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OBTAINING
THE VIEWS
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CARE SERVICES

SHIRLEY McIVER

OBTAINING THE VIEWS OF USERS OF PRIMARY AND COMMUNITY HEALTH CARE SERVICES

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

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PREFACE

This publication is the fifth in a series aimed at helping health service staff to obtain the views of service users, and it is written for anyone who has been given this responsibility, whether nursing, medical, paramedical or managerial. The series presumes no social science background and offers a flexible approach which is very amenable to local adaptation and interpretation.

The booklet provides evidence that users value certain elements, such as the quality of their relationship with the care giver, good communication, appropriate information and a successful outcome to the treatment, whatever the service area. It includes examples of questions to ask users about these 'core concerns'.

Readers are encouraged to combine a number of methods to achieve useful information in different circumstances and with different types of service user, and examples are given.

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1 INTRODUCTION

Obtaining feedback from service users is generally recognised to be an important part of the process of improving service quality, but there is still widespread uncertainty about what are the best ways of carrying this out. There is greater confusion in some service areas than others, and both primary and community health care are areas where, for various reasons, feedback is particularly important yet difficult to obtain.

The reasons are different for each of these service areas. As far as primary health care is concerned, more people receive this than any other form of care. For example, the average number of GP contacts in a year for each person is about four (Office of Health Economics, 1987) and many of these contacts result in a visit to a pharmacist. This means that for many people, a visit to one of the primary care services is a regular occurrence.

From a methodological point of view, the difficulty lies in the wide variety of different kinds of people who use the service. Cultural and language differences create problems in the construction of a single instrument to obtain views.

Community care, on the other hand, is used by far fewer people but for many of these it will affect a large part of their life. The quality of the service can have a major impact on whether they live a rewarding life or one of loneliness and misery.

Many feedback methods will not be sensitive enough to 'fine tune' services to the requirements of users. In any case, users of these services are among the most vulnerable and disadvantaged sections of society – those who for various reasons will not feel able to fill in questionnaires.

In consequence, anyone wishing to develop ways of getting user views in these service areas should not automatically choose a 'patient satisfaction survey'. It is to be hoped that enough has been written on this subject anyway to make health professionals think twice before using a survey (eg McIver, 1991a, 1991b, 1991c, 1992; Winn and Quick, 1989; Shropshire Health Authority/University of Birmingham, 1992).

This is not to say that surveys are useless in all circumstances; in fact nothing could be further from the truth, as Ann Cartwright has shown in her excellent overview of the wide range of issues which are amenable to survey research, *Health Surveys in Practice and in Potential* (1988).

Although finding out about 'patient satisfaction' is the subject with which surveys are most identified, it is probably the subject in which they are least useful. The limitations of surveys and ways of making them more effective as a user feedback tool have been covered in detail in earlier publications (particularly McIver, 1991a) but it is worth summarising them briefly as a reminder.

Limitations of Surveys

The most common form of 'patient satisfaction survey' is one using a structured self-completion questionnaire. There are four main reasons why this method has only limited use in this area:

- ★ The questions usually ask patients to make a judgement about a service or particular aspect of a service, yet patients rarely have knowledge of what standards to expect.
- ★ Questionnaires usually cover a limited number of areas with just a few questions, and these are often set by service providers. This means that questionnaires are often superficial and may easily miss the key issues of concern to patients.
- ★ Not everyone can, or is motivated to, fill in a self-completion questionnaire. Unfortunately low response rates can make a survey of this kind unrepresentative.
- ★ Surveys are of little value as part of a process to improve service quality unless the results are used, and this has proved to be more difficult than expected. There is a tendency for surveys to be carried out independently of the management system, making it difficult for the results to have any impact.

Making Surveys More Effective

Surveys using structured questionnaires are useful for finding out *how many* people have a particular view. They are a way of getting quantitative information – incidences or rates of occurrence. They can be distinguished from ways of getting qualitative information – explanations for why things happen. Qualitative methods, such as unstructured interviews, group discussions and some forms of observation, are less widely known or used in the health service, but are just as scientific.

One of the ways in which surveys can be made more effective is to combine them with a qualitative method. The best plan is to conduct a number of unstructured interviews before designing the questionnaire, with patients or people who have used the service, so that their views on which aspects of the service are most important can form the basis for questions.

It is worth noting that far fewer respondents are needed for qualitative research because the aim is to explore the issues in depth rather than to find out how representative they are. Between 15 and 75 respondents is common.

Fortunately qualitative research has been carried out in most service areas and so it is frequently possible to design a questionnaire by referring to this previous work. It is certainly possible to do this in some areas of primary and community health care, as will be shown later.

Other ways of making surveys more effective are as follows:

- ★ Ensuring respondents know what standards to expect so that they can make informed judgements, or asking questions which elicit experiences rather than judgements
- ★ Asking more questions about a particular issue so that a detailed picture can be obtained (This will mean a longer questionnaire or a number of short questionnaires covering different issues in depth.)
- ★ Using the questionnaire as an interview schedule so that the views of those who are unable or unwilling to complete a questionnaire are included in the survey
- ★ Only carrying out a survey if it is an integral part of the management system within a programme of quality improvement.

Information about Concerns of Service Users

One of the most worrying aspects of the 'patient satisfaction survey' is that questionnaires frequently ignore issues that are important to patients. It would be very unwise to assume that little is known about the views and preferences of users of different health care services.

Research on patients' views is not a new phenomenon. Although is has been openly encouraged by the Government since the Griffiths Report in 1983, research has been carried out since the early 1960s (see for example Cartwright, 1964, 1967; Hugh-Jones et al, 1964; McGhee, 1961; Raphael, 1969). Unfortunately the cumulative findings of this large body of research are often overlooked by those new to the field.

The research clearly shows that there are a number of issues of concern to patients, whichever service they are using. These are:

- ★ The quality of their relationship with consultants, doctors and other staff, particularly good communication and being treated as a person
- ★ Good information to allay anxiety and help bring a feeling of control
- ★ The effectiveness of their treatment and care.

Despite the fact that these issues occur repeatedly, they have frequently been overlooked as areas for improvement from the patient's point of view. There are probably different reasons for this.

As far as the importance of the quality of the relationship between patients and professionals is concerned, the reason may be because most of the detailed research has been carried out by academic institutions and nearly all of it has concerned the doctor–patient relationship (although there is confirmation that it is important in other service areas, as will be shown). This means that the findings have not filtered across into other service areas or to service managers. In order to bring this work to the attention of a wider audience, it has been examined in some detail in this booklet, although by no means comprehensively.

Where the need for good information is concerned, it looks as though the message conveyed in the research of Ann Cartwright and others nearly twenty years ago is finally getting through. Recognition within the Patient's Charter, the setting up of Regional Information Centres, and projects such as the Clinical Information Project at the Royal College of Surgeons are encouraging signs that patient information is beginning to receive the attention it deserves.

The concern patients express about their treatment and care is a more controversial area. Not only are there doubts about whether patients are able to recognise good care, but there is also the whole question of professional autonomy. However, a review of studies in this area shows that patients' recall of particular physical events occurring during a consultation is substantial (Sweeney, 1992). Their ratings correlate with physicians' measures of the technical quality of care obtained from the medical record. This evidence, together with the fact that there has been a slight but definite shift in recent years towards the notion of care as a partnership between professionals and patients (eg Teasdale, 1987; Gooch, 1989), suggests that it may not be long before the patient's view of treatment and outcome is given more legitimacy.

Core Questions

As the quality of the relationship, good information provision and effective treatment and care are important issues to patients in all service areas, a core set of questions can be devised which cover different aspects of these issues. These should be detailed enough to help managers identify problems and devise solutions, although it is worth repeating that in order to get the views of a wide spectrum of users, interviews rather than self-completion questionnaires will be necessary in some instances. Also, a survey should not be considered to be a substitute for the direct involvement of users in service planning and evaluation.

This core set of questions will have to be supplemented by additional questions for different service areas. For example, ease of access is extremely important for many services, although the details may differ for each: thus, where the GP service is concerned, questions about surgery opening times, home visits and out of hours care will be important, whereas transport, parking arrangements, waiting times and signposting are important in outpatient departments.

The cleanliness, comfort and convenience of the environment and facilities are also important, particularly as time spent in an environment increases. For those in residential care, these aspects are of great significance.

A nationally accepted set of core questions with modular additions for different service areas has yet to be devised, although this model has been followed in primary care in at least one instance (Leavey, 1992). One of the difficulties lies in choosing a set of questions which are specific and 'user friendly' enough to provide managers with information of sufficient detail to form a basis for service improvements, whilst keeping the questionnaire or interview schedule brief enough not to be a burden to patients or to managers needing quick analysis and feedback.

The example questions provided at the end of the present booklet may be seen as a step towards this goal, but any self-completion questionnaire or structured interview schedule devised from them should be piloted first and then tested for reliability and validity as described in detail in other publications (eg Carr-Hill, McIver and Dixon, 1989; McIver, 1992; Fitzpatrick, 1991).

If the questions are used as topic guides for qualitative studies using unstructured interviews or discussion groups this will not be necessary but the interviewer should take care not to lead the respondents. In qualitative research it is far better to use fewer, more open questions than a large number of detailed questions.

Those looking for evidence to support the importance to patients of the suggested questions will find it within the different care areas covered in the text. The results of previous research, including examples of studies involving surveys, non-survey methods or user involvement, are given to help the reader gain an understanding of what has been done before. In many cases the reader will find details of a tried and tested user feedback tool or an example which will help them with their own work.

The aim of this booklet is not to give detailed instructions on the methodology of surveys, as this has been adequately covered elsewhere. In any case surveys are not the only method for getting user views on service quality, nor necessarily the best – particularly in the areas of primary and community care. As in earlier booklets in this series, examples of a range of methods are given.

Some of the most effective methods appear to be simple and make use of existing procedures. For example, better use might be made of the complaints procedure. At present this can be inaccessible, complex, slow and stressful for both sides. Responses to complaints have been found to be defensive and complaints analysis is rarely used as part of a quality improvement programme (Mason, 1990; Audit Commission, 1992). Improving this procedure could form a significant element in feedback systems, and some guidance on this has been given by Enfield and Haringey FHSA in their pack *Comments, Complaints and Suggestions.* If this is combined with a method for systematically getting the views of users, such as regular 'end of session' interviews with a small sample of patients, conducted perhaps by a lay volunteer, a fairly inexpensive but potentially effective feedback mechanism will have been established. To combine these with other forms of user involvement, such as patient participation groups or the quality action groups developed by the Norah Fry Research Centre, would be to begin to address the issue of user feedback in the serious way it deserves. It is hoped that examples such as these and others described in this booklet will help those involved in primary and community health care to move towards this goal.

2 PRIMARY HEALTH CARE

Background

For most people, primary health care services are their first point of contact with the NHS. This means that not only will most people have had experience of one or more of these services, but also that these services will be important to the majority of people.

It would be natural to assume that the importance of these services would be reflected in research on patients' views, in the form of a significant number of good quality studies. Unfortunately this only appears to be the case as far as GP services are concerned. The doctor–patient relationship has been the focus of plenty of research, much of it of an academic standard, as will be described shortly.

The picture for other services is less encouraging. Pharmacy services have certainly been examined, through some studies on patients' compliance with instructions and the value of information and good communication in improving patients' self-care (eg Kitching, 1990). Also, in recent years there has been discussion and reappraisal of the role of the pharmacist in health care and this has encouraged research on the way that people use pharmacy services.

Studies of patients' views on the service provided by their dentist appear to be fairly recent in origin, and in the UK most views have been gathered through surveys of the general population (eg Williams and Calnan, 1991) rather than of those currently receiving treatment as is the case in many other services. However there are examples from the USA, and one or two examples of studies carried out by health authorities in Britain.

This chapter examines research on user views in each of the primary care services in order to find out, first, what issues consistently appear as important to patients in their evaluation of these services, and secondly, whether tried and tested questionnaires or other methods exist, which can be used to obtain user views.

GP Services

The study of patients' views and experiences of the service provided by their GPs appears rather uneven. On the one hand there seem to be very few qualitative studies which explore the patients' view of what a high quality service would look like. Most studies use a structured questionnaire based upon a review of other questionnaires, none of which seem to have been constructed following qualitative procedures such as interviews or group discussions.

On the other hand there are some highly detailed academic studies of aspects of the doctor–patient relationship, usually communication or information provision. There seems to be a wider gap between service based studies and academic studies in this area than in others, perhaps due to the fact that GPs have only recently been directly encouraged to find out user views, following the Government White Papers *Promoting Better Health* (1987) and *Working for Patients* (1989).

This does not mean that no good surveys exist or that there is no information about what users of GP services value. It does mean, however, that qualitative work is particularly necessary in order to build up an understanding of what patients consider important, as the service provider's view is often different.

Smith and Armstrong (1989) were able to demonstrate that this difference of view can sometimes be quite extensive. The researchers drew up 20 criteria describing different facets of primary care. Half of the criteria were derived from the Government document *Promoting Better Health* and half from asking 24 patients after a routine consultation what they thought were the most important things about a general practice.

The criteria derived from *Promoting Better Health* were:

- Health education provided
- Easy to change to another doctor
- All children vaccinated
- Regular health checks for adults
- Breast and cervical screening programmes
- Children under 5 having their regular checks in surgery
- A woman doctor available
- Doctors go on regular courses to stay up to date
- Premises well decorated and convenient
- Surgery times when patients want them.

Those derived from interviews with patients were:

- Friendly and encouraging staff
- Staff you know personally
- A doctor who is not hurried and listens
- A doctor who sorts out problems
- Usually the same doctor seeing you
- A nurse working on the premises
- Appointments available within 48 hours
- Waiting time less than 20 minutes
- Not too big a place
- Most tests done on the premises.

In order to find out which of these 20 criteria were of the most importance to patients, a questionnaire was devised which asked for the patient's age, sex and year of completion of full-time education, and then offered 10 forced choice pairs of statements drawn from the 20 criteria. The pairs were selected by a computer program that picked out random pairs from the 20 statements, ensuring that each statement was exposed to every other statement the maximum number of times and that any combination of statements was as likely as any other.

A total of 711 consecutive patients attending one surgery were asked to complete the questionnaire and 88 per cent responded. The findings showed that patients overwhelmingly preferred the patient originated criteria. The top ten criteria were:

1. A doctor who is not hurried and listens
2. A doctor who sorts out problems
3. Usually the same doctor seeing you
4. Appointments available within 48 hours
5. Breast and cervical screening programmes
6. Regular health checks for adults
7. Friendly and encouraging staff
8. Most tests done on the premises
9. Staff you know personally
10. Doctors go on regular courses to stay up to date.

It can be seen that only three of the patients' top ten criteria were derived from the Government document – those ranked 5, 6 and 10.

In a second study on similar lines, Al-Bashir and Armstrong (1991) found that variations in criteria occurred between different sub-groups of patients. After interviews with a stratified sample of 20 people during which interviewees were asked 'How can good general practice be achieved?', common themes were identified and 20 verbatim statements selected to represent these themes. These statements were arranged in unique pairs in questionnaires, as before. Each questionnaire asked respondents to imagine a hypothetical situation in which he or she was about to choose a new doctor, and they were asked to select one statement from each pair to reflect their own criteria for selection of a GP. They were also asked for their age, sex and perceived health status.

Out of 882 consecutive patients approached only 7.5 per cent declined to complete a questionnaire. The data were examined in four sub-groups:

- ★ Women between the ages of 16–44 (relatively high users of GP services)
- ★ Patients over the age of 65 years (relatively high users)
- ★ People who scored their health as 'not good' or 'poor'
- ★ People who scored their health as 'excellent' or 'good'.

The criteria rankings of all four sub-groups were similar, with 'GP is easy to talk to' being chosen the most times by all sub-groups. The main exceptions were services such as cervical smears, routine visits to the elderly and check ups for the healthy, which appealed more to those groups who received them.

Also, a higher percentage of people who rated their health as 'not good' or 'poor' preferred a GP who allows an early second opinion, while of people rating their health as 'good', a higher percentage preferred a GP with an emphasis on preventive measures and 'cost-effective' prescribing.

The age of the respondents was also found to affect significantly their preferences for eight of the statements. More older people preferred a doctor who allows an early second opinion, who gives guidance and protection in their relationship with the hospital, who is kind and attentive, has friendly staff and provides routine visits to the elderly. By contrast, a higher proportion of younger people preferred a doctor who has a special emphasis on preventative measures, such as immunisation and cervical smears, and the provision of regular check ups for healthy people.

These results are interesting and a good reminder that patients with different characteristics may value aspects of a service differently. Nevertheless it is worth noting that the top four statements overall concerned the communication skills of the GP. They were:

1. GP is easy to talk to.
2. GP offers treatment through personal attention rather than drugs.
3. GP is kind and attentive.
4. GP sees things from the patient's point of view.

Another significant study is that of the experiences and views of patients and doctors carried out by Ann Cartwright in 1964 and again in 1977. One of the conclusions that she came to in her 1964 study was that behind the satisfaction of most patients there lies:

> *An uncritical acceptance and lack of discrimination which is conducive to stagnation and apathy.*
>
> (Cartwright, 1964; Cartwright and Anderson, 1981, p. 6)

Over ten years later in a second study, *General Practice Revisited* (1981), involving interviews with 836 people, she and her colleague found that more patients were willing to express criticisms about aspects of their care. From the patients' point of view, the service had deteriorated most in terms of the willingness of doctors to visit people in their homes, but there were also fairly large increases in the percentages of people feeling their doctor was 'not so good' about 'examining people carefully and thoroughly' and 'taking time and not hurrying you'.

The highest percentage of people in the 1977 study felt their doctor was 'not so good' about 'having a pleasant and comfortable waiting room' (30 per cent) and 'explaining things to you fully' (23 per cent).

The study also provided an interesting insight into the views of GPs. One of the least encouraging findings was that both in 1964 and 1977 a quarter of GPs considered at least half of their consultations to be trivial, inappropriate or unnecessary; and in 1977 patients of doctors who thought this were more critical of their GP for not taking time and for hurrying them. The researchers found this 'disappointing' because the later study showed 'no indication of a greater understanding between doctors and patients' despite more specific training for general practice in the interval.

It is not surprising to find that problems with the doctor–patient relationship figure highly in this study, particularly those related to communication and information provision, because these occur consistently as aspects of concern to patients.

One study attempted to discover whether problems for users were similar across different service areas. In 1988 Williams and Calnan sent out 735 postal questionnaires which asked questions about satisfaction with various aspects of general practice, hospital and dental care. Analysis of the 454 responses showed that if information from the specific questions was related to a general question about overall satisfaction with the services concerned, there was a striking amount of convergence in consumer criteria across the care settings. They write:

> *Our findings clearly suggest that issues concerning professional competence, together with the nature and quality of the patient–professional relationship, are consistently the most important predictors of overall consumer satisfaction with general practice, dental and hospital care*
>
> (Williams and Calnan, 1991, p. 715)

The study found that for each service area, a number of other issues were also important. For the GP service, waiting times in the surgery were a significant source of dissatisfaction: 38 per cent said they felt it was too long. A quarter (26 per cent) expressed dissatisfaction with the level of information they received and this rose to 50 per cent where the more specific issue of advice about lifestyle was concerned.

A third (38 per cent) felt that they could not discuss personal (as distinct from medical) problems with their GP and 25 per cent were dissatisfied with the length of time spent in consultation. A further 25 per cent felt their GP did not always take their problem seriously enough.

Issues Important to Users

The results obtained by Williams and Calnan are not unusual and it may help to examine the main areas of interest in greater detail, starting with communication between doctor and patient.

Doctor–Patient Communication

Research consistently highlights problems in doctor–patient communication. A recent review of the literature concluded:

> *Sufficient data have now accumulated to prove that problems in doctor–patient communication are extremely common and adversely affect patient management*
>
> (Simpson et al, 1991, p. 1387)

The large body of research on different aspects of doctor–patient communication can be summarised into three main headings:

★ What patients like
★ The value of patient participation
★ The effect upon health outcome.

Patients like a warm, friendly and encouraging doctor (Freeman et al, 1971; Korsch et al, 1971; Wasserman, 1984), who discovers their concerns and deals with their expectations (Korsch and Negrete, 1972; Larsen and Rootman, 1976; Woolley et al, 1978) and provides clear explanations, information and instructions (Ley, 1983; Eisenthal et al, 1983; Comstock et al, 1982; Stiles et al, 1979). Details of these references and a fuller review of similar studies and findings can be found in Pendleton and Hasler (1983) and Inui and Carter (1985).

One of the hindrances to effective communication is the fact that the patient and doctor approach the consultation from different perspectives and bring with them different expectations and ways of talking about health and illness.

This is not to say that doctors are unaware of the problems. Studies show clearly that they perceive their most difficult tasks to be those of discovering the reason for the patient's visit (Bennett et al, 1978) and persuading the patient to change beliefs or behaviours (Pendleton, 1979; Pendleton and Hasler, 1983). However, these difficulties tend to cause 'doctor-centred' consultation, where the doctor uses closed questions (Fletcher, 1980).

In some cases problems are related to a different understanding of common health terms. Many words have both a medical and a lay meaning and this can cause confusion. For example, Blumhagen (1980) found that 72 per cent of 117 patients with biomedically defined hypertension believed they had 'hyper-tension', a physical illness characterised by excessive nervousness and untoward social stress.

A study by Hadlow and Pitts (1991) showed that there were clear differences of understanding of common medical and psychological terms between doctors, nurses and other health workers and patients. The widest gap in understanding was shown for the terms 'eating disorder', 'schizophrenia', 'depression', 'psychopath' and 'migraine'.

A patient's very different experience of an illness can also cause problems, as demonstrated in an illuminating report of a study examining the process of diagnosing Parkinson's disease. Pinder (1992), through in-depth interviews with 15 patients and 18 GPs, found that whereas for GPs the moment of diagnosis was a very positive moment, enabling prediction and informed management, for patients it marked a point of maximum experiential incoherence. At that time, their two worlds were very far apart. Yet Pinder came to positive conclusions about the value of the doctor–patient relationship because she found that many doctors suggested empathy was possible. All that was needed was for GPs to:

> *... engage in a more systematic and critical scrutiny of the workday assumptions with which they approached patients*
>
> (Pinder, 1992, p. 20)

There is certainly evidence to show that even a small amount of awareness of these issues can make a difference. Evans et al (1987) report an evaluation of a communication skills programme which increased patient satisfaction and reduced anxiety. The programme consisted of a booklet which covered psychological variables in doctor–patient interaction, patient satisfaction, recall and understanding, patient compliance, and a range of suggested consulting techniques designed to increase satisfaction and understanding and reduce non-compliance.

The study took place in Melbourne, Australia, where 20 GPs were allocated to the training group and 20 to a control group. Post-consultation interviews were held with 10 patients of each participating doctor prior to any training and these revealed no differences in patient satisfaction between the two randomly allocated groups.

Doctors in the training group then attended two 3 hour seminars. Within four weeks of the seminars, data were collected from 10 patients of each participating doctor. A total of 400 patients provided data through the use of a questionnaire and the state–trait anxiety inventory. Patients of training doctors reported significantly higher satisfaction, overall and on specific items, than patients of control doctors; and also scored significantly lower on a measure of their feelings of anxiety immediately after their consultation. Similar positive results after training were reported by Inui, Yourtree and Williamson (1976) and Bird and Lindley (1979).

Feelings of being hurried or not having enough time to express concerns or ask for further information are also mentioned as sources of dissatisfaction for patients. The length of time taken by the consultation and its relationship to satisfaction has been examined in a number of studies (eg Howie et al, 1991; Morrell et al, 1986).

One study of 21, 707 consultations measuring length of time, patient satisfaction and health status discovered that 'long' consultations (ten minutes or more) as against 'short' consultations (five minutes or less) were associated with the doctor: (1) dealing with more of the psychosocial problems which had been recognised and were relevant to the patient's care; (2) dealing with more of the long term health problems which had been recognised as relevant; and (3) carrying out more health promotion in the consultation. Patients also reported greater satisfaction with longer consultations (Howie et al, 1991).

A study using a different method came up with very similar results. Over a five month period, patients attending a two partner surgery in Surrey were, depending on the week, allocated to appointments at five, ten, or fifteen minute intervals. Each of the two doctors undertook four experimental surgeries per week where the consultation was audiotaped and timed. Analysis of audio tapes and data for 914 consultations showed that in consultations booked at longer intervals there was a significant trend towards the doctor asking more questions and making more statements explaining the problem and its management, while patients asked significantly more questions and made significantly more statements of their own ideas about the problem. In consultations booked at shorter intervals patients were significantly more likely to report in satisfaction questionnaires that little or far too little time had been available (Ridsdale et al, 1989).

It is interesting to note that in the above study, only two-thirds of patients reported they felt very free to discuss their ideas and concerns, including those taking part in consultations booked at fifteen minute intervals, yet another body of research has demonstrated the value of patients being able to talk freely about their problems and expectations and take part in decisions about their care.

Much of this work derives from research carried out by Balint and colleagues (Balint et al, 1970) who contrasted 'patient-centred medicine' with 'illness-centred medicine'. Byrne and Long (1984) developed a method for categorising a consultation as doctor- or patient-centred, and Wright and MacAdam (1979) also describe doctor- and patient-centred clinical methods.

According to Levenstein et al (1986), the essence of the patient-centred method is that:

> *The physician tries to enter the patient's world, to see the illness through the patient's eyes. He does this by behaviour which invites and facilitates openness by the patient. The central objective in every interaction is to allow the patient to express all the reasons for his attendance.*
>
> (Levenstein et al, 1986, p. 26)

The assumption is that the patient brings expectations of the visit, not necessarily made explicit, and also has some feelings about his problem or problems which may sometimes be a major factor in the illness. The doctor's aim is to understand each patient's expectations, feelings and fears. The doctor will need to apply his or her own agenda at some stage, but the aim is to integrate the two rather than for the doctor to dominate by imposing his or her agenda on the patient.

There is, however, some evidence to show that in certain situations patients prefer a directing style. Savage and Armstrong (1990) reported a study which randomly allocated patients to a 'directing style' or a 'sharing style' of consultation and then measured patient satisfaction. They found that patients who received the directing style were more satisfied except in cases of longer consultations; consultations in which advice was the main treatment; patients whom the doctor judged to have a chronic illness; and patients who judged themselves to have a psychological illness. In other words it was beneficial to those patients whom the GP thought had mainly physical problems and those who received a prescription. The researchers suggest that there may be two broad types of illness:

> *Simple physical illness that responds to the traditional biomedical approach of diagnosis and treatment ... [and] ... chronic and psychological illnesses that have a recognisable large psychosocial component.*
>
> (Savage and Armstrong, 1990, p. 970)

The simple physical illness benefits from the directing style whereas the more complex illness responds better to an interactive approach.

Although more work needs to be carried out to discover exactly how much control, in what circumstances, is conducive to improved patient satisfaction and health outcome, there is evidence available to suggest that patient control, participation and the other aspects of communication mentioned earlier can be related to health outcome.

For example, Kaplan, Greenfield and Ware (1989) studied the relative degree of control exerted by the patient, the amount of emotion expressed by the doctor or patient, and the quantity of information sought by the patient and gained from the doctor, in separate studies of patients with diabetes mellitus, hypertension and peptic ulcer. Physiological changes were measured and recorded, changes in functional capacity, in the patient's own assessment of their progress, and in their ratings of satisfaction with care received. In almost all the studies the differences in outcome favoured the experimental group which had had more opportunity to exercise control, more opportunity to express emotion and had received more information.

Other relevant studies are reviewed by Horder and Moore (1990) who comment that:

> *The literature contains sufficient evidence on the relationship between aspects of communication and the outcome of patient satisfaction, recall, and compliance, for positive correlations to be made.*
>
> (Horder and Moore, 1990, p. 443)

The whole patient-centred approach to doctor–patient communication rests upon an image of the patient that moves away from the traditional passive model to one which is based upon detailed qualitative studies of illness behaviour and which is described well by Calnan (1988).

> *The image of the lay person is of one who is active and critical, who has his or her complex system of theories about illness and medical care, who manages their own health requirements and who is discriminating in their use of medical knowledge, advice and expertise.*
>
> (Calnan, 1988, p. 929)

Information Provision

The issue of information provision is also part of communication, but it is useful to examine it separately because the aspects involved are fairly complex. The common approach of asking patients whether they have received enough information does not do the subject justice. Apart from the dimension of quantity, there are others:

- ★ Is the information given at the right time and place?
- ★ Is it understandable?
- ★ Is it comprehensive?
- ★ Is it accurate?
- ★ Is it up to date?
- ★ Does it use the most appropriate medium?
- ★ Does it include provision for those who do not read English?
- ★ Does it provide the opportunity to get further information or support?
- ★ Is it relevant from the patient's point of view?
- ★ Does it provide the patient with the opportunity to make comments about adequacy and relevance, so that improvement can be continual?

There is also the type of information to consider. The following is an outline of the main areas of patient information, together with details of one or two studies relating to this area. Patients have wanted more information about services for many years and this has now been recognised through the medium of the Patient's Charter. There are a number of studies evaluating general practice information leaflets. For example, Bhopal et al (1990) distributed 5000 practice information leaflets as a result of a survey showing that patients' attitudes towards practice leaflets were favourable and their knowledge of the organisation of the practice was poor. The leaflet was evaluated by assessing patients' attitudes to and use of leaflets, and changes in their knowledge about the practice. Changes in the pattern of consultation with the practice nurse and the timing of incoming telephone calls were also measured.

They found that most patients read, kept and referred to the leaflet and reported it to be useful. Those who had seen the leaflet had significantly greater knowledge on 15 questions on practice organisation than two comparison groups – a baseline 'before leaflet' study sample, and those in the follow-up sample who had not seen the leaflet.

In addition two changes of behaviour were noted: there was an increase in self-referral to nurses (37 per cent compared to 29 per cent); and the timing of incoming telephone calls was more in line with practice policy (eg 23 per cent of calls for repeat prescriptions were made between 12.00 and 16.00 hours at follow-up compared with 11 per cent at baseline). It is interesting to note that the practice population came from one of the most deprived communities in Glasgow where reading ability was likely to be poor, yet most found the leaflet useful. Other studies have found that social classes 4 and 5 and the unemployed benefit most from leaflets (Pike, 1980).

Apart from information about services available, how and when it is best to use them, and the quality or standards of service aimed at, it is also useful to provide information about how to make suggestions and complaints. Enfield and Haringey FHSA have developed a proforma for this to include in leaflets or as signs, available in their *Comments, Complaints and Suggestions* pack which provides guidance on practice-based procedures for dealing with this issue.

A second area of information is that concerned with illnesses, treatment and tests. Many hospitals produce fact sheets for patients' surgical procedures but these are of varying quality and are rarely field-tested or evaluated. The Royal College of Surgeons in 1992 began a project to design and evaluate patient information leaflets on hip replacement and hernia repair with a view to establishing good practice in the area (Meredith, 1992).

Self-help groups can also be a source of advice and information about particular illnesses and an evaluation of the usefulness of such groups has been carried out by Trojan (1989).

A closely related area is that of information about drugs – for example, how to take a given drug, the dosage, precautions, possible side effects and what to do if they occur, how to recognise if medication is not working and what to do in that case. A survey of almost 9000 patients revealed that 55 per cent did not know exactly when, how, or with what to take their medication (Busson and Dunn, 1986). The Association of the British Pharmaceutical Industry (ABPI) has agreed that patient information leaflets as package inserts will be introduced and a summary of the ABPI's policy on this is given in Wells (1990).

The last major area is that concerning health promotion and illness prevention, an area which received increased emphasis in the 1990 contract for general practice. A system designed to be easily accessible and make use of the high level of contact between GPs and patients is described by Stanley and Tongue (1991). This is a computer software system which provides a broad range of information about health on a terminal for patients in general practice waiting areas. A practice library system is described by Collings et al (1991).

Finally it is worth emphasising the necessity of developing information for patients *with* patients so that the material is tailored to their needs; also the importance of evaluating the usefulness and impact of information. There are a number of ways this can be done (see, for example, Bhopal et al (1990) referred to earlier; and also, in a more general sense, Munro (1992), who looked at the quality of existing information provision within an outpatients department).

Access to the GP Service

In the area of patient views of primary care, the quantity of studies on doctor–patient communication is rivalled only by those on access to the GP service. Cartwright lists some of the relevant aspects in an examination of the subject in her excellent book on health surveys (1988): proximity to the doctor's surgery, time taken to get there and methods of travel available, frequency and times of surgeries, waiting time at the surgery, delays in getting appointments, the willingness of the doctor to visit patients at home, the doctor's availability in emergencies, the willingness and availability of the doctor to consult on the telephone, and the doctor's manner and approachability.

All of these aspects were studied by Richie, Jacoby and Bone (1981) in a national survey of 5,373, of whom 89 per cent were interviewed. Cartwright examines the methodology of this survey in some detail and compares it with others, providing details which will be useful to those wishing to carry out a similar study.

Another study covering most of the issues related to access is that reported by Allen, Leavey and Marks (1988). The study involved interviews with 793 people in North West England. Three findings were reported as being of particular interest:

1. The results showed surgery waiting times for both open access and appointment systems were considerably longer than in earlier surveys. Also there was a high level of dissatisfaction with appointment systems. The proportion of those with open access systems who preferred their system (90 per cent) was much higher than the corresponding proportion of appointment users (60 per cent). This finding contradicts other studies where patients have been found to prefer the system they are used to (Arber and Sawyer, 1979), and to be more likely to be put off seeing their doctor in open access systems (Wilkin and Hughes, 1987). The researchers recommend a mixed system as the ideal.
2. The results also showed higher levels of dissatisfaction with waiting times for out-of-hours visits than in studies ten years ago, although the waiting times were approximately the same as reported earlier. A quarter of the respondents had tried to contact their doctor outside normal hours in the previous year and of those visited, only about half were satisfied with the length of time they had had to wait. The researchers comment that this may well reflect higher expectations of respondents.

3 Out of a list of nine factors, more patients (45 per cent) thought direct telephone access would improve the service than any other item.

Home Visits

Deputising services available during out-of-hours care often seem to be rated less highly by patients than a service provided by known GPs (eg Cartwright and Anderson, 1981), or receive criticism from a sizeable proportion of respondents (eg RIPA-SCPR, 1988, 20 per cent in one district; Gibson and Walmsley, 1991, 25 per cent).

Patients' satisfaction with care received during out-of-hours contact was examined in a study reported by Bollan, McCarthy and Modell (1988). They found that although 70 per cent described their contact as a positive experience, respondents with children were significantly less satisfied than older patients – a fact which could be explained by lower expectations or a reluctance to voice criticism among the elderly, or real differences in the nature of out-of-hours care.

Interestingly the researchers had evidence from recording cards completed by GPs for the study that the doctors considered a larger proportion of calls from older patients to be absolutely necessary than those for children. Also, younger patients expressed greater satisfaction with visits by GPs than with visits by deputising services.

Bollan, McCarthy and Modell report that their respondents did not have a clear conception of the deputising service and this may have affected their expectations and satisfaction. Recommending that practices

> *... review management of out of hours calls on a regular basis [because] the manner in which practices manage their patients' requests for help out of hours is likely to be a sensitive indicator of the quality of care provided by that practice,*
>
> (Bollan, McCarthy and Modell, 1988, p. 832)

they also suggest making better use of opportunities to help parents understand and manage childhood illnesses (so that they will be better able to decide whether an out-of-hours call is appropriate), telephone access for advice, and better written information about their practice's out-of-hours arrangements.

The suggestion made by Bollan and colleagues that practices should encourage telephone access for advice is interesting because telephone use in primary care has not been widely studied, although it has been well documented in the USA.

There is some evidence to suggest that a high proportion of patients have never attempted to telephone their doctor and a substantial minority believe it is not permissible. However, in the survey carried out by Allen, Leavey and Marks (1988) mentioned earlier, just over a third of all respondents (35 per cent) said they thought they were able to telephone and speak to their doctor personally and 27 per cent (216) said they had actually telephoned and asked to speak directly to their doctor on some occasion. Of these 216, the majority (65 per cent) had done so without any difficulty and a further 15 per cent after some insistence, but 12 per cent said they had been refused and told to come to the surgery. The 'success rate' in the districts studied ranged from 64 per cent to 91 per cent.

In 1991 Lesley Hallam, at the Centre for Primary Care Research, University of Manchester, reported on the first stage of a large study of telephone access to GPs and practice nurses. Of the 1459 doctors who responded to the postal questionnaire, only 3 per cent said they were not prepared to accept day time calls from patients except in an emergency.

Some (20 per cent) reported that they routinely reserved fixed regular times of the day for handling patients' calls. However, willingness to accept patients' calls contrasted sharply with the estimated number of patient calls received in the average working day. Nearly 60 per cent estimated that they received four calls or fewer, although doctors who reserved time received more calls on average than those who did not.

There was also a significant relationship between the estimated number of calls received and the steps taken to inform patients that the doctor was accessible by telephone. Nearly a quarter of GPs reported that they took no steps to inform patients. Over half relied on word of mouth alone, personally or through reception staff. Hallam concludes:

> *At a basic level there seems to be a need for detailed recommendations and guidelines on telephone needs and telephone organisation in general practice ... Family health services authorities could have a substantial role in setting standards and maintaining them.*
>
> (Hallam, 1991, p. 632)

Surgery times may also make it difficult for some people to visit their doctor. Bradford FHSA conducted a postal survey of a random sample of 5,000 adults. An analysis of the 53 per cent who responded showed that for those in employment, the young to adult ages, and particularly those with children, there was a marked preference for early morning surgeries. Many men had a preference for 7.30–10.00 am surgeries, while women with children, especially those working, preferred 8.00–10.30 am. In the evening later start/finish times (eg 5.30–8.00 pm) were preferred by these groups. Elderly people preferred later surgeries in the morning and early surgeries in the afternoon.

The convenience of surgery times for working men and women is particularly important with regard to opportunities for health promotion and prevention. The researchers suggest that it might be possible to hold an early morning and late evening surgery once a week. These sessions could be specifically designated and promoted for these groups, as could mid-morning and early afternoon surgeries for elderly people (Atkinson and Gardner, 1991).

Practice Receptionists

Among the other issues that recur in studies of patients' views, the GP's receptionist is often a consistent source of dissatisfaction for a significant minority of patients. In their literature review of consumer feedback in the NHS, Jones, Leneman and Maclean (1987) devote a small section of their chapter on GP services to this topic, citing a number of studies. Included are Cartwright and Anderson (1981), who found that patients were less likely to regard the receptionist as helpful if they asked them why they wanted to see the doctor, something that 37 per cent of patients said happened all the time or sometimes. A study by Social and Market Survey Research (Gibson and Walmsley, 1991) found that a third of patients thought the receptionist gave advice or took decisions which should be taken by the doctor.

Environment and Facilities

Satisfaction with the environment and facilities, the focus of much research in other health care services, has not been extensively examined in primary care. One major study which did ask questions on this subject was carried out by RIPA/SCPR (1988). They found that approximately 15 per cent of respondents thought the waiting room was depressing, 10 per cent found it noisy, 19 per cent found it uncomfortable, and about 16 per cent found it stressful.

Other Issues

Analysis of complaints can also yield information about patient dissatisfaction. An analysis of 1000 formal complaints made about GPs in an eight year period between 1982 and 1989 showed that the most common circumstances in which patients complained was when they believed there had been a failure to visit (25 per cent). Commonly these were not outright refusals to visit but instances of the receptionist or GP persuading the caller to bring the patient to the surgery instead. In addition, 5 per cent of complaints concerned a delay in visiting where a visit was made too late, in the opinion of the complainant, so that the patient had either died or suffered an outcome which might have been prevented.

The second most common criticism was failure to diagnose (20 per cent). Complainants became aware of what they believed to be the correct diagnosis through seeing another doctor or from a post mortem. The 'missed' diagnoses covered a wide range of clinical conditions but the most common were appendicitis, ectopic pregnancy, perforated peptic ulcer, early pregnancy and myocardial infarction. In an additional 5.4 per cent of complaints, the complainant reported that the GP made the diagnosis only after a number of contacts and therefore late, so as to prejudice the outcome. An example which appeared a number of times in this category was delay in diagnosing carcinoma of the breast (Owen, 1991).

Development projects designed to enable primary health care services to address the needs of carers established that carers wanted sympathy, flexibility, partnership, information and access to the full range of health and social care services. These projects have been set up by the King's Fund Centre Carers Unit (see 'Useful Addresses', p. 89).

Summary

It can be seen that there are a wide range of issues that have been found to be important to patients, associated with access, the consultation, information provision and home visits. A regular way of finding out patients' views on these issues needs to be developed and methods for doing this are examined in the next section.

Ways of Obtaining User Views

Non-survey Methods

Looking first at non-survey methods, apart from the research on doctor–patient communication, most studies of patients' views of primary care tend to be large scale population surveys. This means that there are few examples of the use of non-survey methods.

One exception is a study reported by Jones and Tippens (1989) using a type of interview method called 'critical incident technique' (CIT), which asks patients to talk about their experience of using a particular health care service and then separates out 'critical' or key incidents which are favourable or unfavourable.

In the study reported by Jones and Tippens, patients were seen in a private room by trained interviewers from outside the practice. A total of 48 patients were interviewed and 207 incidents recorded. The ratio of good to bad incidents was approximately 2 to 1 but some negative comments surprised the doctors in the practice. For example, the presence of trainees was not very well received; and those who wanted to change to another doctor in the same practice were finding it difficult. Also, there were problems with repeat prescriptions and obtaining chiropody services. The writers comment:

> *CIT is considered to provide a useful and relatively inexpensive way of finding out what patients like and dislike about the service they are getting and the results are of immediate practical value.*
>
> (Jones and Tippens, 1989, p. 1465)

Another method which has worked for many GPs is the patient participation group. The first group was started in Berinsfield, Oxford, in 1972 and there are now about 750 in the UK (Pritchard, 1981; Hutton and Robins, 1985; Durno, 1992). The Royal College of General Practitioners supports the idea and the

DHSS (1986) document *Primary Health Care: An Agenda for Discussion* mentions patient participation groups as a useful way of improving the quality of the practice.

There are two main types of group: 'open' and 'nominated'. Open groups are formed from open meetings which any patient may attend. Nominated groups are formed from representatives of other community groups and associations. The five methods of starting an open group, together with a description of the kind of activities in which they have usefully been involved, can be found in a leaflet available from the National Association for Patient Participation (see 'Useful Addresses').

A study of one such group is reported by Hutton and Robins (1985). The authors wanted to determine what patients wanted and expected from the group – the Collingham Health Centre Users Group, Nottinghamshire. Some of the services they provided were successful and others less so. Also, some topics at meetings attracted more people than others and so a survey was carried out to help the group develop in the right direction.

They found that the social events and health talks provided appealed to a minority of patients but there was plenty of support expressed for fund-raising events, providing transport for those who could not reach health facilities, visiting and helping the sick, elderly and disabled, and collecting prescribed drugs for those without transport. Lack of awareness of the group was a problem, and 'careful and controlled' advertising was considered by the writers to be the way forward.

Members of patient participation groups and other lay people have also been involved in visits to general practices. Durno (1992) describes assessment visits involving doctors and lay people. The visiting teams spent the first hour of the day in the reception area where three main aspects were observed and recorded: the number of telephone calls received, the number of patients dealt with at the reception desk, and a 'mock up' record to show how records were set out and how repeat prescriptions were handled.

Time was also spent with the receptionists discussing their role in the practice. The visitors met representatives of the doctors, health visitors, district and practice nurses and the practice manager. They also interviewed patients who had agreed to meet them after their consultation.

Durno comments that patient participation groups 'could benefit from arranging a formal visit to their own practice using the methodology described here'.

Other ways of obtaining feedback using non-survey methods, such as observation and focused group discussions, are described in McIver (1991a).

An under-used method is the analysis of complaints, but this works best when combined with another method to give a balanced view and when the complaints procedure is easily accessible and user friendly. Currently the procedure cannot be said to fit this description, but there are signs that the picture is changing. A Complaints Consortium consisting of a number of London FHSAs is working to improve procedures (see 'Useful Addresses'). One of the members, Enfield and Haringey FHSA, has issued a useful guidance pack called *Comments, Complaints and Suggestions* which includes a model procedure that a practice can implement as a whole or use as a checklist for assessing the system it already has in place.

Surveys

Turning to surveys, there are a growing number of 'off the shelf' survey questionnaires available for most service areas. Primary health care is lagging behind slightly but at the time of writing there were four main alternatives.

1. Ann Cartwright and colleagues at the Institute for Social Studies in Medical Care have developed and piloted a postal self-completion questionnaire of 50 questions covering most areas of concern. A booklet giving details of

the questionnaire also includes advice on how to carry out a postal survey (Cartwright, 1989). As the survey is geared towards sampling the local population using the electoral register lists held by FHSAs, the booklet is probably of most use to FHSAs and CHCs.

2 Ralph Leavey and Ali Wilson have developed and piloted a series of questionnaires based upon a modular design at the Centre for Primary Care Research, University of Manchester. These are stored on a computer database and different combinations can be produced on request (see 'Useful Addresses').

3 The MOPS Survey was developed through a steering group of nine FHSAs and designed and piloted by GALLUP. It includes 97 questions in ten sections: access to surgery, surgery premises, getting to see the GP, telephoning the surgery, home visits, surgery staff, services available, prescriptions, making use of hospitals, and a general section. The format is self-completion and the average length of time taken to complete the questionnaire is said to be 17 minutes.

Those wishing to use the MOPs Survey can buy the whole package, including instructions for analysis, in either disk format (£150 + VAT) or paper format (£70 + VAT) and it is suitable for FHSAs or practices. Those practices without facilities or time for computer input and analysis can go through their FHSA or buy this service at extra cost from the suppliers (see 'Useful Addresses').

4 The College of Health has developed and piloted an action pack for GPs to get feedback from patients called *Ask the Patient* (see 'Useful Addresses'). This is a nicely produced pack with clear and concise instructions on how to get patients' views by interview, questionnaire and observation, and a template of everything needed, including questionnaires, for under £20.

Other possibilities are a questionnaire described by a research fellow at the General Practice Unit, University of Bristol (Baker, 1990, 1991) and a questionnaire being developed by Social and Market Survey Research (see 'Useful Addresses').

How are practices to choose a suitable way of getting patients' views from this array of methods? Bearing in mind the general advice about different methods given in the Introduction, they should consider using a combination as the most effective solution. A fairly inexpensive mix would involve:

- An improved complaints procedure, making it much easier for patients to mention problems and suggestions
- A patient participation group
- Interviews with a small, but well mixed, sample of surgery attenders at regular intervals (eg 20 per three months) using an experienced volunteer (eg someone from the patient participation group) (This person could also observe and generally try to see the practice from the patients' point of view.)
- A large sample questionnaire survey (postal, telephone or home interview) using the practice list, occasionally (eg once every 2–3 years) (This could be done through the FHSA or an outside organisation.)

The most important part of the 'patient views system' would be the way it was built into the practice management process so that the results were monitored and used to improve the service offered to patients.

Other Services

There has been far less consumer feedback research on dentistry, pharmacy and optician services than GP services, particularly in Britain.

Dentistry

In the USA, Hengst and Roghmann devised a questionnaire for users of dental services as long ago as 1978. The research team responsible for developing many patient satisfaction questionnaires in the USA have also devised one for dental care (Davies and Ware, 1981).

A detailed questionnaire consisting of 42 questions covering dentist–patient relations, technical quality of care, access, patient waiting time, cost, facilities, availability, continuity, pain, auxiliaries performing expanded duties, staff–patient relations, staff technical quality of care, and office atmosphere has been developed by Chapko et al (1985).

Many of the issues patients consider to be important aspects of GP service also apply to dentistry services. Zimmerman (1988) investigated patient views on the importance of different aspects of care before attending an appointment at a preventive dentistry clinic.

He compared these responses with their satisfaction with the same items after the appointment and also the extent to which they intended to change a number of their oral hygiene habits. The dental students involved in providing care at the dental hygiene clinic also received a questionnaire asking how they rated the importance of the same aspects of care.

Patients' top three items were first 'Carefully explain the condition of the patients' teeth and gums', followed by 'Give the patient careful instructions for what to do to improve his/her teeth and gums' and 'Explain everything he is doing to the patient'.

The dentistry students also rated the first two items within their top three but they ranked 'Explain everything he is doing to the patient' seventh. This seems to support other studies which show that professionals often under-estimate patients' needs for explanations about treatment and care.

When patient preferences were linked to those of the practitioner, the less the absolute difference between the entire set of preferences of a practitioner and patient, the more satisfied was the patient.

Further, the more satisfied the patient, the more likely they were to report planning to make changes in oral hygiene. Lastly, reported behaviour change was a significant predictor of change in objective dental health measured using the Gingival Inflammation Score.

In Britain some health authorities have devised questionnaires to collect the views of patients using dental services based at health centres and clinics.

Sandwell Health Authority, for example, devised one in 1988 covering waiting room facilities, appointment arrangements, staff attitude, examination and treatment, travel arrangements, and a general section.

The survey sampled 20 per cent of patients booked during a week at all clinics in the district. The majority of patients were of school age and the questionnaires were completed by the accompanying parent or other relative.

The results of the survey encouraged recommendations about:

- ★ Investigating why nearly one fifth of parents felt they had no choice over the time and date of the appointment
- ★ Investigating the possibility of advising patients about the length of time they may have to wait when delays have begun to build up
- ★ Providing more chairs, more comfortable chairs and arranging better use of space in some clinics
- ★ Providing more up to date reading material and more appropriate reading material for children
- ★ Providing a play area for children
- ★ Providing drinks vending machines at health centres and clinics.

Ali Wilson and Ralph Leavey devised questionnaires about different aspects of dental care using the same Modular System developed for asking patients for their views about GP services at the Centre for Primary Care Research, University of Manchester (see 'Useful Addresses').

Pharmacy

Recent discussion and reappraisal of the role of the pharmacist in health care has resulted in an upsurge of interest in the way that people use pharmacy services.

A consumer survey carried out among 2000 adults by a market research company for the Institute of Pharmacy Management Conference in 1991 found that 60 per cent of respondents said they visited a pharmacy at least once a month and half of those who visited pharmacies had at some time sought the advice of the pharmacist or pharmacy staff. Fifty per cent said they always followed the advice given and a further 48 per cent nearly always followed it.

However pharmacies were among the least enjoyable places to shop, with little scope for improvement, according to the findings of another survey reported at the conference, looking at consumers' views on buying a range of different goods.

Of the limited number of suggestions that respondents could think of to make shopping in pharmacies more attractive, more than a third were for Sunday shopping hours. Other suggestions covered parking, seating, service quality, product range and facilities for children.

As well as examination of the attitudes and expectations of pharmacy customers, speakers at the conference looked at the opportunities for pharmacies to carry out their own research and gave advice on how to go about it (Institute of Pharmacy Management International, 1991).

Academic research has looked in more depth at how and why people make use of pharmacy services. Cunningham-Burley and Maclean (1988), for example, interviewed a random sample of mothers with at least one child under five years old in order to elicit their perceptions on health and illness.

The mothers in the sample (54) were also asked to keep a health diary for a period of three to four weeks. The diaries provided information on home remedies and proprietary medicines, as well as on the variety of illness episodes which took place.

The findings showed that two factors underlay the mothers' use of pharmacists: a concern not to bother the doctor with trivial conditions, and a need for authoritative advice and help to back up their own decisions or to help them to make their own decisions about how to respond to children's health problems. The researchers concluded:

> *A considerable strength of the pharmacists' role seems to be that they form part of a convenient lay health network ... Their unique position could well be developed to provide an important link between lay and professional responses to illness.*

The researchers also suggest that local pharmacists could become more involved in information dissemination and health advice relating to the use of medicines and in other areas of health education because they are accessible to the general public, particularly mothers with young children. But they qualify this by adding:

> *However, without attention being focussed on how to develop the role of the pharmacist to promote more effective primary care, the existing ad hoc practices with considerable variation in attitude and use, will only exacerbate the existing ambiguity in their role within or alongside the primary care team.*
>
> (Cunningham-Burley and Maclean, 1988, p. 125)

In 1991 the Health and Social Policy Research Unit in the Department of Community Studies, Brighton Polytechnic, was funded by South East Thames RHA to carry out an interview survey of the views of the public on an extended role for community pharmacy.

Hargie, Morrow and Woodman (1992) report a questionnaire survey of 261 members of the public about their views on community pharmacists. The majority of items in the questionnaire required the respondents to complete two scores – one indicating which was most representative of their current personal experience of pharmacy, and the other the response they would regard as ideal.

In terms of interpersonal contact, 56 per cent selected 'Feel totally at ease about asking the pharmacist for advice and so will ask if I need to' while 86 per cent wished this to be the case.

The most preferred approach for dispensed medications (expressed by two thirds of the sample) was for the pharmacist personally to hand over the items, and at the same time provide the opportunity for full patient involvement. The predominant current experience was that these were given out by a member of staff other than the pharmacist.

With respect to facilitating privacy, only 15 per cent reported being taken out of the main shop floor area into the dispensary or private consultation room when discussing private or personal matters, whereas 57 per cent wished this to happen.

Responses to the question of what they liked most and least about going to the pharmacy revealed that the favourable elements were staff helpfulness and positive attitudes, convenience, promptness and immediacy of the service, and wide product range. On the negative side, respondents most disliked having to wait and having to present embarrassing health problems.

Also of interest was that in terms of professional image, the survey highlighted the tension between the business and health aspects of the community pharmacist. The overwhelming preference was for a health oriented pharmacist, although the current experience of one third of the sample was that of the pharmacist as business person.

In the USA, Mackeigan and Larson (1989) have developed a 44 question self-completion questionnaire to measure patient satisfaction with pharmacy services. Enough details are given in the report for those wishing to construct a similar questionnaire to do so.

Optician Services

It is more difficult to assess the situation as far as opticians are concerned because market research carried out by private businesses is not usually made publicly available. There are some studies on aspects of treatment published in specialist journals. For example, Thompson, Collins and Hearn (1990) investigate the relationship between contact lens wearers' motivation, satisfaction and compliance and the interpersonal communication skills of optometrists.

Not surprisingly they found that the results of the study were consistent with those from other health care settings showing that the doctor–patient relationship is important in determining patient outcomes and success with treatment. The data showed significant interactions between the optometrists' interpersonal skills and aspects of patients' satisfaction and motivation to wear lenses.

The Role of FHSAs

The former Family Practitioner Committees were transformed into Family Health Service Authorities in 1990 with a responsibility to assess the primary health care needs of their local population and monitor the adequacy of local service provision.

The transformation has involved them in major changes:

I Moving from an administered service provided by FPCs to a managed service

II Moving from paying for a treatment of illness service to developing a service which promotes good health

III Moving from a service devoted almost exclusively to the interests of contractors to one where the main objective is to deliver family health services which are more responsive to consumer needs and which promote the health of the local population.

If the number of requests for information from the King's Fund Centre Consumer Feedback Resource are an indicator of interest, FHSAs have taken their new responsibilities seriously and have responded to them quickly. Dozens of requests for information on consumer feedback were received from FHSAs in the first few weeks of the change and 250 copies of a free leaflet about user feedback in primary health care went within a few months.

Many FHSAs are carrying out research in the area of user feedback and it is only possible to mention a few examples of different types of projects.

Some of the survey work undertaken by FHSAs has the aim of enabling them to give guidance to local GPs on getting the views of patients. One example is the survey of people registered with a large general practice commissioned by North Yorkshire FHSA. This had two aims:

I To establish the extent to which the objective and subjective requirements of patients are being met by a Primary Health Care Team

II To provide guidance and help to GPs and FHSAs to ensure that the local demands of patients are being met.

Information from a sample of 594 people was obtained using a combination of interviews and postal questionnaires (Jefferson and Martin, 1990).

The College of Health has been working with Merton, Sutton and Wandsworth FHSA to help them develop methods of obtaining patient feedback. This involved an eight month training programme about the processes involved in carrying out consumer audit in general practices, including patients' views of community and secondary services (College of Health, 1992).

Avon FHSA has carried out a postal questionnaire survey of a random sample of people taken from a practice list about their views and preferences on different aspects of the GP service. They have also run a survey of GPs on their attitudes towards the FHSA, and plan to carry out studies of complainants' satisfaction with complaints procedure and a study of patient satisfaction with dental services.

Wirral FHSA are conducting a number of consumer research projects as part of a wider programme of quality improvement work. One project with the aim of examining the effectiveness of Wirral Health Authority's discharge policy involved interviews with a sample of elderly patients discharged from geriatric wards. Also, postal questionnaires were sent to the patient's GP.

Another project involved a patient satisfaction survey of two potential fundholding practices, and a third project an evaluation of the quality of the consultation process in a GP's surgery from the patients' perspective.

Wirral FHSA were also involved in a consultation exercise to find out the views of local residents on the draft Community Care Plan produced by the DHA, FHSA and local authority. Eight hundred copies of the draft plan were circulated to key public access points. In addition 8000 leaflets and 200 posters were spread throughout the Wirral.

As part of a Community Care Awareness Week, ten public meetings were held during afternoons and evenings in different parts of the Wirral and nearly 500 Wirral residents attended these sessions (Fillingham, 1992).

Greenwich and Bexley FHSA have carried out a postal questionnaire survey of 2000 local residents on their views of the services provided by their GP. The FHSA has also been involved in training GP receptionists in customer relations.

Birmingham FHSA has commissioned the MVA consultancy to undertake a city-wide study into patient usage and attitudes towards many aspects of primary health care. A random sample of 1000 people are being interviewed in their homes and a report is due out at the end of 1992.

FHSAs are also interested in improving the quality of their own services and some have developed quality programmes. Brent and Harrow FHSA, for example, have carried out a survey of GPs to assess their satisfaction with the services provided to them.

The FHSA has also formed a Patient Needs Task Group in order to identify patients' needs and discuss how the FHSA can respond to these needs. The Task Group has identified the type of service it considered they should be providing to patients:

★ Acknowledgement of receipt of all mail from patients
★ A prompt reply to all queries
★ Clear and precise replies to patients, both verbal and written
★ Facilities to ensure patients can be seen in private if required
★ Respect of patients' rights to complete confidentiality
★ A courteous and helpful response to queries
★ The availability of an interpreter if possible
★ A personal service – patients should know who is dealing with their query.

They have developed a questionnaire for patients to complete after they have visited the FHSA and are considering developing another one for telephone enquiries, and others for groups of clients such as complainants and patients exempt from paying prescription charges (Woods, 1991).

As mentioned earlier in this booklet, Enfield and Haringey FHSA have developed a *Comments, Complaints and Suggestions* pack which provides guidance on practice-based procedures for dealing with complaints. This FHSA is part of a Consortium of London FHSAs working on issues related to complaints and complaints procedure in primary care services (see 'Useful Addresses').

Finally, medical audit advisory groups based at FHSAs are also interested in patients' views on health services and the King's Fund Centre runs a medical audit information service and database of projects which can provide details of work in this area.

Summary

There has been plenty of research on patients' preferences as far as GP services are concerned. The overview provided makes it quite clear that the nature of the GP–patient relationship, good communication, appropriate information and easy access all figure very highly in a good quality service from the patients' viewpoint.

A wide variety of methods for monitoring the quality of GP services are available, from 'off the shelf' survey questionnaires to qualitative methods such as patient participation groups. It is advisable to use a combination of these methods in order to record the views of different types of patients and to capture explanations as well as statements about preferences.

The views of users of dentistry and pharmacy services have been less widely researched but studies suggest that aspects such as those mentioned above are common factors, important to users of most services.

FHSAs are in a good position to establish databases of information on user preferences and views about local health services. It is important that they liaise with health authorities and local authorities in order to build up a common database and avoid duplicating research. There is some indication that many have started this process, although it is too early to say whether the initiatives will result in services which are more clearly influenced by the preferences of users.

3 COMMUNITY HEALTH CARE

Background

The complexity of service provision combined with the vulnerability of most service users makes community health care a difficult area, both for researchers and for those planning projects to find out user views.

It is probably fair to say as general guidance that patient satisfaction surveys using self-completion questionnaires will be useful in few circumstances. There may be some exceptions such as facilities and environment at health centres, but interview-based quantitative surveys and qualitative research will probably be necessary in most cases.

Apart from the fact that many service users will be unable or unwilling to fill in questionnaires themselves, there is also the issue of whether self-completion questionnaires can cover in sufficient detail the aspects of care important to those reliant on services for their continuing health and well being.

One of the difficulties in identifying relevant examples of projects collecting user views lies in the fact that local authorities also have a major responsibility in this area and they have a different tradition of consulting users. A separate body of consumer views research exists (see Harding and Upton, 1991).

The one point on which writers offering advice within both traditions agree, however, is that user participation and involvement are the aims, rather than obtaining user views. Achieving these aims is not as straightforward as carrying out research on views, although research itself can bring problems for management, as will be described.

In an article examining Griffith's report *Care in the Community* where he recommends a greater say and choice in services for people, Suzy Croft and Peter Beresford (1988) comment:

> *Talk is cheap when it comes to participatory services. Finding a way of making it a reality is a hard, unglamorous slog.*
>
> (Croft and Beresford, 1988, p. 44)

The authors are writing about social services but their comment is also true for community health services. One of the problems is a lack of knowledge about *how* to involve users. Very few health service professionals have experience of anything more than 'patient satisfaction surveys' or a limited form of consultation, which are clearly a considerable number of steps away from 'user participation'.

These steps have been described in various publications, some showing more steps than others, but the basic principle of a continuum stretching from passive recipient to active participant remains the same.

One of the oldest and most well known models is Sherry Arnstein's (1969) 'Ladder of Citizen Participation':

1. Manipulation
2. Therapy
3. Informing
4. Consultation
5. Placation
6. Partnership
7. Delegated power
8. Citizen control.

In steps 1–3 there is one-way flow of information aimed at achieving public support through public relations. Steps 4–5 see the information flow become two-way. Agencies collect information from service users and lay people, although this information may or may not be used to inform plans because the professionals still hold all the power. Steps 6–7 are those leading to real participation and sharing of power until at Stage 8 lay people control the funds and make the decisions.

There are not yet many examples of projects or programmes in community health care which are at Stage 5 or beyond but the numbers are growing and there is plenty of advice available to those ready to start working up the ladder (eg Croft and Beresford, 1990; NHSTD, 1993; National Consumer Council, 1992; Winn, 1990; Winn and Quick, 1989).

Before examining this advice in a little more detail, it is worth remaining briefly at the stage of informing, particularly the process of collecting information about local views, in order to identify when this is useful and what constitutes good practice.

Reorganisation of the NHS into purchasers and providers of health care operating through a contracting process has meant that many health authorities, FHSAs and local authorities are setting up databases containing information about the health needs of local people and their views about services and service priorities.

Different View Points

Research has shown that local people and service users frequently have very different views on health, health services and priorities to service providers. For example, a study involving interviews, discussion groups and questionnaires with local people, health professionals and those in the voluntary sector in West Lambeth (Dun, 1989) found a number of differences between professional and lay people.

When asked 'What does being healthy mean to you?', the top response for lay people was 'living life to the full' whereas for professionals it was 'absence of illness/pain'.

When asked 'What does it mean for you when people talk about a place being a community?' the top response for lay people was 'friendliness/neighbourly feeling' whereas for professionals it was 'people caring for each other/local network'.

There were considerable differences in view on local health problems also. To the question 'What are local health problems?', the top six responses in order were:

	Lay People	**Professionals**
1	Dirt/rubbish	Inadequate health services
2	Traffic	Mental health (eg depression)
3	Air pollution	Housing problems
4	Physical health	Poverty
5	Poor housing	Lack of 'care in the community services'
6	Dog's mess	Physical health (eg heart disease)

The findings did show, however, that local lay people were not very different from professionals in their views about having a say in local health services: most lay and professional people thought lay people did not have enough say.

More recent examples of ways of collecting information from the local population to aid purchasing are given in *Local Voices* (NHSME, 1991) and *The Public as Partners* (Healthgain Conference/NHSME, 1992).

It is easy to see how the views of local people about their health needs and priorities can be useful to purchasers/commissioners of health and social care but it is not as clear whose views should take precedence in decisions about local health service priorities. Research by the Needs Assessment Unit, St Bartholomew's Hospital Medical College (Bowling, 1992) found that the general public, GPs, consultants and directors of public health all had different views on priorities. The top three priorities were:

	Public	**GPs**	**Consultants**	**Directors of Public Health**
1	Treatment for children with life threatening illnesses	Community services / care at home	Services for people with mental illness	Family planning and services for people with mental illness
2	Special care and pain relief for people who are dying	Services for people with mental illness	Treatments for children with life threatening illnesses	Preventive services
3	Medical research for new treatments	Long-stay care	Community services / care at home	Health education

Surveys to elicit views about priorities may well uncover conflicts of interest or differing opinions, and ways of resolving these will have to be developed. It is difficult to see how consensus or compromise will be achieved without dialogue and that suggests considerable lay involvement at all stages of the process. Surveys alone provide information, they do not create dialogue. The role of the public in service prioritisation is not as simple as it appears, although Kennedy (1992) provides an example of dialogue with local people in York over health service care of the elderly which seems to have worked well.

Less controversial is the importance of including the views of service users in planning services. When views on community care services are examined, it is no surprise to find that here as in other areas users have different views on priorities to professionals.

In 1990 the King's Fund Centre adapted the search conference method in order to consult disabled people and their carers about their reactions to the new policies contained in the 1991

NHS and Community Care Act. Many of the concerns expressed bore little relation to the provision of health and social services which form the focus of the White Paper.

People were concerned about problems of access to public places, the generally low income of disabled people and unpaid carers, the difficulty faced by most disabled people in gaining employment, and mobility problems – especially for those dependent on public transport. Participants were most concerned of all about:

> *Who would listen to what they had been saying and if people did listen would it make any difference?*
>
> (Wertheimer, 1991, p. 41)

This is really the crux of the matter. Good practice involves not only adopting an appropriate method to elicit views but also improving services from the user's point of view as a result.

Implementing Change as a Result of Research

The series of steps needed to carry out the whole process from surveys or market research through to changes in services can sometimes be very long. In 1985 South Birmingham Health Authority embarked upon a programme of market research using Aston University's Public Sector Management Research Unit. The research, which took three years and cost £75,000 (see Luck et al, 1988, for a detailed account), did not bring about changes as easily as was originally expected.

Speaking at a conference in 1992, Richard Miles, Director of Health Care Purchasing for the health authority, said that in hindsight he considered that the programme was not totally integrated into the health authority's policy-making structure and so it was not followed up and used as thoroughly as it could have been. The two main lessons learnt were:

★ To beware of keeping results from those people who are responsible for making changes

★ To beware of doing so much that the results cannot be coped with.

It may be thought that obtaining user views about services is an easier option than involving service users in planning and monitoring services, but this is not necessarily the case. Direct involvement in the process overcomes that large gap between research and management.

The most effective way to achieve a user influence on services is likely to be a combination of feedback and involvement. This involvement can (and ideally should) be at many levels, from commissioning research on user views (eg Davis and Fleming, 1992) to planning (Living Options in Practice, 1992) and evaluating services (eg Whittaker, 1991).

Just as research on user views can be divided into a series of essential stages (see McIver, 1991a), so establishing user involvement can also be broken down into stages. These have been described in a number of publications (eg National Consumer Council, 1992; Croft and Beresford, 1990) but specifically in relation to this service area in *Consumer Participation in Community Care: Action for Managers* (NHSTD, 1993). A brief summary includes:

★ Agree what is meant by consumer participation
(eg draw up a written policy with users).

★ Put consumer participation at the centre of community care
(eg ensure all staff are aware of the policy and understand its implications).

★ Establish clear aims and outcomes
(eg policy should include outcome measures for judging how successfully the policy is being implemented).

★ Make sure participation is personal
(eg build time spent with consumers into the workloads of senior managers).

★ Establish a range of channels
(eg provide a choice of ways for consumers to participate and take account of the needs of different client groups).

★ Create equal opportunities
(eg strategies for encouraging participation by members of black and minority communities and other hard-to-reach users and would-be users).

★ Establish leadership
(eg a senior manager with designated responsibility for implementation and monitoring of policy).

★ Allocate resources
(eg consider funding local consumer groups directly through support workers, facilitators etc).

★ Establish information and communication strategies
(eg make sure consumers receive the information they require for effective participation).

★ Learn from participation
(eg review and where necessary revise consumer participation policy and strategies with consumers).

Obtaining user views and establishing participation in the planning, monitoring and reviewing of services should not preclude the development of other ways to protect service users, particularly those in residential care. Requirements such as incident reporting can be written into contracts. Some examples from North America are provided by Winkler (1990).

This section has given a brief general introduction to the subject of user feedback and user involvement in community health care services. The following sections will take a more detailed look at different settings, services and client groups.

Service Settings

The type of setting in which the service is provided, whether this be at a health centre, in a residential home, daycare or at the home of the patient/client, will be a major influence on the type of issues which are important to users of that service.

The client group will also be important but it may be possible to identify many concerns shared by a range of client groups. A useful booklet which goes some way towards achieving this is *Community Life: A Code of Practice for Community Care* (1990). The checklists provided in the booklet can be easily turned into questions to ask users and an application of this for users of mental health services is given in McIver (1991c).

Some examples of user feedback studies in the various settings – residential care, health centres, daycare and homecare – may also be helpful to those wishing to monitor service quality from the user perspective.

Residential Care

This care setting accommodates the most vulnerable individuals and probably those least used to being asked their views on service quality. It is highly unlikely that a self-completion questionnaire will collect useful information in this setting.

Interviews or discussion groups are a better choice, especially with the elderly or infirm, but if these are conducted by staff, residents may be afraid to be critical. The ideal would be an interviewer who is independent and who spends time getting to know residents before carrying out the interviews, so that they feel comfortable with the person and have confidence in them.

The 'Quality for People' project based at Orpington Hospital, Bromley, has taken this approach. In addition to interviewing residents to determine what they think is important for a good residential service, the project team has worked with those who will eventually receive the feedback, in order to determine what it is they need to know. The aim has been to develop:

> *... simple, but hopefully accurate ways of feeding back information from residents to different parts of the service system. These will be used to form 'monitoring mechanisms'.*
>
> (Kerruish and Reardon, 1992; see also 'Useful Addresses')

Another useful example is the DoH funded 'Caring in Homes' initiative which was, at the time of writing, drawing up practice guidelines and packs following completion of two and a half years work.

The initiative has covered detailed work in a broad range of care homes on a number of issues. One project, 'Inside Quality Assurance', carried out by researchers at CESSA, the Polytechnic of North London, has included user views of service quality.

The project coordinator, Leonie Kellaher, writes that information collected using the pack they have developed, especially that from residents, 'can direct more sensitive staff training programmes' (New Developments, 1992; see also 'Useful Addresses').

For younger residents, such as those with learning difficulties or those suffering from mental distress, a better method may be to facilitate the development of user groups in which residents can explore issues of concern to them and feed these to management.

There are a number of projects of this type in services for people with learning difficulties, and information about them is available from the information exchange on self-advocacy and user participation run by the King's Fund Centre Community Living Development Team.

Similar user groups for people suffering from mental distress are generally termed 'patients' councils' and advice on how to develop them can be obtained from The Patients Council's Support Group and MIND's user involvement information pack (see 'Useful Addresses').

Health Centres

In their arrangement of different services within one building, health centres resemble outpatient departments, and some of the issues – particularly those concerning convenience of appointment time, length of waiting time, comfort of waiting environment, and availability of facilities such as telephones, lavatories and refreshments – will be similar (see McIver, 1991b, for research on the views of outpatients).

Apart from issues concerning the appointment procedure and waiting environment, which will probably fall within the domain of the Centre Manager, there are also issues around treatment and care which are the responsibility of the various professions concerned.

It is likely these professions will want to carry out their own monitoring of service quality from the user viewpoint and this is covered in a separate section (see also the section on GP surgeries and the examples of 'Core Questions' given at the end of this booklet).

An example of a project using the College of Health's *Ask the Patient* pack to obtain user views at a health centre is described by Burchell (1992).

Daycare

Most studies of user views of daycare seem to concentrate on the acceptability to patients/clients of the activities and treatment programmes they engage in and the effect these have upon their health.

In many cases these studies take the form of questionnaires listing activities and asking respondents to rate them (eg Turner-Smith and Thomson, 1979; Rothwell, Lorimer and McKechnie, 1989). This approach will probably miss those issues about treatment and care which less structured studies have found are important to patients/clients.

If questionnaires or structured interview schedules are used (and interviews are recommended for users of day centres), it is better to ask more specific questions (see examples of 'Core Questions') and to use these in conjunction with other methods.

An example of a study which made good use of multiple methods to assess day hospital provision is reported by Nolan (1987). Direct and participant observation, structured and semi-structured interviews and the compilation of a field diary were used to compare therapeutic activity in two different day hospitals for the elderly.

Studies of user views of day centres often show that users and staff have different priorities and expectations about treatment. For example, nearly half the sampled attenders at a mental health day centre in East Lambeth said that the visit helped them because they enjoyed meeting people, whereas no one in the sample mentioned therapy (Holloway, 1988).

In another study, attenders at an adult training centre for people with 'mental handicaps' in Scotland felt that in the long term the Centre did not make a positive contribution to their lives and wished for ordinary jobs (Jahoda, Cattermole and Markova, 1989).

This means that it is important to establish with users the aims of the particular daycare facility. In fact in many cases it is difficult to see how a daycare facility can be assessed without considering its place within the wider picture of local community care provision.

This is a complex question and calls for a study which is wider than the traditional 'satisfaction survey'. An example is the evaluation of a travelling day hospital reported by Powell and Lovelock (1987). This involved information obtained from four sources:

1. Records, case notes and documentation held by members of the travelling day hospital (TDH) team
2. Direct observation of all aspects of the TDH activities
3. Interviews with a sample of the various consumers of the service – the elderly people, their relatives, and professionals within and outside the TDH team
4. Statistical material relating to the service.

The researchers comment:

> *By seeking the views both of those in direct receipt of the service and those whom it aimed in different ways to support or relieve, we could examine from these consumers' perspectives the extent to which the TDH was fulfilling its broad aims.*
>
> (Powell and Lovelock, 1987, p. 18)

The use of multiple methods also enabled them to gain a broader picture of the place of the travelling day hospital within the local community and to provide advice on ways of developing its role within a community oriented psychogeriatric service.

Homecare

Research on user views of the services provided to those living at home generally focuses on the needs of a particular care group, such as elderly people with dementia (National Consumer Council, 1990), those with a physical disability (College of Health, 1990), or those suffering from mental distress (Richie, Morrissey and Ward, 1988).

Having said this, it seems that a number of issues occur regularly as important to those receiving care at home, whatever the reason. These are: information, co-ordination of care, flexibility of care, recognition of the needs of carers, and respect for the individual.

Information

Better information provision to patients is necessary in most areas of the NHS, but it is especially important for those trying to manage health problems at home. This includes information about:

- ★ Relevant health problems or conditions
- ★ What professionals are visiting and the nature of their job
- ★ What support services are available should they need them
- ★ What financial benefits, physical aids etc are available.

Getting this information to those who need it can be difficult, especially where people are isolated, sensorily impaired, or do not speak English or read their own language.

In many cases there are key workers, such as GPs, who need this information to hand. Strategies for improving information distribution should be developed in order to help workers pass on information and to make it more easily available to people at places they visit regularly or by phone. It would also help if health and social information services were integrated.

Co-ordination of Care

For the service provider, co-ordination is largely a question of organising different services to support an individual in their home, but for the service user other issues become important. For example, does the professional or transport arrive at the expected time? Do they have to repeat the same information about themselves many times to different people?

Jocelyn Cornwell's (1989) research on the views of elderly people and their carers about community health services describes the situation clearly.

> *Elderly people very often use more than one service at a time. A disabled old person who lives alone and has a fall, for instance, may be admitted first to hospital and then to residential care. This one person could have had contact with most, if not all, of the following: GP; home help / home care assistant; meals on wheels; district nurse; night sitter; bath attendant (voluntary or statutory organisation); specialist community nurse; chiropodist; physiotherapist; occupational therapist; geriatric visitor / liaison visitor / liaison nurse; medical social worker; hospital medical and nursing staff; hospital therapist; residential care staff.*
>
> *The involvement of so many agencies and organisations in the provision of community services means that the professional relationship between individual consumer and professional is at a premium. Without this, old people and their carers can very quickly begin to feel that although their problems are being 'dealt with' – dressings changed, shopping done, bathing and toileting completed – they are not truly cared for.*
>
> (Cornwell, 1989, p. 10)

Flexibility of Care

Flexibility, an issue closely associated with co-ordination of care, is about the service user or carer having a choice over when professionals visit so that they are not forced to choose between the different services they need because they are planned for the same time, or between these services and other activities important to them.

Service users and carers need the help they receive to fit in with their lifestyle and particular situation rather than with the demands of the providing organisation(s). Listening to what people say they need and when they need it may sometimes make life more difficult for the organisations concerned but the alternative is often a bad match between needs and services – over-provision or under-provision of care.

Recognition of the Needs of Carers

In 1989 Jocelyn Cornwell commented in her booklet on elderly people and community health services that:

> *There is even less published material about the preferences of carers than about the preferences of the general public.*
>
> (Cornwell, 1989, p. 7)

Hopefully this situation has begun to change following a number of initiatives highlighting the needs of carers. The leaflet 'Carer's Needs' which provides a ten-point plan for carers and guidelines on good practice, plus information about projects involving carers, can be obtained from the Carers Programme at the King's Fund Centre (see 'Useful Addresses').

Respect for the Individual

Those who need care in the community are frequently the kind of people who are easily stereotyped and so are often treated in a particularly demeaning way. Elderly people are seen only in terms of their age (ageism), those suffering from mental distress are seen as mad, people with learning difficulties are considered to be subnormal, people with physical and sensory disabilities are thought to be helpless – and members of black and minority ethnic communities who fall into these categories are subject to racism as well.

It is easy to forget about the rights of individuals if the person is 'mad' or 'subnormal' and unfortunately users of community care services often complain that this happens – that their views are not respected or they are not allowed to retain their dignity.

Lack of respect for certain care groups is the result of ignorance and insufficient training, but this in itself is evidence of a wider problem. Staff looking after people in these care groups are among the least qualified and most poorly rewarded.

The problems caused by stereotyping are not just ones of attitude; they are frequently structural and organisational as well. Racism, for example, has resulted in fewer treatment options for black and minority ethnic groups suffering from mental distress. Members of these groups consistently receive higher doses of drugs, more ECT, less individual attention from consultants and less psychotherapy (Good Practices in Mental Health, 1988).

Another example is the fact that district nurses rather than health visitors work mainly with old people, yet the emphasis on health prevention and promotion provided by health visitors could help to develop a more positive approach towards ageing (Cornwell, 1989).

Health care providers will not be able to fulfil the requirements of the Patient's Charter to provide care with *'respect for privacy, dignity and religious and cultural beliefs'* unless they address the issue of stereotypical attitudes and the organisational structures maintaining these attitudes.

Services

A wide range of services are provided by health professionals working in the community. For the sake of brevity these have been broadly divided into nursing (including health visitors, district nurses and community nurses) and professions allied to medicine (occupational therapy, physiotherapy etc). It is not the intention here to cover each area in depth but instead to provide a few references within each category.

With one or two exceptions these professions do not have a long history of consumer feedback research but the picture is changing quite rapidly. It is worth contacting relevant professional organisations (eg the Chartered Society of

Physiotherapy, the Royal College of Nursing, the College of Speech Therapists etc) for recent information on the issue.

Nursing

Within this area, surveys of the health visiting service appear to be the most common. Field et al (1982) is a good example of an interview survey which collected detailed information using tape recorders from 78 first-time mothers in Cambridge.

Weatherley (1988) sent a self-completion questionnaire which included both structured and open-ended questions to 50 families in a health visiting caseload within a GP practice in Edinburgh. She achieved an 82 per cent response rate and found that nearly all respondents answered the open-ended questions. The future plan was to use the open-ended questions as a way of monitoring routinely the effectiveness of the service.

Poulton (1990) incorporated a survey of clients using a self-completion questionnaire within research to monitor health visiting standards of service. While this approach is laudable it would have been preferable to have set the standards with the participation of service users and to have involved them in the design of the questionnaires, to ensure that the quality issues for users were addressed.

Drennan (1987) provides an interesting example of a community development approach to health visiting. In this project members of a local community decided how they wanted to make use of a health visitor, and it was clear there was an interest in opportunities to discuss aspects of health in an informal, non-threatening environment.

A project aimed at developing methods of getting user feedback on aspects of the health visiting, district nursing and school nursing services is described by Burman (1991).

Examples of research on user views of the community psychiatric nursing service are given in McIver (1991).

Professions Allied to Medicine

A variation on the self-completion questionnaire design called 'priority search' is described by Trevelyan (1992), who used this method to find out user views of a physiotherapy outpatient service. The method involves collecting user views on what they consider to be important aspects of the service during focus group discussions, followed by the development of a questionnaire in which the important aspects are paired and respondents have to make a mark along a continuum between the aspects to indicate which they consider to be most important.

Trevelyan found that although the method proved to be an effective way of conducting a survey because the results clearly identified how users felt the service could be improved, some people found it difficult to complete the questionnaire:

> *A number of respondents had difficulty in understanding the concept of paired comparisons.*
>
> (Trevelyan, 1992, p. 95)

A survey of elderly physiotherapy outpatients conducted by McCallum (1990) adopted a traditional approach using a postal self-completion questionnaire but the focus of the questions was unusual. Particular attention was paid to perceptions of treatment outcomes.

In order to be able to link presenting conditions to outcome, respondents were asked to sign the questionnaire, which they were sent immediately after discharge. The questionnaire contained both structured and open-ended questions, including one asking about the most important outcome of treatment. Pain relief was the most important outcome for many respondents.

Also, the most frequently reported problems were those judged to have the most successful outcomes. Soft tissue lesions and degenerative joint disease of the cervical spine were among the most frequently presenting conditions, and treatment outcomes for these conditions were among those judged by patients to show most improvement.

Work on the development of standards for physiotherapy by Bromley, Sutcliffe and Hunter (1987) includes a model patient questionnaire.

Stockwell et al (1987) investigated which treatments users of an occupational therapy service in a psychiatric unit found most helpful. Vaughan and Prechner (1985) found that users of a psychiatric daycare service felt that occupational therapy activities such as arts and crafts and social activities had contributed as much to their recovery as psychotherapy.

Users of many community services often want more information about what a particular service does (eg Trevelyan, 1992; Weatherley, 1988), and Beynon (1992) explains why this is particularly important as far as the occupational therapy service is concerned.

A publication based upon interviews with different types of elderly people details areas in which chiropody services need improvement, including services for black and minority ethnic people and those in private nursing homes, and suggests some solutions (Age Concern, 1989).

Other surveys of patients' views of chiropody services are reported by Salvage, Vetter and Jones (1988), Vetter, Jones and Victor (1985), and Jay (1987).

Care Groups

Even a superficial glance at the literature will reveal that the different categories of people typically in receipt of community care have been the subject of considerable research. Until recently, however, the views of service users were largely absent from these studies because it was thought difficult if not impossible to get useful or 'truthful' information.

This has changed over the last few years and ways of getting the views and opinions of all categories of people have been developed. The aim of this section is to provide a basic guide to one or two references and sources of information on user feedback work for the different care groups.

People Suffering from Mental Distress

McIver (1991c) provides an overview with plenty of references for both community and acute care. MIND have developed a user involvement information pack (see 'Useful Addresses'). A recent project developed in 1992 by Newcastle Health Authority is involving a local mental health users group in the contracting process (see 'Useful Addresses').

People with Learning Difficulties

Whittaker (1990) and Whittaker, Gardner and Kershaw (1991) provide examples. The King's Fund Centre runs an information exchange on self-advocacy and user participation for this client group (see 'Useful Addresses'). Crocker (1989) provides a useful discussion of some of the methodological difficulties involved in conducting surveys with this client group. Baxter et al (1990) discuss the issues and services of importance to black and minority ethnic people with learning difficulties, and include references and resources.

People with Physical and Sensory Disabilities

The Living Options in Practice Project has been working with eight localities since January 1990 to establish systems for user participation and embark on action planning towards good practice services. A series of publications have been produced, including one entitled *Achieving User Participation* (Fiedler and Twitchin, 1992).

Badger, Cameron and Evers (1989) report on research involving interviews with people with disabilities to discover their opinions on services in Birmingham. In 1990 the College of Health carried out a consumer audit of services for people with a physical disability for Parkside Health Authority. This included interviews and group discussions (Davies, 1990).

See Brimblecombe (1985) and Ayer (1984) on the needs of parents of young handicapped children living at home.

Elderly People

Age Concern, CESSA and the Centre for Policy on Ageing are all useful sources of recent research (see 'Useful Addresses'). Hadridge (1992) has written a literature review focusing on the unmet health needs and untreated health problems identified by older people and their carers.

Cornwell (1989) describes different types of elderly consumers and their experiences of community care as well as giving guidelines for good practice and resources for action. Farquhar, Bowling and Grundy (1991) describe a study which showed that elderly people's needs differ depending on the locality in which they live.

The National Consumer Council (1990) have published a guideline study on consulting consumers, looking at elderly people with dementia living at home, and their carers.

Harding and Modell (1989), Williamson (1985) and Williams and Fitton (1991) give details of the views of elderly people and their carers about discharge from hospital. Muriel Skeet (1982) provides an excellent although less recent analysis of studies of this area where, as she comments herself, findings are 'disappointingly similar' despite covering more than a decade. Wilkin and Hughes (1987) is a study of the views of elderly people in residential care.

Parents and Children

Belfield (1988) examines research on consumer perceptions of family planning and looks at enquiries to the Family Planning Information Service. Thomas and Hare (1987) report on a study of women's views of daycare laparoscopic sterilisation.

McIntosh (1988) reports on an interview survey of mothers about their attendance at birth preparation classes. Mason (1989) and Garcia (1989) provide an 'off the shelf' postal self-completion survey to find out women's views of maternity care. Taylor (1985) describes a questionnaire survey of mothers' views of their experience of antenatal wards.

The Association for Improvements in the Maternity Services (AIMS) has recently (1992) published its submission to the House of Commons Health Committee in 1991, *Childbirth Care – Users' Views*.

A few other useful references from among the many in the area of maternity care are Garcia (1983), Oakley (1984) and O'Brien (1978).

Moss et al (1986) examine mothers' views of the health visiting service during the first six months after birth, and among many other studies, McIntosh (1985), Simms and Smith (1984), Clark (1984) and Field et al (1982) give consumer views of the health visiting service.

Newcastle Inner City Forum/Newcastle CHC *What We Need Is ... : Women, Health and the Health Service in Newcastle upon Tyne* (1983) is an interesting report of a project involving six women's groups looking at services for mothers including pregnancy testing, abortion, miscarriage, and ante- and postnatal care.

Mayall (1986) includes descriptions of parents' and children's experiences of community services; Cooper and Harpin (1991) contains parents' own stories about their experiences of using the NHS; and Alderson (1990) describes parents' experiences of their involvement in consent to operations.

Krementz (1990) gives children's accounts of their experience of hospital; Bewley, Higgs and Jones (1984) describe attitudes to illness and health care of adolescent patients at an inner London GP surgery; and Lewis et al (1977) describe an innovative project where children refer themselves to a school nursing service.

Carers

The Carers Programme at the King's Fund Centre is a good source of information about research on carers' views and about projects developing carer participation in service planning. There is a support network for carers, workers and others and a free newsletter *Carelink* (see 'Useful Addresses').

A detailed account of a series of consultations with the carers of elderly or disabled relatives and friends is described by Barnes and Wistow (1992) and should prove helpful to others wishing to organise a similar project.

Williams and Fitton (1991) report a survey of carers of elderly patients discharged from hospital.

Terminal Care / Bereavement

Higginson, Wade and McCarthy (1990) interviewed terminally ill cancer patients and their family members to discover their views of hospital, community and support team services. Bowling and Cartwright (1982) describe a study of spouses of the deceased.

Black and Minority Ethnic People

The Services for Health and Race Exchange (SHARE) project set up at the King's Fund Centre in February 1991 is a good source of information about research on health and race, including projects involving user views and user involvement (see 'Useful Addresses').

Summary

Anyone taking a glance at the area of user feedback in community health care will probably be overwhelmed by the sheer volume and variety of material available. A closer examination reveals that most of the detailed qualitative studies of user preferences and views have been carried out by researchers and development workers within specific care groups. Many of the studies with a service or professional focus, on the other hand, have been questionnaire surveys collecting responses to questions about satisfaction.

No doubt this situation is largely due to different timescales, funding, expertise and other resources, but professions would benefit by reading some of the more detailed work available on the particular care groups who use their services before conducting their own user feedback research.

It is unlikely that community care services can be tailored to suit users' needs and preferences without the detail provided by qualitative research. This is one of the reasons why a much higher proportion of user feedback work in community care has the aim of user participation or user involvement. When users and carers are involved in a number of different ways in the service planning, monitoring and evaluation process, they are more likely to be able to have an impact upon the quality of the service.

4 CONCLUSION

As changes occur in the organisation of primary and community care, and responsibilities move from one profession to another – from health visitor to GP (as in Child Health Surveillance) or from health to social services – there is a need to exchange experience and information, as well as develop new ways of working.

It is within this context of an increasing overlap between primary and community health care services that a comparison of user feedback work in the two areas can be useful.

In the area of GP services there has been a large amount of detailed academic research on the nature of the GP–patient relationship. This work provides a valuable insight into the broader relationship of the professional and service user.

It is highly likely that features patients like in doctors will also be liked in other professionals:

- ★ Warm, friendly and encouraging
- ★ Discovering concerns and dealing with their expectations
- ★ Providing clear explanations, information and instructions.

Factors which hinder good communication between doctor and patient – different perspectives and different languages – also apply in many cases. The notion of patient-centred care is as appropriate to other health professions as it is to GPs.

In some areas of community health care, on the other hand, there has been a more widespread attempt to involve users in service planning and evaluation. Certainly there is a body of experience in encouraging user participation which is not present in primary health care (apart from patient participation groups).

This experience would be particularly useful to professionals engaged in standard setting, enabling them to create user-based standards. They may also find help in developing ways of involving users in the monitoring of standards.

Although there are differences in user feedback work across the two care areas, there are two striking similarities. The first is evidence that users frequently have completely different views to professionals on health priorities and what constitutes a good quality service. Professionals should never assume that they know what users consider to be important.

The second is that users seem to value certain elements, whatever the service. They appear to have a clear idea of what they consider important: the quality of their relationship with the care giver, good communication, appropriate information, and a successful outcome to the treatment.

The recognition that a number of 'core concerns' exist led to the example questions given at the end of this booklet, although these are meant only as suggestions to encourage future work in the area.

The fact that example questions are given should not lead readers to concentrate on questionnaires or interviews at the expense of involving users more directly in service planning and development.

Collecting user views and ensuring that they influence decisions is not an easy option but there is no doubt that user involvement in the decision-making process itself calls for more substantial cultural and organisational change.

There are one or two action research projects currently under way which examine aspects of this process (eg Taylor, 1992) but more research is needed into the factors which help or hinder effective user involvement.

An indication of what some of these may be is given by Stoller (1977). A sociologist, Stoller was also a participating member of the boards of directors of two health-related organisations in the USA. The by-laws of both organisations required a majority of lay members on all policy-making units.

She found that although the formal organisational structure called for equal participation by providers and consumers in policy-making, this alone was not sufficient to break down the traditional practitioner–patient interaction patterns that participants had brought with them from earlier experiences in the health care system.

She suggests that a number of prerequisites are necessary before real partnership can take place. Two of the most important are:

1. The need for consumers to develop a sense of group identity to match the occupational identity shared by the providers. This sense of identity should enable the consumers to recognise the value of their particular perspective on health care issues.
2. A sense of consumer competence. Lack of self-confidence is likely given the situation, which is a familiar one to professionals but likely to be less so for lay people – particularly those in low income groups.

In the two organisations studied, the behaviour of the providers reinforced the lack of consumer self-confidence by channelling communication along technical lines and failing to encourage consumer contributions.

Stoller concludes that partnership will only emerge when the different perspectives of the provider and consumer are recognised and an attempt is made to negotiate the expectations of their newly defined roles.

> *The conflict that may accompany this role negotiation serves a positive function during the early history of such organisations by allowing participants to work together to construct an effective organisation.*
>
> (Stoller, 1977, p. 177)

It is clear that both staff and consumers need to be prepared for these changes through information and training, and a communications strategy would be a step in the right direction.

Local people need to feel that the traditional culture of the NHS is changing towards a more participative style in which their views are respected, both with regard to their own health and the care provided to the community.

This perception can be encouraged through initiatives such as local patient's charters, health newspapers, public meetings, exhibitions, improved complaints procedures, telephone help-lines etc.

Where staff are concerned it is important that direct care staff as well as management are involved in training and development to encourage user involvement, because it is their responsibility to put principles into practice on a day to day basis.

The transition training workshops developed by West Lambeth Health Authority provide an example. In one workshop participants follow two lines of enquiry about the situation of people with severe disabilities. They ask how people in society are vulnerable and they focus on one person's experiences.

This leads to deeper insights into the dangers of unquestioned segregation, deprivation of choice, under-development of abilities, disrespect and isolation. The trainers believe that:

> *Transition training leads participants to expect that service users will share community places, make choices, develop their contribution, experience the dignity of valued social roles and gain friends.*
>
> (Lemmer and Braisby, 1991)

Rather than blaming direct care staff for having 'bad values' or 'resisting change', Lemmer and Braisby point out that planners and managers often under-estimate the level of commitment required to work with vulnerable groups of people in a society which tends to shun and devalue them.

The answer is to help staff develop an understanding of the rationale for community care and to introduce the elements on which a core philosophy and vision of a more desirable future can be built. That is:

> *To empower direct care staff to give them a stake in a vision which in turn empowers service users.*

It is hoped that the research described in this booklet, together with the examples of projects and useful addresses will also help staff in this task.

EXAMPLES OF CORE QUESTIONS

The following are some examples of questions to ask users, whatever service is being provided. Responses are not given because a number of formats are possible and there is no clear evidence to suggest that any one is better than all the others.

Some of the most commonly used formats are:

1 Yes / No / Comments

Examples can be found in earlier booklets in this series.

2 Responses suggested by interviews with patients

For example:

When the doctor examines you, is he gentle?

☐ No, I find him rough.
☐ Sometimes he is a bit clumsy.
☐ Yes, he is always gentle.
☐ It depends which doctor I see.

3 Response scales

Scales such as 'very satisfied' to 'very dissatisfied' or 'excellent' to 'poor'. A study comparing these two response formats found that the five scale 'excellent', 'very good', 'good', 'fair', 'poor' performed better than the six scale 'very satisfied' to 'very dissatisfied' (Ware and Hays, 1988).

As there appears to be little firm evidence to enable a selection between these three main formats, a combination to suit the type of question seems to be the best way forward.

The 'Core Questions' have been divided into three areas: treatment and care, information provision, and outcome. It should be noted that these are not the only questions that could be asked in these areas.

In the area of outcome, for example, the questions could be combined with others seeking to measure health status or quality of life. Those new to the area may find Bowling's (1991) review of quality of life measurement scales useful. The UK Clearing House on the Assessment of Health Outcomes will be able to provide information about others working in this area (see 'Useful Addresses').

Treatment and Care

1 Were you greeted in a friendly manner by the (person you saw) ?

2 Did you know the name of the (person you saw) ?

3 Were you frightened during your visit/when the person visited ?

If yes, is there anything some one could have done to help you feel less frightened ?

4 Did the (person you saw) seem interested in what you had to say ?

5 Did you find it easy to talk to the (person you saw) ?

6 Did the (person you saw) take enough time to listen to what you had to say ?

7 Do you think the (person you saw) examined you thoroughly enough ?

8 When they examined you, were they gentle ?

9 Did the (person you saw) explain things in a way you could understand ?

10 Did you leave wishing you had asked more questions ?

11 Did you feel that you had some say in the treatment you received ?

12 Did you feel happy about the treatment you received ?

13 Any other comments about the way you were treated ?

Information Provision

1 Were you given any written information (before your visit/about the service) ?

2 At the time you received it, did the information tell you what you wanted to know ?

3 In hindsight, could the information have been better ?

If yes, in what way could it be improved ?

4 Would you have liked to talk to someone at the time you received the written information ?

5 Were you given any written information during your visit (by the person who visited you) ?

If yes:

(a) Have you found this information easy to understand ?
(b) Has it raised any worries in your mind ?

6 Are you suffering from any illness or condition you would like more information about ?

If yes, what is this illness ?

7 Do you need information about:

(a) Keeping healthy ?
(b) Other services available to help you ?
(c) Self-help groups ?
(d) Any drugs/medicine you have been given ?
(e) The treatment you are receiving ?
(f) Other ? (please describe)

8 Were your expectations about the visit (to or by the person you saw) satisfied ?

If no, please describe your expectations.

9 Do you know how to make a complaint should you need to?

10 Do you have suggestions about how we can improve the information we provide ?

Outcome

1 Were you told what the effect of your treatment would be ?

2 Has the treatment had the effect you expected ?
If no, please explain what was unexpected.

3 Has the treatment worked as far as you are concerned ?
If no, please explain why not.

4 If you were prescribed any medicine or tablets, have you taken them all as instructed ?
If no, please explain why not.

5 Have you taken any medicines or tablets not prescribed ?
If yes, please describe them.

6 Were you given advice about how to help yourself get better ?
If yes, have you followed this advice ?

7 Have you any questions about your treatment which you still need answers to ?
If yes, write them here:

8 Do you feel better for your treatment ?

9 In retrospect, was it worth having the treatment ?
If no, please explain why not.

10 Is there anything that could have been done to make the treatment better, from your point of view ?

USEFUL ADDRESSES

Primary Health Care

College of Health

St Margaret's House
21 Old Ford Road
London E2 9PL
Tel: 081 981 6719

Medical Audit Information Service

King's Fund Centre
126 Albert Street
London NW1 7NF
Tel: 071 267 6111

Ralph Leavey

Senior Lecturer
School of Health
St Martin's College
Lancaster LA1 350
Tel: 061 224 5256 (home)

London FHSA Complaints Consortium

Fedelma Winkler (Convener)
Director of Planning
Barking and Havering FHSA
117 Suttons Lane, Hornchurch
Essex RM12 6SD
Tel: 0708 472011

Managing Patient Satisfaction Surveys (MOPS)

Geoffrey Frew
75 Sheen Lane
East Sheen
London SW14 8AD
Tel: 081 878 8566

National Association for Patient Participation

Mrs Ann Smith (Hon. Sec.)
50 Wallasey Village
Wallasey
Cheshire L45 3NL

Social and Market Survey Research Ltd (SMSR)

Victoria House
82 Beverly Road
Hull HU3 1YD
Tel: 0482 211200

Community Health Care

Age Concern
21 Old Ford Road
London E2 9QD
Tel: 081 640 5431

Carers Programme
King's Fund Centre
126 Albert Street
London NW1 7NF
Tel: 071 267 6111

Caring In Homes Initiative
Leonie Kellaher
(Inside Quality Assurance)
CESSA, Polytechnic of North London
62–66 Highbury Grove
London N5 2AD
Tel: 071 607 2789

Centre for Policy on Ageing
25 Ironmonger Row
London EC1
Tel: 071 253 1787

Information Exchange on Self-Advocacy and User Participation
Community Living
  Development Team
King's Fund Centre
126 Albert Street
London NW1 7NF
Tel: 071 267 6111

MIND User Involvement Information Pack
Publications Mail Order Service
4th Floor, 24–32 Stephenson Way
London NW1 2HD
Tel: 071 387 9126

Newcastle Mental Health User Involvement Project
Carole Craddock
Research Assistant to the
  Contracts Department
Newcastle Health Authority
Scottish Life House
2–10 Earthbound Terrace
Newcastle upon Tyne NE2 1EF
Tel: 091 281 5011

Quality for People Project
Portnalls Unit
Farnborough Hospital
Orpington
Kent BR6 8ND
Tel: 0689 862899

Services for Health and Race Exchange (SHARE)
King's Fund Centre
126 Albert Street
London NW1 7NF
Tel: 071 267 6111

UK Clearing House on the Assessment of Health Outcomes
Lorraine Bate, Manager
Information Resource Centre
Nuffield Institute for Health
  Service Studies
University of Leeds
71–75 Clarendon Road
Leeds LS2 9PL
Tel: 0532 459034

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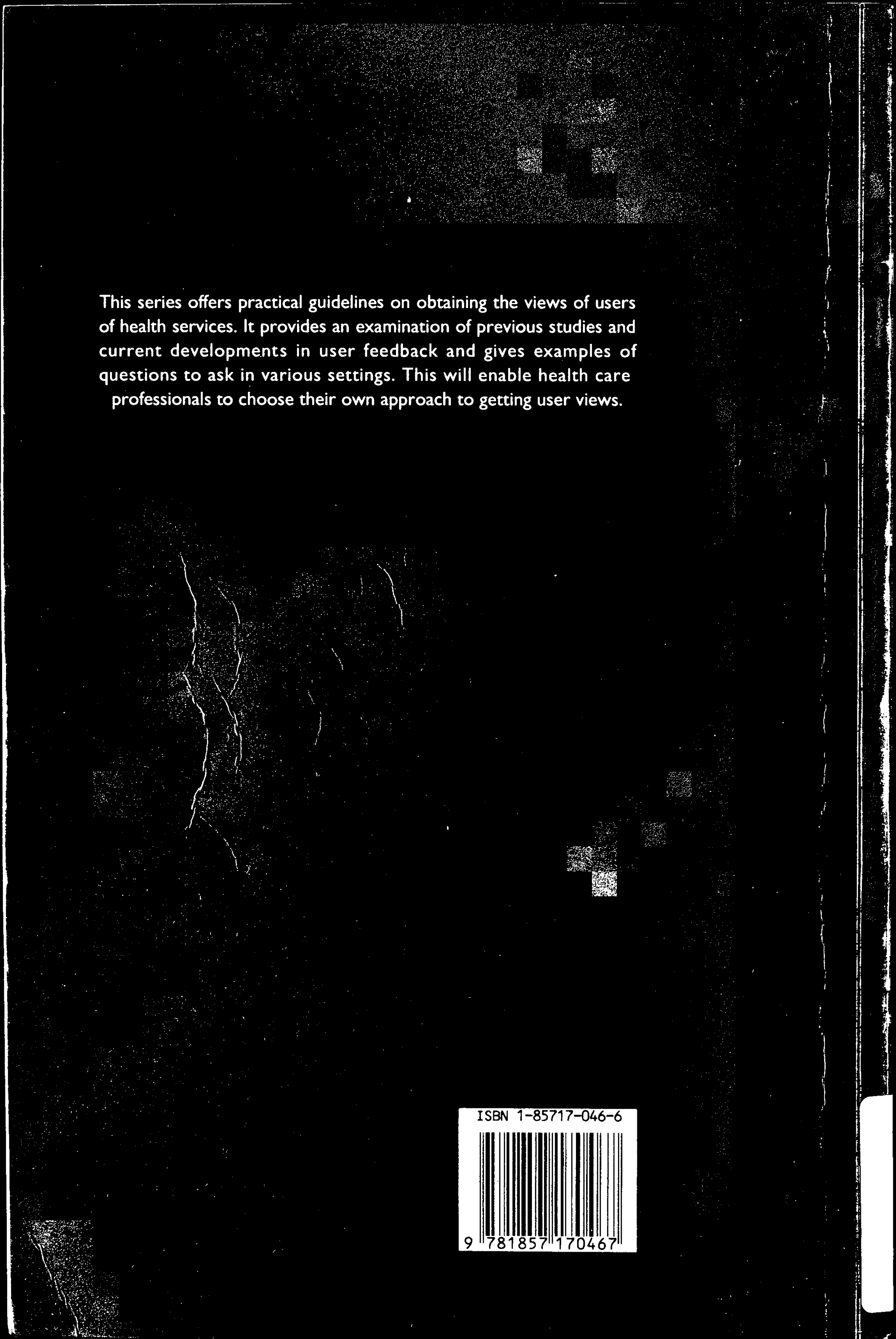

This series offers practical guidelines on obtaining the views of users of health services. It provides an examination of previous studies and current developments in user feedback and gives examples of questions to ask in various settings. This will enable health care professionals to choose their own approach to getting user views.

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