development projects. The second group consisted of 'mechanisms within the health service to enable it to receive opinions and initiate action on them', such as patient participation groups in general practice and locality planning. The third group was aimed at changing staff attitudes and behaviour, for example through the employment of organisational development consultants.

The review found many isolated new initiatives but seldom a concerted programme of action.

In 1992, the NHS Management Executive produced 'Local Voices', a review of local initiatives for giving people a more effective voice in the shaping of health services (NHSME, 1992). This report called for 'a radically different approach to that employed in the past. In particular, there needs to be a move away from one-off consultations towards on-going involvement of local people in purchasing activities'. The report emphasised that local people would have little confidence that they could influence health authority decisions unless there was such on-going involvement, and unless local views were either acted upon or the reasons for not doing so were fully explained.

'Local Voices' suggested that the essentials for involving local people were listening, informing, discussing and reporting. The aim should be to give local people the opportunity to influence the debate at appropriate stages throughout the purchasing cycle. This would require a communications strategy, and the strategy should combine the giving of information, dialogue, consultation, participation in decision making and feedback. The onus would be on the health authority to ensure that the exchange is a positive one and to 'ensure that local people have an early and tangible influence on purchasing decisions'. It was acknowledged that building a continuing dialogue with local people is 'unlikely to be an easy or quick process. It will require perseverance, diplomacy and resources'.

The problems of making a reality of the consultation process were addressed in a review for Swindon Health Authority. This report (Taylor, 1990) suggested: 'dialogue needs to be created with consumers at the collective and representational levels relating to the groups and networks that exist to articulate their interests'.

Acknowledging that 'consumer involvement will not just happen', the Swindon Health Authority report considered that making involvement a reality could involve 'changing fundamental ways of working' and 'being realistic about the time it takes to build up new forms of partnerships'.

These themes were echoed in two recent reports published as part of the King's Fund's work on London. The GLACHC report 'A User Perspective' (1992) emphasised that it is essential to involve voluntary organisations, user groups and Community Health Councils in any programme of quality assurance or process of needs assessment. 'London Health Care 2010' (King's Fund, 1992) argued that, to bring about change in London's acute health services, it is essential that there is the political will and the involvement of Londoners and those working within the capital's health services. One of the report's recommendations for carrying through the development programme for primary and secondary care is 'to involve Londoners in designing services to meet needs which they have helped to identify'.

There exist numerous dimensions to the key policy theme of user involvement in health. These dimensions encompass issues of self-care, individual responsibility for health, health education and promotion, self-help groups, the community health movement, user satisfaction surveys and other forms of feedback, complaints procedures, public consultation, and greater participation in the planning and development of services. This section summarises participants' views about three aspects of user involvement in health care: self-care, complaints procedures and consultation.

Self-care

Robert Gann's 'Health Care Information Handbook – Resources for Self-Care' (1986) stated: 'as we approach the year 2000, there is a growing recognition that, following eras of advances in public health and medical science, the key to further real improvements in health is the involvement of the informed individual in his own well-being ... There is a realisation that medical science and technology have come to a point where further improvements in health can only come about by people becoming active and informed partners in health protection and promotion'.

A scenario for health care in the 21st century defined for the King's Fund as part of its work on London (King's Fund, 1992) has included the possibility that in the future information technology (IT) developments could result in greater public access to health information, treatment options and tools of self-diagnosis. In the group discussions we explored participants' reactions to such ideas.

Among all groups there was strong and widespread disapproval of the use of IT for self-diagnosis. Self-diagnosis tools were compared with looking up symptoms in medical books, and access to such information was seen as 'dangerous' or 'harmful'. One participant commented that 'looking things up can lead people to start ordering the coffin!'

One possible explanation for people not being in favour of computer self-diagnosis was that it was invariably seen as an alternative rather than as complementary to face-to-face interaction with a doctor. Many participants commented on how they also thought that it might be used by the NHS as a cheap option:

> *When you start reading medical books then you find you've got all the symptoms – you need a professional to help you interpret this information ... to me it sounds like an opt-out to save money.*
> (parent of child with cleft lip and palate)

However, some participants felt that IT systems could be of indirect benefit to patients by assisting doctors in making their diagnoses. Participants expressed fears that GPs' knowledge was sometimes inadequate or not up-to-date, and felt that access to IT systems could improve doctors' diagnostic skills. These views were articulated particularly by participants with illnesses that GPs see infrequently and those suffering from chronic conditions.

There was more widespread agreement that IT systems could be of use for helping either the patient or doctor obtain information on the best treatment options, for example, the hospitals, clinics and doctors which specialise in the treatment of specific illnesses. Also, some participants thought that IT systems (such as localised forms of

Ceefax and Oracle) could usefully provide information about self-help support groups and the availability of complementary practitioners.

Complaints procedures

Complaints were identified by participants as a vital means of feedback. However, participants did not just want to voice grievances, but were concerned that there should be procedures for constructive criticism:

> *But complaints are only one way of finding out what people feel about the service – they should be looking for feedback ...*
>
> (participant with diabetes)

> *It's to do with helping to improve the service in the future and not just an outlet for frustration when things go wrong.*
>
> (participant with multiple sclerosis)

In general, participants were unclear about who to complain to, where to complain and how to complain, particularly in the case of hospital services. Participants appeared to have better access to information on procedures for complaining about primary care, and were reassured by the knowledge that they could 'vote with their feet'. Some participants had decided to change their GP. Groups were unanimous in wanting more information on complaints procedures:

> *I've no idea who you complain to if something goes wrong in hospital is there a committee I should apply to? Nobody has ever told me.*
>
> (participant in patients' group)

Participants identified a number of reasons why they found it difficult to complain. Lack of information on complaints procedures was exacerbated by feelings of powerlessness, particularly in relation to hospital doctors:

> *It's more difficult to complain to hospital doctors because they have such a high status.*
>
> (participant with asthma)

> *I've tried complaining in the hospital but they have such a way of talking down to you – making you feel so horrible – that you go away cringing, feeling worse than you started.*
>
> (participant in colitis/Crohn's group)

Participants also perceived difficulties in making the effort to complain when they were ill or recovering from illness:

> *If you're sick you are too tired to complain.*
>
> (participant with asthma)

The third difficulty identified by participants was that they feared the consequences of complaining:

> *If you complained about your GP you'd have problems in the future – and it's unlikely anyone would take you on.*
>
> (participant with asthma)

> *I've sued the hospital – that's why I can't get much done now – I won*

> *my day in court, but now I can't get anything at the hospital.*
> (participant in elderly group)

And, finally, participants with mental health problems felt that they faced particular difficulties in being listened to, or taken seriously:

> *If someone beats you up in hospital – or steals something from you and you complain – do you think they are going to believe someone with a mental illness? – of course they don't.*
> (participant in mental health group)

There was a common fear that doctors and other medical staff would not deal with complaints fairly but would respond as professionals whose first loyalty was to each other rather than the aggrieved patient. Participants stressed that there needed to be a local, independent body or person to whom patients could go if their complaint was not dealt with satisfactorily within the system. There was a feeling that without channels for independent redress, complaints might not be dealt with 'fairly':

> *Who can you complain to at the hospital? – they [the medical staff] all club together – they stick together… There should be someone independent – but it would have to be someone with the authority and power to change the situation – otherwise it's no good.*
> (participant in mental health group)

There was a common wish to keep procedures simple and non-bureaucratic. It was thought that complaining should not necessarily involve putting the complaint in writing, which, as a National Consumer Council report (1988) on good practice for complaints procedures has pointed out, can act as a deterrent:

> *You shouldn't have to put it in writing – you should be able to complain by speaking to someone – it needs two-way communication.*
> (participant with diabetes)

Participants felt that health service users need to have recourse to a service that was wider than a complaints procedure and would include feedback and suggestions to improve the service. One participant explained:

> *… people won't want to use a department which is called complaints; it's too negative – something like client services would be better; especially if you are still having treatment – otherwise if you go to the complaints' department, they [the medical staff] will think that you have got it in for them!*
> (participant in colitis/Crohn's group)

Most participants were not interested in or in favour of suing when 'things went wrong'. Comments were frequently made about not wishing 'to go like America'. But this response depended on whether any damage had resulted:

> *As long as you haven't got ill from it [the mistake] then I think all you would want is a written apology, but if there has been some damage as a*

> *result, then you would have to take them to court because you'd have to live with it.*
>
> (participant from parents with toddlers group)

In April 1991, nine Family Health Services Authorities in London formed a consortium to collaborate in the development of good practice and improve the quality of their complaints-handling procedures. The consortium's report (London FHSA Complaints Consortium, 1991) identified five basic standards for complaints procedures: 'they should be independent and impartial in their investigations; speedy; accessible; effective in resolving the grievance, where possible; and effective in improving services'.

In relation to improving accessibility, the consortium is developing practice-based complaints procedures. They have suggested that Family Health Services Authorities should try to ensure that complainants are aware of their right of access to records and could make leaflets available in appropriate languages, as well as advertising the availability of interpreting services.

The GLACHC report on users' views of acute services for the King's Fund (1992) also emphasised the need for greater efficiency and accessibility of complaints procedures, stating that 'a comprehensive range of patients' rights should be guaranteed, backed up by a more efficient system for complaints and redress. Information about how to make complaints and obtain redress should be disseminated, thus enabling both users and those working on their behalf to pursue a grievance'. According to the London Family Health Services Authority Complaints Consortium report (1991) Community Health Councils are involved in up to half of the complaints received by FHSAs. Most Community Health Councils reported that their involvement was helpful because they 'were able to highlight issues which the complainant might not otherwise have seen as important'. However, not all Community Health Councils were prepared to represent a complainant at a hearing.

Consultation

There exists a growing awareness among consumer organisations, health care providers, and policy-makers that users can make substantial contributions to health policy debates by participating in decision-making about health service development.

Winkler (1986) argues that a partnership in decision-making is a crucial part of user-involvement and identifies five ways in which users may contribute to health service development: 'Users, because of their ability to be blunt, can introduce items to the agenda that would otherwise not be there; [they] can force a change in the language which symbolises the way users are thought of by providers; [they] can challenge conventional ways of doing things that predetermine outcomes; [they] can begin to introduce change by challenging accepted priorities and ways of doing things, [and] the user representative can act as a channel for information otherwise blocked by the hierarchical system'.

In general, participants in our group discussions felt that it was important that users and potential users of services had an active say in their development. How intense or prolonged they wanted that involvement to be, however, varied a great deal. In some groups there was a desire for a high level of involvement through, for example, attendance at health authority meetings:

> *We should be involved – it affects us – we are the people who are going to use it – we need to make sure it [NHS] is still there.*
> (participant in sixth form centre)

> *... we pay for it and we should have a say in what it does and how it's managed ... for the people and by the people, it's the only way we will get the changes to the service that we want.*
> (participant in Community Health Foundation group)

> *There should be a greater role for people – similar to the role they have in education where schools have governors – there are professional skills which people should not get involved in like teaching skills and medical skills – but there are other areas where people have a lot to offer and should and can get involved.*
> (participant in complementary users' group)

Other participants wanted the NHS to be accountable to public views through the general democratic process, but were not particularly interested in being actively involved:

> *Through the post, a questionnaire maybe, but not going along to meetings – it's best to leave it to them, people who know.*
> (participant in parents with toddlers group)

> *Complaints are only one way of finding out what people feel about the service – they [the NHS] should be looking for feedback – how about a survey on what people think about the food?*
> (participant with diabetes)

Many participants thought it was crucial for service users to have ready access to well written literature on health topics:

> *Along with getting people involved, there must be information made public about the NHS and there needs to be literature available to people on what is meant by 'good health care' – perhaps the King's Fund could produce that for ordinary people.*
> (participant in patients' group)

From all groups there were feelings of frustration that even when views were given, they were not acted upon or taken seriously:

> *Let's face it, the people that are using the health services are never going to govern them.*
> (participant in NCHR group)

Also, there was a feeling that the very structure of the NHS worked against accountability and effective consultation:

> *The NHS has gone off into this self-contained and non-democratic world.*

> *In the first place, it used to be an institution which was led by professionals but now it's management-led. Why can't it be run in a more democratic way – it is divorced from any notion of community responsibility, other than the Community Health Councils but these have a very resticted role ...*
>
> (participant in complementary users' group)

All these feelings could influence attitudes towards becoming involved. People were sceptical of how much notice was taken of views obtained from consultation, and our discussions indicated a general view that mechanisms for public feedback and consultation do not necessarily mean that the public have the opportunity to influence decision-making:

> *It's very important to involve people – the fact that this group is still going strong after two years must count for something – for people's commitment ... but none of our representation on the cuts or hospital trusts has got anywhere, no one took any notice.*
>
> (participant in patients' group)

McIver (1992) has drawn attention to the crucial distinction between 'consultation' and 'opportunity to influence' and argues that the two principles are commonly confused by those involved in consumer feedback in the NHS.

The National Community Health Resource (Jeyasingham, 1991) has also noted that a common cry from community groups around the country is 'we've been telling them our needs for years, but nothing ever changes'.

A key issue concerning public consultation and participation in health service development, and one considered in the selection of groups for this study, is that of representativeness. People joining voluntary organisations or health forums are more likely to be white, middle-aged and middle-class, and less likely to put forward views held by people in other categories, such as teenagers or ethnic minorities. This issue has been highlighted by McIver and Carr-Hill (1989) in their discussion of ways in which users can be involved in the health services planning process. They mention how voluntary organisations who are asked for their views are likely to represent the needs of particular categories of more organised, powerful users and thus are concerned that more powerful groups will gain resources at the expense of weaker ones.

The funding of London's health services

Support for the National Health Service

Quantitative opinion polls (Bosanquet, 1989) on public attitudes towards the funding of health care show strong and growing support for the principle of the National Health Service, i.e. that the state should be the dominant provider of health care, and growing opposition to the idea of a 'two-tier' health system, where the NHS is available only to those with lower incomes. The annual opinion poll on British social attitudes by Social and Community Planning Research (Rentoul, 1990) found that 64% of those interviewed opposed the idea of a two-tier system in 1983 and 74% in 1989.

It was clear from our group discussions that participants saw health care as a right, paid for from taxation, and some objected to any idea that the NHS is 'free', while people 'pay' for private medicine:

> *We always talk about the NHS and a private service – but look at it the other way – we pay already for the NHS. We are not getting it free – we pay for it. When we say private medicine and NHS we are making a difference – and there isn't a difference – except that the NHS treats people regardless of their situation.*
>
> (parent of child with cleft lip and palate)

> *After all it isn't free – we've paid in for it all our lives.*
>
> (participant in carers' group)

Our findings are consistent with those of other studies which have suggested that a significant proportion of people would be prepared to pay more towards the NHS. The following quote was a typical response:

> *I wouldn't mind paying one or two pence on the income tax to help the NHS – it is a very good thing – I've travelled extensively and I can honestly say what we have here is a very good system compared to a lot of other places. And, it's very important to preserve and build on it and not demoralise it further.*
>
> (parent of child with cleft lip and palate)

During the course of one discussion, a participant asked whether others in the group thought 'there should be a means test on earnings' for using the NHS. This was strongly rejected by others in the group who argued that it should be available to everyone but they felt that the problem of resources was because:

> *... we do not pay enough per head and we should increase contributions from the higher wage earners.*
>
> (participant in the mastectomy group)

A Gallup poll for the *Daily Telegraph* in November 1991 found that 62% of those interviewed claimed that they would be prepared to pay at least £1 a week more in taxes for increased health care spending, although the annual opinion poll for NAHAT and the HSJ carried out by Research Surveys of Great Britain Ltd at about the same time found rather less support for additional taxation (44% were unwilling, 42% willing and 14% unsure) (Davies, 1991). In the latter poll, most support for extra taxation was found in London (53%). This finding needs to be considered alongside the finding that, compared with other parts of the country, Londoners have the lowest opinion of their health services (see page 22).

The balance between public and private health care

The quantitative opinion polls referred to earlier have found that, in spite of the spread of private health insurance during the 1980s (in terms of the number of private hospital beds and the level of private medical treatment), there has been no parallel increase in public support for private health insurance. On the contrary, there has been a small decline in support for private provision. Rentoul (1990), commenting on this evidence, concludes that increased use of private health care cannot be taken to indicate a shift in general attitudes away from support for collective welfare provision.

Our data reflect these findings and illuminate further the reasons why people support state provision, and why, at the same time, some opt for private treatment. As stated on page 24, the group discussions, without exception, endorsed their commitment to London's future health care services being provided for most people by the NHS, and definitely did not want a 'two-tier' system where the NHS simply provides a 'safety-net' service for a minority unable to take advantage of private health care. Many participants were unhappy with what they perceived as 'creeping privatisation' of the health service:

> *It still bothers me that it will drift towards more private health care in London ... there will come a time when people can't afford it – individual circumstances change – and we will be left with an NHS like the American system which is not satisfactory at all.*
>
> (parent of child with cleft lip and palate)

> *As more people opt out of the NHS so it will deteriorate ... I think they [the government] are trying to wear us down – to the point where we will opt for private medicine – we'll be so desperate.*
>
> (participant in elderly group)

A recent survey of private health care insurance and the future of private health care in the UK (Laing and Buisson, 1991) found that 12% of the population was covered by private insurance in 1990, and geographically London had the highest concentration of people with private cover (estimated at 17%). A relatively small percentage of participants in our group discussions had experience of private treatment. Those that had, all also supported the NHS. Again, these views are comparable to those of other studies. From the available evidence, Taylor-Gooby (1985) has concluded that 'most of the people who want private care also strongly support the state sector'.

The advantages of private health care

The advantages of private health care identified by participants included shorter waiting times for treatment, more personal care and respect, better food, greater privacy, and less sense of being processed through an over-stretched system:

> *You jump the waiting list ... you get it done ... you have more pleasant surroundings ... when I had a major operation in an NHS hospital I was stuck in the corridor for three weeks because they were so full ... privately you get patient comfort, better food ...*
>
> (parent of child with cleft lip and palate)

> *When my husband had his operation privately, the surgeon phoned me afterwards to tell me that it was all all right – when I went to the ward it was all beautiful and very gentlemanly with nice people. And they had all the equipment – all mod cons.*
>
> (participant in mastectomy group)

> *At the private place, they're calm, you're calm – they sit you down, the nurses come and talk to you – they make you feel welcome before you see the doctor – it's quiet.*
>
> (participant in sixth form centre)

> *If you pay for a service, you may find that your self-esteem increases, you are seen in a very positive way – that is reflected by the fact that you are in good and comfortable surroundings.*
>
> (participant in NCHR group)

Even when participants were not in favour of the principle of private health care, some could identify a specific situation or emergency when the circumstances dictated that it was necessary to 'go private' to receive quicker treatment either for themselves or their family:

> *This woman was told she had to have a mastectomy after they had removed two lumps; the surgeon told her you will have to wait four weeks before we can even do the x-ray. She asked 'Why have I got to wait so long?' and he said 'Well, it's lack of funds and all this business'. She asked what if I go privately and he said 'That's ok, I can do it tomorrow' and she said it seemed just a joke to him.*
>
> (participant in mastectomy group)

> *If I had the money, I'd use private medicine, not for myself but for the children – when you see your children in pain or really sick, you just want the best for them and if that means going private and I had the money, then I would.*
>
> (participant in parents with toddlers group)

However, participants were aware that such benefits were available only because the numbers using private health care are small relative to those using the NHS. No group or individual participant expressed any confidence in the ability of private health care to handle the volume or range of work carried out by the NHS. The view was expressed that, if private medical services had to cope with the numbers and range of work seen by the NHS, it would not do the job as well or as cheaply.

Disadvantages of private health care

Certain groups were identified as being neglected by private health care, such as elderly people, psychiatric patients, and people with chronic conditions:

> *It's impossible to sustain the range of services provided now if the majority of people went private – BUPA have just announced they will not insure people with psychiatric illnesses for example.*
>
> (participant in patients' group)

> *The majority of private health care only deals with the more palatable sides of medicine and many people are caught in the dilemma of thinking they are covered for private care but finding out they are not – especially for long-standing diseases.*
>
> (participant in NCHR group)

> *I've just had a letter telling me I'm almost at the end of my money for this*

> *year – luckily my next appointment isn't until April when the next year starts. But as time goes on I'm going to need more appointments and what happens then – because I won't have the money to pay for them.*
> (participant in mastectomy group)

> *... there would be no preventive medicine without the NHS.*
> (participant in mastectomy group)

Some participants expressed the view that private medicine exploits NHS resources:

> *It's wrong – treating private patients in NHS hospitals, but it's money, it all comes down to money ... they shouldn't mix them – there should be private hospitals for private patients ...*
> (participant in elderly group)

> *I don't think the NHS should have private patients in there, jumping the queue ... consultants should come clean too on how much work they do for the NHS and how much privately ...*
> (parent of child with cleft lip and palate)

> *In NHS hospitals, it's the NHS that's paid for all the equipment, so why are they [private practitioners] allowed to use it – that's all wrong ... Private medicine ends up lowering the standards in our NHS hospitals ...*
> (participant with asthma)

> *We are wasting money on a private health system – it [private health care] doesn't train anybody, it uses NHS resources – it doesn't put anything into the system, it just takes money out.*
> (participant in mastectomy group)

Some participants expressed the fear that a private system may encourage doctors to suggest unnecessary or over-interventionist treatment, as a means of making more money:

> *You go along and have a consultation and someone says you need this or that out – but you can't be sure that it's necessary – it could be contributing to someone's bonus!*
> (participant in patients' group)

> *You don't have a different relationship with a doctor or consultant at the hospital because you're private – the only difference is that they'd try to find something wrong with you.*
> (participant in carers' group)

A commonly expressed view among participants was that people were increasingly being 'driven' to the private sector by the current 'state' of the NHS:

> *People are using it [private health care] more now because they can't get the treatment they need on the National Health because of the problems of funding ... when you are ill and have to wait – you get frightened and that's when people turn to private health care – but it's not the right way forward – it's bad.*
> (participant in patients' group)

The point was also made that because most private health care in this country is 'bought by the employer as a perk of the job' people may find themselves without cover just when they most need it, for example, after being made redundant or during retirement. In the mid-eighties, Griffith *et al.* (1985) reported that private health insurance was the third most important employment perk.

Some participants expressed the view that they had no choice about buying private health care, as they were unable to afford it:

> *We don't want more private medical care if you've got to pay for it; we ain't got no money.*
> (participant in parents with toddlers group)

Concluding remarks

Overall, there was the feeling that the NHS provides the best treatment, as opposed to care and 'hotel-type' services, which were the perceived advantages of private health care:

> *It depends what is wrong with you – I think for minor operations where there are long waiting lists it [private medicine] is fine – but if you had a major accident, you'd want to be in an NHS hospital.*
> (parent of child with cleft lip and palate)

> *If you have anything seriously wrong with you – a long-term illness – the best place to be is in the NHS.*
> (parent of child with cleft lip and palate)

This finding echoes a recent study by Cant and Calnan (1992) which examined why and in what circumstances people decide to use their private health insurance. The majority of subjects in this study saw no differences between the public and private sector in terms of the standard of technical care. The main perceived benefits of using the private sector were 'speed and convenience and buying those creature comforts which are the gilt on the cake'. These views were echoed by some participants in our group discussions, who commented:

> *you may get seen quicker and get a colour television and a telephone, but I don't think the medical treatment is any different – after all it's the same doctors as in the NHS.*
> (participant in elderly group)

> *He [her husband] got the same surgeon to do the operation as in the NHS, so you get the same expertise and the treatment was the same, but what you pay for is the handshake and the frills.*
> (participant in mastectomy group)

A small-scale study of Afro-Caribbean women's use of private consultations with general practitioners (Thorogood, 1992) suggested that 'their control over their own health care' was extended by buying this additional service and that 'the historical and cultural knowledge and experience of black people lessens the grip of the ideological barrier to the use of private health care.' The study concluded that 'private doctors are used, in addition, to provide services which the NHS appears either unable or unwilling to provide; that is – time, attention, personal service, second opinions, politeness and a degree of patient control'.

In the discussion with representatives from black health users' groups, however, the point was made that institutionalised racism can be as prevalent in the private health sector as the NHS. And the research by Cant and Calnan concluded that 'while in theory private health insurance should enable subscribers to have a choice of health care, in practice, this choice is limited. Inadequate knowledge, concerns about financial cost, ideological beliefs along with the gatekeeping role of the general practitioner suggests that the notion of consumer choice and sovereignty in private health in the UK is a myth' (Cant and Calnan, 1992).

Londoners' health care priorities

The setting of health care priorities and the allocation of health care resources are increasingly seen as areas in which the public should properly, and could usefully, contribute to decision-making (Hadorn, 1991). However, there have been very few studies of public priorities conducted to date and there is therefore little comparative data available.

The best-known attempt to discover the patient's view on the principles which should guide rationing was undertaken by the Oregon Health Services Commission in the United States. The Commission attempted to combine technical measures of the benefits of treatment with a systematic approach to constructing a list of social preferences for rationing to provide a formula for resource allocation. The major problems of such exercises are that they require participants to understand the expected health benefits, risks and costs of the services being evaluated. Also, they may take insufficient account of ethical questions and certain socio-economic groups in the population tend not to take part.

Rationing in the NHS has tended to take place implicitly through limited budgets, waiting lists and gate-keeping by general practitioners. Making the rationing process explicit allows for the possibility of public discussion of competing interests and values.

It was decided that one element of our group discussions should be to elicit participants' views on priorities for future health service development. The aim was a modest one, and did not involve asking participants to think in terms of actual financial resources, but simply to discuss the relative importance that they attached to various aspects of health service development.

Towards the close of the discussion groups, each participant was asked to allocate counters (15 in total) between six major health service areas:

- Preventive programmes, health promotion and education
- Hospitals and all hospital-based services
- Primary care, health centres, GPs and other primary health care staff and services

- Complementary therapies and medicines
- Research and development into prevention, treatment and cures
- Information technology for aiding self-diagnosis and providing information on treatment options

The scope of each service area was described, prior to the allocation of the counters, and participants were told that they should allocate their counters on the basis of how important they thought each service area should be in the future. The collective results for the individual allocation of counters was reported back to each group at the end of the discussion. For the purposes of these findings, the number of counters allocated to each service area was totalled for all the groups, and percentages calculated.

Official government policy is to attach less priority to in-patient hospital services and give higher priority to primary care services, preventive programmes, health education and promotion. Our study, however, shows that participants overall gave almost equal priority to hospitals (22%), preventive programmes (20%) and primary care services (19%). Participants frequently mentioned the need for a balanced and well resourced package of health care services, provided in both the primary and secondary care settings, each contributing to a choice of treatment options.

Hospitals were given a high priority in almost all the group discussions but, particularly, amongst some of the 'expert' user groups (e.g. participants with multiple sclerosis or asthma, and parents with children with cleft lip and palate). They tended to feel that the medical knowledge that they had about their own condition was greater than that of most general practitioners. One of the reasons why these groups gave higher priority to specialist hospital care than to primary care may be related to their perceptions of GPs' more limited knowledge and experience of chronic illnesses and less common conditions. Participants in the mental health group also gave a high priority to hospitals because their experience of access to primary care services was far from satisfactory. The groups which gave the highest priority to primary care tended to be those where their general practice had been responsive to individual medical needs and provided a wide range of treatment options, including complementary services.

A study conducted by Sheffield Community Health Council (Trent, 1981) which asked people to state where their priorities lay in the NHS, also gave a high priority to hospital services. We would tend to agree with other commentators (Trent, 1981; Cornwell, 1984) who have suggested that the public are, perhaps not surprisingly, reflecting the priority that both government spending patterns and the medical profession (for example, through their career choices and the distribution of consultant merit awards) still attach to general and acute hospital services, relative to other health services.

Quite strong differences of opinion were expressed on the priority which should be given to preventive programmes, health education and promotion. The lowest priorities were given by those groups which considered health education and promotion to be either ineffective (e.g. parents with toddlers) or of limited benefit to health (e.g. carers and elderly groups) or of little direct benefit to their medical condition (e.g. parents with children with cleft lip and palate and the mental health group). The highest priorities for preventive programmes were given by groups which were predominantly middle-class (e.g. mastectomy group) and those with direct experience of effective health education (e.g. participants with diabetes and the patients' group).

Lower priority was attached overall to research and development into prevention, treatment and cures (16%), complementary therapies and medicine (16%) and information technology for self-diagnosis and treatment options (7%). The groups which attached highest priority to complementary medicine were those with direct experience of using complementary services (e.g. the Community Health Foundation group, NCHR, and the counselling group). Also, complementary medicine was considered important by individuals within other groups who had a medical condition which had not responded satisfactorily to orthodox medicine but had benefited from complementary treatment.

In some instances, participants with experience of complementary medicine within the primary care setting gave a lower priority to this as a separate service area on the understanding that, in the future, access to complementary treatment would be available as a service provided within primary care. Particularly low priority was given by all groups to IT developments (see pages 51–52) and, where it was given any priority, it was solely for obtaining information on self-help support groups and treatment options and availability. No groups attached importance to the use of IT for self-diagnosis.

Age, gender, class and ethnic differences

The views expressed in the group discussions were analysed as a whole to ascertain whether there were perceptible differences on the basis of participants' age, gender, class or ethnic origin. Although such differences were identified and have been highlighted throughout this report, these were not the major determinants of participants' views. It was the participants' medical condition and their direct experience of treatment and health care services which primarily formed their opinions and perceptions. For example, participants with chronic physical conditions (e.g. multiple sclerosis, colitis or Crohn's) and those with mental health problems were more likely to express high dissatisfaction with health care services regardless of their individual social and economic characteristics.

Many of the views expressed during the discussions were shared by participants of all ages. For example, old and young participants were equally critical of health care services. The assumption that a 'gratitude barrier' exists among older people, making them more reluctant to criticise the NHS, was unsubstantiated. People of all ages were similar in their views about the unsatisfactory relationship between medical staff and patients. Both young and older participants felt they were not treated with sufficient dignity and respect and their opinions were not adequately sought or taken into account when deciding on treatment.

There were, however, some differences between the age groups. Younger people tended to be more enthusiastic about the importance of health promotion and prevention programmes. Older people, on the other hand, tended to feel that such programmes were either ineffective or of limited real benefit to health. Participants of all ages identified that the health service attached the highest priority to health care for children and the lowest priority to geriatric services.

There were a number of differences between the views of female and male participants. Women tended to have more experience of using health care services, both for themselves and in their roles as parents and carers. This meant that women had a richer and more varied range of views, embracing both good and bad experiences and usually formed over a long period of time. The greater contact between women and health services is paralleled by their greater involvement in self-help groups (and, to some extent, in the higher participation rates of women in our discussion groups). The study also found support for the concept of choice in the gender of medical staff providing treatment in the primary and secondary care settings.

Many of the views expressed in the discussion groups were shared by participants from all social classes. They were similar, for example, in the level of satisfaction or dissatisfaction they expressed with the treatment and care provided by the NHS. The stereotype of the middle-class patient having access to more information and being treated with greater respect by medical staff was not substantiated by the discussion group participants. All participants agreed that quicker access to treatment and greater recognition of the rights of the patient were most likely to be achieved through complementary medicine and private health care.

There were social class differences in the priorities attached to the various service areas. Working-class participants gave a higher priority to research and development into new cures and treatment whilst middle-class participants thought that health promotion and preventive programmes were of greater importance. In addition, middle-class participants expressed interest in playing an active role in consultation on health service issues.

Participants from black and ethnic minority groups expressed a number of views which either were not identified by white participants or highlighted differences in their experiences of treatment and services. The black and ethnic minority participants felt that, in general, their communities were less well served by the NHS and private health care. Participants identified a number of reasons for this. For example, there were particular medical conditions such as sickle cell anaemia which were prevalent in black and ethnic minority groups but which were felt to receive insufficient priority and resources within the NHS.

The discussion group participants also identified a number of barriers to obtaining adequate health care by black and minority ethnic communities. These included: the failure of the NHS to properly address the different religious and cultural needs of those using health care services; the lack of appropriate information in relevant languages on services and treatment; and assumptions that an extended family structure will provide care and support for sick and recuperating relatives. In addition, there was criticism of the lack of black and ethnic minority images in health service literature and, in particular, in relation to health promotion and education.

CHAPTER 5

Conclusions and recommendations

In the group discussions for this study, participants used their personal experiences and observation of health care services to identify ways in which they believe services should be organised and developed. Their views provide a useful and 'down to earth' counterbalance to those of health care professionals and policy-makers, and it is clear that they have a vital part to play in service and policy development.

Many of those attending the group discussions saw their participation as a good opportunity to contribute to the current debate on health service planning in London. However, they recognised that for public participation to be effective, health service managers, policy-makers and politicians must be responsive to the views expressed and demonstrate how those views have influenced decision-making.

The findings from some previous studies suggest that public attitudes tend to exhibit an in-built conservatism which is constrained by past experiences and an acceptance of the status quo. However, our study provides scant evidence of such limitations. For example, participants expressed a willingness to identify and endorse alternatives to traditional health care such as complementary medicine, counselling and a greater reliance on self-help.

It has also been argued that the gratitude felt by users of health care services can influence their assessment of the quality of the care received. However, the findings of this study suggest that, even for older users of health services, a sense of gratitude is less prevalent than the view that access to good-quality and appropriate health care is a right and paid for through tax and national insurance contributions. Thus, a sense of gratitude appears to have a decreasing influence in shaping lay opinion.

Other commentators have suggested that the process of exploring public views through research with users could divert them from using other channels for participation and complaint. On the contrary, in our study those contributing to the research commented that participation in the group discussions had helped to arouse and widen their interest in health care issues and thus would help to sustain their longer-term involvement.

Previous research has also suggested that lay views are frequently shaped by the influence of the medical profession, with the public attaching similar priorities to individual health care services. Our findings suggest a weakening influence for professional medical opinion and an increased awareness of its fallibility. This has led the public to challenge professional wisdom and seek to independently define their health priorities.

Our study has identified a number of ways in which, as lay users of health services and as members of the public, participants had a unique perspective of health care needs and priorities. In particular:

1. Participants did not always agree with the relative priorities for service development proposed by professionals and official policy. For example, whilst recognising the benefits of more day surgery and a wider range of treatments provided in the primary care setting, participants attached importance to the retention of London's hospitals as 'centres of excellence'. Also, participants wanted greater equality in health care provision through an enhancement of geriatric and mental health services.
2. Participants recognised the importance of technology, but felt that this should not be at the expense of providing for the care and comfort of the patient.
3. Participants stressed that the emotional and physical needs of patients and their relatives should be considered of equal importance in providing curative and preventive treatment. Counselling services were identified as one way of making a significant contribution to the healing process.
4. Participants argued that the sharply defined boundaries between services tended to produce a fragmented and sometimes patchy response to overall needs. They felt their health care needs related to them as a whole person, encompassing their social situation as well as their medical condition.
5. Participants felt the medical profession as a whole did not treat patients with sufficient dignity and respect, and more importance should be attached to patient opinion on diagnosis and treatment.
6. Participants saw consistency as a vital element in the development of good doctor-patient relationships.
7. Participants felt the amount and range of information which health care providers consider appropriate for patients often falls short of what patients want in order to make informed choices and decisions.

The study's findings reinforced the view that people's concern with health care extended well beyond their direct interest as a patient or consumer of health services. For example, participants had a wider perspective on the role of the NHS and its relationship with private health care which was held irrespective of their own personal capacity to purchase private treatment. Also, participants were concerned for the NHS to provide adequate health care for groups whose needs are generally neglected by present health care provision, for example, the homeless, mentally ill and refugees.

Finally, the findings of this study provide an insight into the importance of organisational factors as determinants of people's use of health services. Participants identified the following main deterrents to seeking orthodox health care:

1 The difficulties of obtaining access to treatment within a time which the individual considered was appropriate for their condition.

2 The restriction of treatment to a setting which the individual considered inconvenient or unacceptable, e.g. access to counselling restricted to a hospital setting.

3 An unhelpful response at the first point of contact for treatment, e.g. from a receptionist in a primary care practice.

4 A fear that, should the treatment require a period of stay as a hospital in-patient, facilities for aftercare or convalescence will be inadequate.

5 A lack of confidence in the range of treatments offered in orthodox medicine.

6 A previous episode of treatment where the individual experienced or observed a poor-quality medical response or care.

Many of the findings in this research identify improvements which participants wanted for London's health care services and some of these would lower the barriers to reporting ill-health. In the short term this would increase demand for some services. However, in the long term, earlier diagnosis and treatment of medical conditions may well lead to fewer demands for the more costly curative treatments.

Recommendations

The findings of this study on the views of Londoners about health care in the capital lead to the following recommendations:

1 The NHS should continue to provide comprehensive health care for all Londoners as a right with access irrespective of the individual's financial resources or economic status. The notion of the NHS as a 'safety net' service operating for those with limited or minimal financial means is strongly rejected.

2 More resources should be directed to the NHS to ensure standards and quality of health care are enhanced and consideration should be given to ways of increasing tax revenue specifically for this purpose.

3 Whilst recognising a limited, continuing role for private health care, NHS resources of equipment, trained personnel and in-patient facilities should be for the exclusive use of the public health sector.

4 Well resourced central hospitals acting as 'centres of excellence' should be maintained to continue to provide treatment and advanced research and development for medical conditions requiring specialist knowledge and expertise.

5 Primary care in London should be resourced to offer an expanded range of services including minor surgery, specialist clinics, social care and community support.

6 The nursing profession should consider how the increased technology of specialist nursing could be counterbalanced by more emphasis on the care and comfort of the patient. This could be addressed through training, resources or individual remuneration.

7 The NHS should recognise more fully that the people using the health service are from diverse religious and ethnic backgrounds and may, therefore, have differing needs in terms of diet, communication and health care. Recognition of this diversity of health care needs should be central to the planning and management of health services and the training of medical personnel.

8 There should be recognition, through resource allocation, training and status within the medical profession, that those in receipt of lower standards of health care in the so-called 'cinderella services' (e.g. geriatric, mental health) have a right to equality of health care in a public service.

9 Effective communication and liaison should be improved between all service providers in the primary care setting to ensure health care and community support are not fragmented but delivered as an integrated service appropriate to the individual's needs.

10 Access to aftercare services and convalescence should be more widely available and an individual's need for such services should be assessed without assuming existing family members or friends can provide the necessary support.

11 Counselling should be provided within the NHS for patients experiencing anxiety and stress which is either contributing to their illness or the result of their treatment. Counselling services would be most appropriately, though not exclusively, provided in the primary care setting.

12 Consideration should be given to how complementary treatment could be made available by the NHS within the primary care setting.

13 In managing the allocation and routines of health service personnel, there should be recognition of the high value which patients place on consistency of contact with medical staff, both in the primary and secondary care settings.

14 For both in and out-patients and those using accident and emergency services, the patient should be kept properly and promptly informed of the mechanisms of the 'queuing' or appointment system, their progress within it and any reasons for delay.

15 Where a GP appointment system exists, a degree of flexibility should be exercised by the practice to ensure patients receive sufficient time with their GP and the consultation is not artificially 'cut short' by the constraints of an allotted time.

16 Both in primary and secondary care, patients should have the choice to receive more information, both verbal and written, on their medical condition, treatment options and any required changes in lifestyle. Medical staff should be encouraged to develop contacts with self-help groups to help patients acquire information and access to their support services.

17 Health promotion and education needs to address the wider social issues of poverty, poor housing and inadequate access to community-based services as well as more specific issues on health and individual lifestyles.

18 Before embarking on a programme of consultations with health care users, those responsible should make explicit what role the findings will play in the decision-making process. They also need to identify how the dialogue can be constructively maintained and developed by recognising that the contribution of both health care users and professionals is equally valid to policy development.

19 The NHS should continue to explore effective ways of involving health care users, at the earliest opportunity, in the establishment of service priorities.

20 Complaints procedures should be improved by establishing locally based, independent and impartial bodies to receive and investigate complaints; by making the system more user-friendly and less formal; and by accepting verbal as well as written complaints.

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APPENDIX 1
List of Discussion Groups

Group types	Distinguishing features, rationale for inclusion	Groups	Location
Frequent or 'expert' users of one particular speciality	Long-term users, likely to have established views, may also have views on how services have changed over time, detailed knowledge of particular speciality	Asthma group Mastectomy group Colitis and Crohn's group Multiple sclerosis group Diabetes group Mental health group Counselling group	Fulham & Ham. West London London-wide London-wide West London Camden South East London
Frequent users of a range of medical specialities	Knowledge of a range of services, likely to have views on how well services work together and give patients a package of care. Able to draw comparisons between different types of services	Elderly persons' group	Sydenham
Users of services on behalf of others	Likely to have informed views about support services in relation to needs of carers. Perspective on how relatives and friends of patients are treated	Carers' group Parents with toddlers group Cleft lip and palate group	Somers Town Wells Park London-wide
Users of complementary therapies	Will be able to compare conventional with complementary services, articulate reasons for opting for non-conventional services	Community Health Foundation North London Complementary Users	London-wide North London
General users	Although there is unlikely to be a 'typical' user, this group would try and get at the 'person in the street' view. Likely to have less articulated views and less experience of the NHS	School 6th form 6th form centre Sydenham patients' group National Community Health Resource group	Tower Hamlets Islington Forest Hill London-wide

APPENDIX 2
Characteristics of the sample

The discussion group participants

A total of 146 people participated in the discussion groups: 28 men and 118 women. Their ages ranged from 16 to 86 years, with most age groups being well-represented. Just over three quarters (77%) of the participants were white. 6% of participants defined their ethnic group as black-Caribbean and black-African and 8% as Indian/Pakistani/Bangladeshi. Twenty-nine participants were caring for between one and four children under 18 (on a full-time basis). Between them they cared for a total of 52 children.

Over one third (36%) of the participants were employed full or part-time and another third (32%) were retired. The remainder were either in full-time education (16%), registered unemployed or disabled (10%) or caring for the home full-time (6%). The participants' main source of income obviously reflected their employment situation. Thus, one third (36%) obtained their income mainly from their employment and a further third (32%) received an occupational and/or state pension. The remainder were either supported mainly by their parents (16%), lived entirely on state benefits, such as income support or invalidity benefit (12%), or were supported by 'other' means (3%). The occupations of the participants in employment were classified according to the Registrar General's classification. Of these, 65% were in professional, managerial or technical occupations and a further 23% were in skilled non-manual work. Only 12% were in skilled manual, partly skilled or unskilled occupations.

The participants were asked some general questions regarding their health status. When they were asked whether they suffered from any long-term illness or handicap which limited their daily activities or work, 36% stated that they did so. However, when asked to make an assessment of the state of their health as a whole, 46% described it as 'good' and a further 43% as 'fairly good'. Only 11% described their health as 'not good'.

Exactly half of the participants stated that they had attended a casualty or out-patient department of a hospital as a patient during the last year (excluding a straightforward ante or post-natal visit). Forty-one per cent of the participants had been in-patients in a hospital overnight or longer during the last five years. The participants had personal experience of a wide range of medical conditions and illnesses including: arthritis; asthma; cancer; colitis; diabetes; hearing and sight impairment; heart disease; multiple sclerosis; and psychiatric disorders. Most participants had both recent and past experience of treatment for their own medical conditions. All participants also had experience of the health service through their relationships with friends and relatives.

The cared-for

Twenty-two participants attended the three groups set up specifically for carers, where issues relating to caring were discussed. These 22 between them were currently caring for 20 adults or children. (The relatives being cared for by six of the participants had recently died.) Of the cared-for, 12 were male and 8 female. Their ages ranged from 18 months to 85 years, but were concentrated in the very young and the elderly age groups. Carers were either looking after their own young children or an adult son or daughter with learning difficulties or were caring for an elderly spouse or sibling.

The medical conditions or illnesses which the cared-for suffered from included a cleft lip and palate, impaired hearing, Alzheimer's disease, a stroke and arthritis. The cared-for relatives who had recently died had had a number of illnesses, including Parkinson's disease, motor neurone disease and dementia.

Further information

Further information about the characteristics of the group participants and about the discussion schedule is available from the LRC.

KING'S FUND LONDON INITIATIVE

WORKING PAPER NO. 14

Londoners' Views on the Future of Health Care is one of the final tranche of a series of papers which initially were prepared to inform the work of the King's Fund Commission on the Future of Acute Services in London.

The King's Fund Commission on the Future of Acute Services in London has published its report on the future of health care in the capital, *London Health Care 2010.* The King's Fund remains committed to a wide-ranging programme of research and development which will contribute to improving health care in the capital.

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