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Reducing Barriers to Health Care

A study to Measure and Understand Inequalities in Health Resulting from an Inequitable Balance Between Health Service Use and the Need for Health Services

Phase Two (RBG 99XX8)

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Executive Summary

This report describes a research programme, funded by NHS Executive Trent, designed to follow on from earlier work that examined whether there were inequalities in the access to and use of health services.(1)

A lot is known about the occurrence of health inequalities, but much less about reasons for them.(2;3;4;5;6) In general, health inequalities may arise because of differences in the incidence of ill-health generally, and in the incidence of specific diseases; and differences in the outcome from disease whether or not the incidence is different. These outcome differences may arise because of different provision and/or uptake of health care.

In this report, reasons behind the differences in health service use and outcomes for equivalent disease levels are examined, especially focussing on those associated with differences in decisions to seek and use health services. Findings from four linked studies using various qualitative and quantitative methodologies are presented, followed by our recommendations for practical steps that could be implemented by the health service to improve access and reduce health inequalities.

In summary, this research programme has:

1. identified a wide range of factors that influence the way people access health services and interact with health professionals;

2. investigated how the importance of specific barriers varies with age, sex, socio-economic circumstances and individual health;

3. explored how barriers may operate for different individuals and explored the complex interaction between individual beliefs and experience and the decisions they make about accessing health care;

4. triangulated findings with the experience of health professionals and generated some specific recommendations for where health service providers could improve access by tackling some of the common and important barriers identified in this report.

Recommendations

With the benefits of the mixed-methods iterative approach, the study establishes the most important issues requiring attention. Other ideas suggested about what constitute major barriers to access are seen as far less important and, therefore, of lower priority for attention.

Examples of barriers that we have found to be of relatively minor importance are:
- concerns about confidentiality;
- worries about health professionals' skills;
- barriers to service use being greater for the very elderly.

Our specific recommendations, based on the evidence of this study, relate to organisational, educational and cultural issues. If access is to be improved for all population groups, it is important that health professional and health service managers are made aware of the factors that influence service use.

- ***Education and information***

  Health education in schools needs to address how to use health care as well as how to recognise important symptoms and provide first aid.

The health service needs to reverse the impression that it is always substantially overworked and that use must be restricted to serious or acute illness.
The general public, patients and health professionals all need to be kept better informed about health services that are available and how to access them.

- ***Drug side effects***

  Health professionals and the pharmaceutical industry need to recognise the extent of public concern about the side effects of medication and its consequent barrier to service use.
  Better explanations and reassurance need to be provided.

- ***Encouragement and empowerment***

  Certain specific groups, namely females, those from poorer socio-economic circumstances, and the younger elderly, have been identified as needing the most encouragement to use health services as they were found to be the least assertive and have the most limited access to resources that facilitate service use.

- ***Professionals' attitudes***

  Health professionals need to be made more aware of the impact of their attitudes and manner on decisions to use health services. More attention to communication skills should not only be provided as part of health professional training, but also included as part of Continuing Professional Development.

- ***Resources and service design***

  Health care needs to be delivered and organised in ways that reduce barriers to use. For example, the Advanced Access initiative in primary care(7) could be extended so that access to chronic disease management programmes becomes easier and that primary care is not just seen as something for serious and acute illness. In accomplishing this, primary care provision will need even more to be provided by health professionals other than general medical practitioners.

- ***Transport***

  Local health services such as primary and community care need better transport systems to be provided. These could include increasing both public and voluntary sector provision as well as better publicity about existing services. Access to hospital care was not seen as a major problem, but better internal transport within increasingly large hospital sites, (both indoors and outdoors) should be provided.

- ***Individual assessments***

  In interventions to reduce barriers to service use, everyone needs to beware of making assumptions about and applying stereotypes to people. Service providers should always treat people as individuals and assess potential barriers to those people's need of health care.
  For example, in drawing up a health care management plan, a specific assessment should take into account what potential barriers to service use might exist for that individual patient.

While the present research has not conducted a controlled trial of the benefits of these recommendations they do provide the basis for what would be useful further research, or for piloting in practice.

General Introduction

Background to the study

This report describes research designed to follow on from earlier work that examined whether there were inequalities in the access to and use of health services.(1)

Health inequality is a rather general term – but it is most usually applied to the situation when a gender, age, ethnic or social class group has a different health experience from others in a different group. The term inequality usually implies that this is a situation about which society should, if possible, do something to alleviate, and the causes of which are, in part or wholly, social rather than only biological.

A lot is known about the occurrence of health inequalities, but much less about reasons for them.(2;3;4;5;6) In general, health inequalities may arise in a number of ways – because of:

- differences in the incidence of ill-health generally, and in the incidence of specific diseases
- differences in the outcome from disease – whether or not the incidence is different. These outcome differences may arise because of different provision and/or uptake of health care.(1)

These two may not go hand in hand: a classical example has been breast cancer, in which the incidence is lower in women of more disadvantaged social groups, but the outcomes are better in more affluent groups.(8)

A two phased, mixed methods research programme

This research programme, funded by NHS Executive Trent, investigates health inequalities as they relate to the use of, and access to, health services. In the first phase of the programme the incidence of diseases was measured for a selected range of conditions (for example, angina, chronic respiratory problems and dyspepsia) in a way that was independent of health services use. It determined relevant health services usage and outcomes for these cohorts and demonstrated differences in need/use and need/outcome relationships in different social groups and for different health problems.(1)

For example, there are differences in investigation and treatment for angina symptoms between different social groups (see below).

In this report of the second phase of the programme, and building on the findings from phase one, four linked fieldwork stages are described and their findings reported. The different research methods and iterative process have been used to identify and explore in detail reasons behind the differential use of (and outcome from) health services in those with apparently equivalent need and between different groups.

Aims and objectives of Phase 2

To understand some of the reasons behind the differences in health service use and outcomes for equivalent disease levels, especially those associated with differences in decisions to seek medical help and differences in professional decision-making, by:

- using focus groups to generate lay and health professional explanations about reasons behind differences in use and outcomes of health care in different population groups;
- designing a questionnaire and carrying out a population survey to quantify these reasons;
- using interviews to detail and characterise in depth the main reasons behind differences in usage and outcome.
- using follow up group interviews with health professionals to confirm and verify findings established in the preceding three stages and produce recommendations for interventions to improve access.

Phase 1 overview

Phase 1 of the research programme showed that even if the incidence of a disease does not vary between different population groups, inequalities can arise if one such group has very different usage of an effective intervention from another. The NHS, therefore, can have an important influence (either beneficially or adversely) on outcome differences associated not only with different supply of services, but also different use of services for equivalent levels of need and supply - referred to here and elsewhere as the "use/need ratio".(4)

The graph below illustrates an example of our findings in relation to the use of revascularisation in angina. In Sheffield electoral wards there was a clear inverse relationship between the ratio of use of services to angina prevalence, and material deprivation.

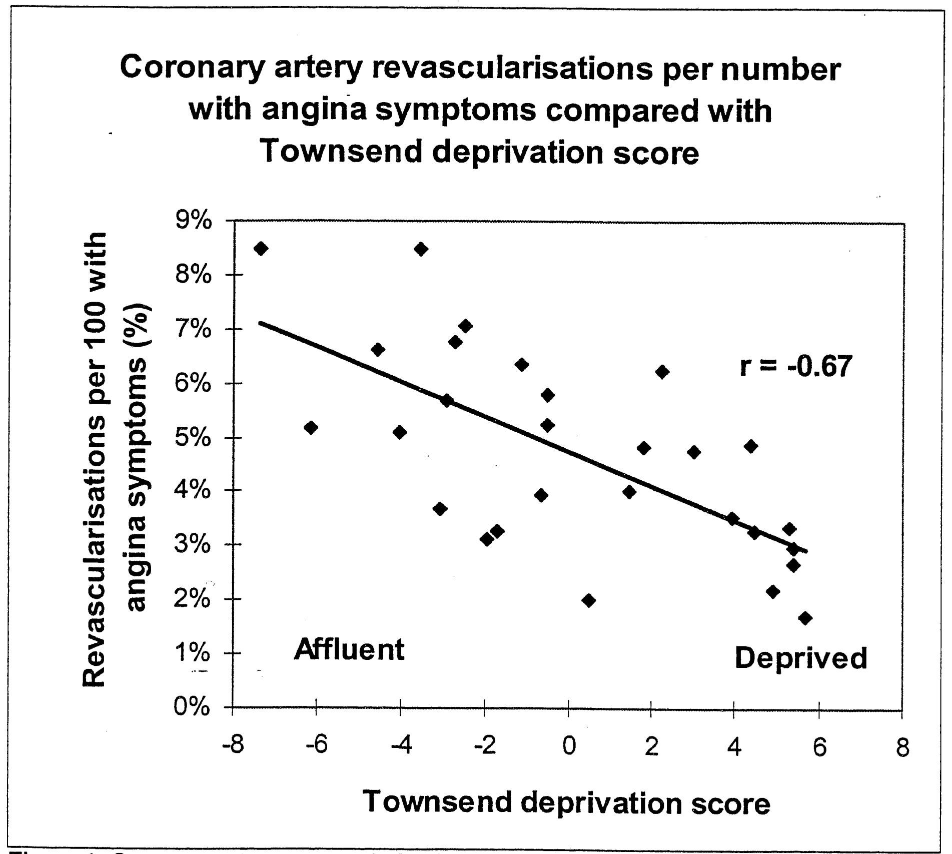


Figure 1 Coronary artery revascularisations per number with symptoms of angina compared with Townsend deprivation score in each electoral ward in Sheffield, (from Payne and Saul, 1997).

However, differences in use of health services for equivalent need work in opposite directions for different conditions and the table below illustrates some of our findings.

Table 1 Different use/need ratios for different conditions

Intervention and condition	Correlation of underlying condition with deprivation	Correlation of use/need ratio with deprivation
Coronary revascularisation in angina	Strongly positive (ie higher angina prevalence in the deprived population)	Strongly negative (ie less use, for equivalent need, in the deprived population)
Clinic attendance for musculo-skeletal disorders	Positive	None
Use of gastroscopies in those with symptoms of dyspepsia	None	Positive (ie more use, for equivalent need, in the deprived population).
Emergency admissions for chronic bronchitis	Positive	Positive (ie more use, for equivalent need, in the deprived population).

Conclusions

Having investigated the epidemiology of differences in service utilisation, the important next step is to investigate reasons behind the differences. By understanding these reasons, it is hoped that recommendations can be made for effective interventions to counter inequalities in use of, and access to, health services.

Phase 2

Introduction

Phase 2 of the research programme examines reasons behind the differences in health service use and outcomes for equivalent disease levels, especially those associated with differences in decisions to seek and use health services.

In this part of the report the different components and results of the four stages of Phase 2 will be described in detail.

In addition to each stage of the research programme producing substantive conclusions that have been written up and presented,(9;10;11;12;13) the analysis from each stage has been used to inform the next stage. The focus group analysis was used to construct the postal questionnaire in order to quantify the qualitative explanations for differential service use. The survey analysis informed the development of the schedule used in semi-structured depth interviews to examine the salience of the reasons for differential service use within and between sub-samples of population groups and selected conditions. Finally, follow up group interviews were convened with health professionals to discuss the main findings and make recommendations for interventions to improve access.

Stage One - Focus Group Study

Introduction

The focus group study forms the first stage of Phase 2. It aimed to develop **understanding of reasons for differences** in the use of, and access to, health services.

The focus group method has been used because the group process is especially valuable for exploring people's knowledge and experiences and pursuance of participants' own priorities.(14;15;16;17;18)

Methods

The focus groups involved participants from the 'lay' public and various health-related occupations and were convened in separate groups to take particular account of their perspectives, experience and status.(15;18;19;20)

Recruitment

103 participants were purposively recruited into the study over a 4 month period (October 1999 – January 2000). Firstly, 50 participants (27 general public, 23 health worker) were recruited to one of 8 focus groups. Then 53 primary care workers, attached to 6 general practices, were recruited into a second phase of 6 focus groups.

Inducements to attend: refreshments, taxis, travel expenses and/or parking permits were provided to all participants. £10 gift vouchers were given as 'honorarium' to the public participants at the end of their session.

The Sample

The 4 general public focus group sessions involved 17 women and 10 men from a wide variety of city areas, occupations, ages and ethnic groups; they comprised a mix of current and past users of services, with varying frequencies of use and amounts of criticism.

The 4 health worker focus groups and 6 primary care meetings involved 60 women and 16 men from 9 health related occupations/professions working in a variety of clinical specialities and settings. These included 24 doctors, 27 nurses, 9 administrative staff, 6 allied health professionals, 5 psychiatric staff and 5 health students.

Data Collection

The researcher moderated all the sessions, with a member of the project team attending as assistant moderator. The moderator hosted and introduced the session, outlined details of the project and research topic, explained the protocol (for the session), asked the questions and guided the discussions; she also recorded some details on flipcharts.

The discussions were audio-taped on two machines operated by the moderator and her assistant. The assistant also made notes of the discussion, including non-verbal details.

The question areas

1) Why individual people do/don't **use** services in relation to participants':
   - own experience
   - family; friends, and personal contacts' experiences.

2) Why different social groups do/don't **use** services, in relation to:
   - age
   - sex
   - class
   - occupation
   - ethnicity

   i.e. not just deprivation

3) Why for different groups, with different conditions, there are different patterns of:
   - **use/non-use** of services, and
   - **referrals/access** to services

   e.g. angina, bronchitis and dyspepsia

The specific content of questions varied across the sessions but the general order and format of topics to cover remained constant.(16;21;22) In later sessions, a higher proportion of closed and confirmatory questions were asked, referring to ideas and issues raised in early sessions.

Saturation of Categories

By the 8th session, no new issues were being raised, suggesting 'saturation of the categories' was near.(15;23) However, community perspectives were under-represented within the staff focus groups, leading to the setting up of the primary care meetings.

- 6 primary care meetings were conducted in January and February 2000. The meetings were held in general practice premises across contrasting areas of the city.

- The moderator briefly outlined details of the project and purpose of the meeting, asked the questions and guided the discussion. The assistant recorded the participants' occupations and made detailed notes of the discussion, constituting the data for analysis.

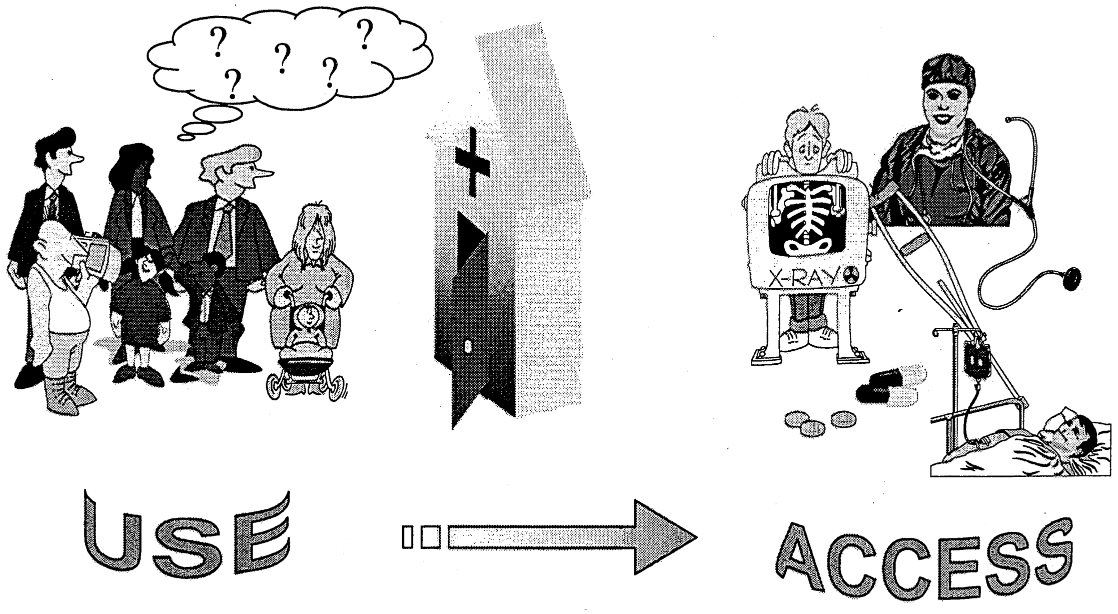
- The questions again addressed differences in **use** of services and differences in **access** to services. The questions relating to 'use' focussed on the practices' populations and broadened to consider general population differences. The 'access' questions were asked in relation to practices' different referral rates to secondary services.

Defining use and access

In this report 'use of services' includes initial decisions, decisions to continue and/or return to services. The term 'access to services' is used specifically to refer to the influences on 'patients/users' progressing through the healthcare system. This incorporates health professionals deciding on, and indeed patients being provided with, healthcare interventions, referrals and/or discharge.

The picture below portrays our distinction between use and access.

Use of & Access to Services



Methods of Analysis

Data were indexed manually, as well as on computer, using the qualitative data analysis software 'Atlas.ti'.(24) Similar themes and issues within and across sessions were grouped together into categories, then associations and relationships between them identified.

The detail, sequence, emphasis and consensus/divergence within the discussions was emphasised in the analysis, rather than just the frequency, as befits the qualitative, focus group methodology.(14;15;16;22)

Findings

Within the 14 focus groups, many hundreds of topics and ideas and detailed explanations of factors and issues were suggested as contributory influences on the ways people use and/or provide access to services. The participants discussed the various influences in different ways and to varying extents. Within the mass of influences identified, there are many that are broadly similar: these have been grouped together and categorised. In addition, many relate to each other. Many factors and issues are seen to combine together, to influence the final outcome of use or access to services.

Diagrammatic representations of the key issues and processes in use of and access to services are shown in figures 2 and 3.

To assist reading, the influences relating to decisions by the public to use services are distinguished from those relating to access decisions made by service providers. Nonetheless, many of the issues and factors are the same or mirror each other, and operate in similar ways: they are intrinsically connected.

Influences on people's decisions to use services (figure 2, page 18)

Use of services includes initial decisions, decisions to continue and/or return to services and also relates to how people use them: as frequent or rare users, with negative or positive expectations; as passive 'patients' or active participants; and as 'appropriate' or 'inappropriate' users. It involves issues such as compliance, motivation and purpose, as well as details such as timing.

Main Findings

The participants in both public and professional focus groups identified hundreds of influences on decisions to use a service. Examples of these are:

- *Knowledge of a service/treatment*
- *Misdiagnosis or late diagnosis*
- *Doctor's manner*
- *Hours of work*
- *Fear of hospitals*
- *Relationship with professional*
- *Stoicism*
- *Difficulty getting appointments*
- *Ownership of a car*
- *Side effects from drugs*
- *Feelings of guilt/self-blame*

From our analysis of this large number of issues, five main categories emerged. These combine to influence decisions to use services. These categories are listed below with their associated sub categories and illustrative quotes. The quotes are referenced by participant's identity, [file number, type of group and transcript line numbers]. (See appendix 1 for example of issues within 'experiences' category). The five categories are shown diagrammatically in figure 2.

1. **People's attitudes, feelings and beliefs:** to life and self; to health and illness; to health care: systems and treatments; and to health professionals

> *OM. I think a lot of people are full of fear…they know some people that's had similar and they just have that ugly picture…the fear gets hold of people at times [P2 public: 1734-1746]*

> *PS. If you come from…the poorer parts of Sheffield, I think we're a damn sight hardier… and we just expect this. We're a lot like "wash your face and you'll feel better"… When you get to the affluent side of the city…like my daughter, they're in a great 4 bedroom house and they've loads of money, and if her finger hurts she's at the doctors [P4 public: 1370-1374; 1397-1399]*

2. **People's prior experiences:** of life; of health and illness; of health care: systems and treatment; and of healthcare staff/professionals

> *MB. I been put off by their abrupt manner, or they couldn't care less...now and again a nice one turns up, but most treat you rather indifferently [P10 public: 543-548]*
>
> *GA. Well my father...had a stroke at 47 and they said…he's not going to get better, we're wasting hospital money to give him physiotherapy because he'll never walk again… We paid, cos we wanted the therapy…That was in an area that they didn't have the finances and they didn't want to use them on somebody that they thought it was a waste of time for [P5 public: 1309-1320]*
>
> *DG. My doctor is very good because he prescribe alternative medicine...rather than take a tablet…I think that's excellent [P4 public: 896-900]*

3. **People's knowledge, abilities and skills:** formal; socio-cultural; and natural

> *GA. Some people are more demanding … if they're more educated about their bodies and what their bodies need [P5 public: 1331-1344]*

4. **People's socio-economic circumstances:** social environment, (e.g. family, housing); economic factors, (e.g. employment status, affluence)

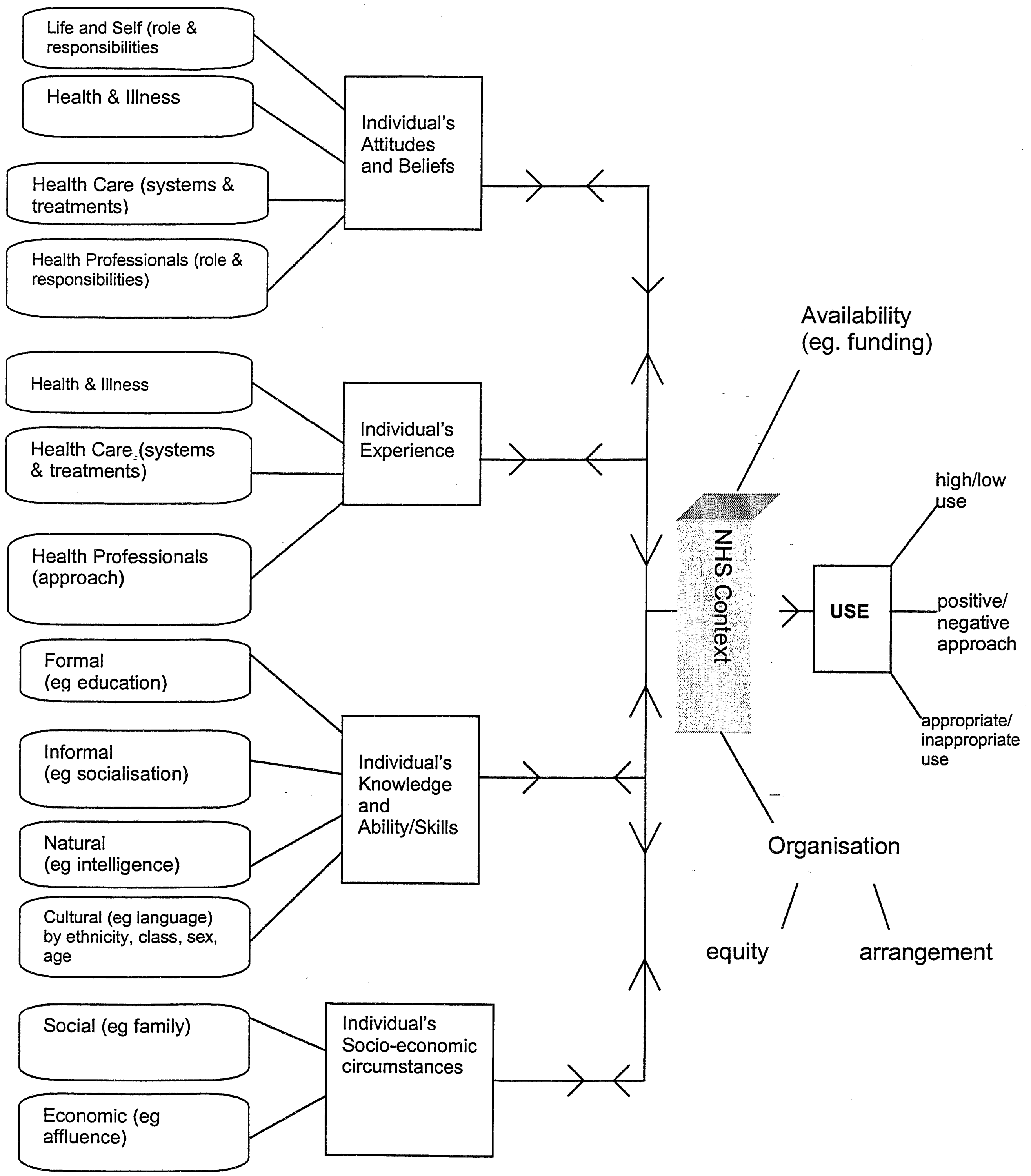
> *P.T. Some patients would actually say "Can I only come once a week because I can't afford to come more?", or "Is there any way I can have my physio nearer to my house because it's 2, 3, bus journeys to get to the hospital?"...One of the big issues for them was cost, or whether they could have an ambulance so that they didn't have to pay [P 3 hospital and community profs: 838:851]*
>
> *G.P. Young mums tend to come to us if they have no-one else to talk to...and people come to the surgery to the specialist clinics, the clinics are more approachable and more convenient [P9 primary care staff: 764-769]*

These four types of influence combine together in various and complex ways to influence people's decisions regarding use of services.

5. The **NHS context** serves to block or enable individuals to carry out their intention to use services. This fifth category comprises details relating to the way the NHS is funded, organised and distributed.

> *JP. I do get put off, cos you can't get in our doctors, it's like a two weeks appointment system…(so) I just keep putting it off…It's ridiculous…not getting in when you're poorly, when you need them...*
> *RA. (I'm the same) as what you ladies have been talking about. Can't always get a doctor under 2 weeks...got half a dozen doctors all in one place but you can't get in. That's the biggest fault (murmurs of agreement). [P10 public: 806-809; 846-853; 901-912].*

Figure 2: Factors and Issues Influencing Use of Services by the Public



Influences on access to services (figure 3 page 21)

In this report, the term access to services is used specifically to refer to the influences on 'patients/users' progressing through the healthcare system. This incorporates health professionals deciding on, and indeed patients being provided with, healthcare interventions, for example, screening services; tests and treatments; transfers and referrals; advice and/or discharge.

Main Findings

As with the influences on public decisions to use services, the public *and* professional participants identified a large number of influences on access to services. For example:

- ***Professional's knowledge of services available***
- ***Level of skill/training***
- ***Resource allocation***
- ***Workload of professional***
- ***Empathy (regarding impact of health problem)***
- ***Beliefs about responsibility (for own health/illness/treatment)***
- ***Age of patient***
- ***Patient-professional relationship***
- ***Waiting list/service availability***
- ***Past experience of treatment effect***
- ***Attitude to private health care***

From our analysis of the numerous issues, four categories emerged. These combine together to influence access to services. These categories are listed below with their associated sub categories and illustrative quotes. (See appendix 1 for example of issues within Health Professionals' 'experiences' category). The four categories are shown diagrammatically in figure 3.

1. **Health Professionals' attitudes to and beliefs about** health care; health and illness; the public/patients, and role and responsibilities (their own and others)

   MJ A lot of doctors have got very good skills at putting people off, if, if they want to. You can actually be quite manipulative if you want to as a GP I think. SK So the doctor's attitude itself will influence… DS Oh, yeah, absolutely. And there's some you know, not very good GPs out there, I think. You know, are very skilled at um, at sort of cutting down the timid people and getting rid of them. [P 7: 1387:1399]

2. **Health Professionals' experiences of** health care: system and treatments; patients approaches to services/professionals, and experiences of other health professionals

   LC Resources are a huge problem. I mean, if you take it from working perhaps the chronic side… we've had patients who can stay in hospital for about 3 or 4 months because the funding isn't there for them to have 30-odd pounds-worth of social services a week. SM That's blocked the community rehab team as well. We've got patients that could very nicely go home and have their ongoing treatment under the community rehab team but we're waiting funding, and we can be waiting for months for their home carer …which time they don't by need community rehab team any more because you've got them so good in the hospital that they're totally independent [P 3: 1587:1608]

3. **Health Professionals' knowledge, abilities and skills, in relation to** formal education and training; informal learning; social and economic background; communication and interpersonal skills; and technical/instrumental skills and expertise

   O.T. There are so many new initiatives all the time…you really can't keep up to date with them all…and some don't have the communication networks to realise what's available [P3 hospital and community professionals: 1400-1414]

DS Certainly in secondary care there are some phenomenally bad communicators. Lots of very middle class males, who ...actually think they're good communicators, and when you sit and listen to them, I can think of one consultant particularly ... who actually thinks he's a tremendously good counsellor ... When I was an SHO he got me to sit in on one of his counselling sessions talking to a woman who, there was a discussion as to whether she was going to be resuscitated or not and he was trying to talk to this family. The family would say one thing, and he was saying something completely different. He had his agenda and they had their agenda and he basically made sure that they took up his agenda and you know, there was absolutely no communication going on what-so-ever. [P 7: 2069:2106]

These three types of influence combine together in various and complex ways to influence health professionals' decisions regarding access to services.

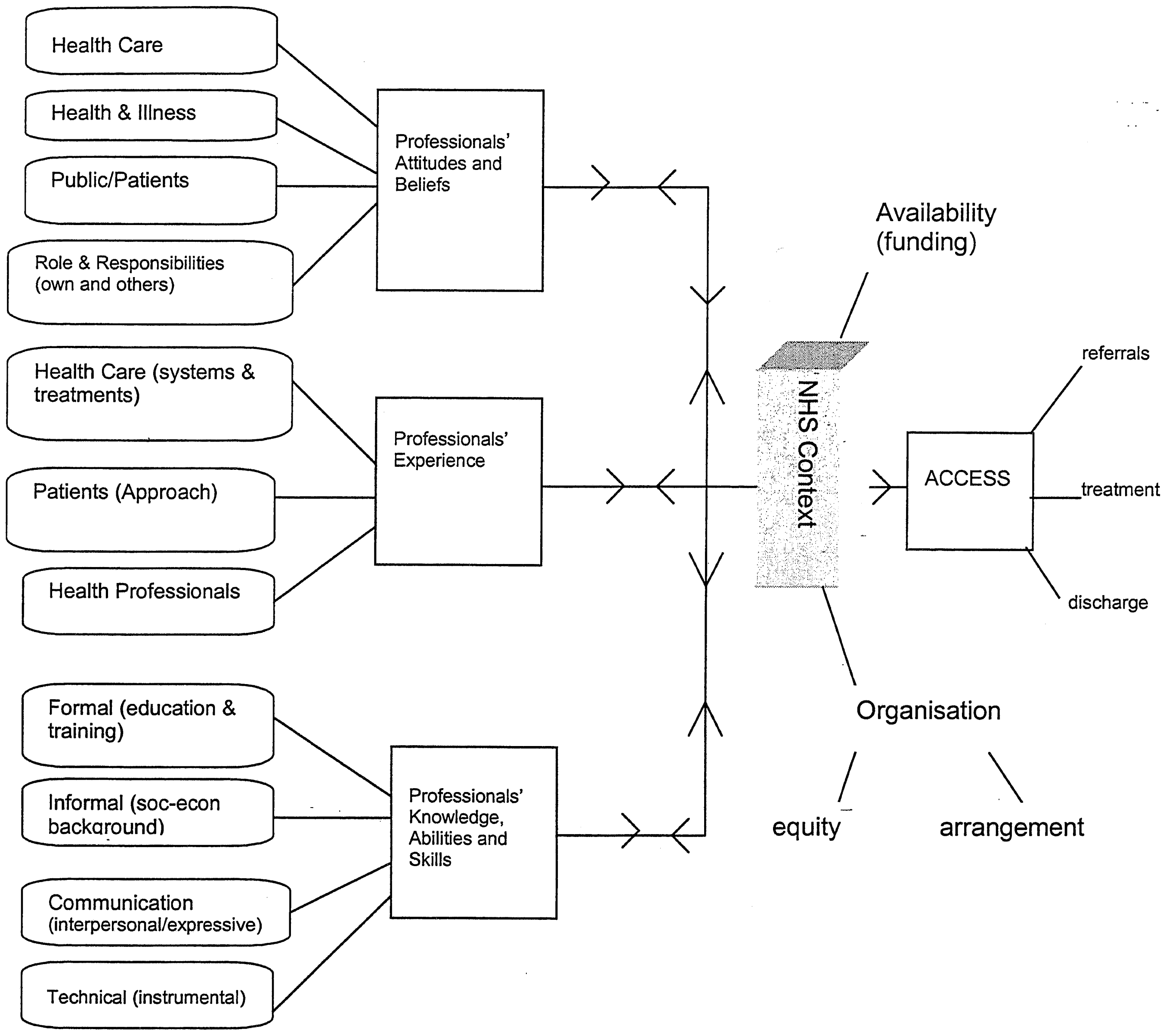
However, and echoing public decisions to use services, a health professional's ability to actually provide access is also influenced and/or constrained by:

4. **The NHS context** within which s/he works. This again involves various aspects, relating to NHS funding, organisation and distribution arrangements.

O.T. In OT we tend to look if people on the wards…live in a nursing home. We won't cut them out completely but they go right to the bottom of the list [P3 hospital and community professionals: 1743-1746]

H.V. My client group don't get the same level of service as compared to other practices with less needs, because health visitor caseloads are based on the number of under-fives in the practice, not their actual needs. Sometimes people need services but they are just not available...it's also like this in chiropody and other service areas [P9 primary care staff: 119-123]

Figure 3: Factors and Issues Influencing the Public's Access to Services



Discussion

Positive and negative effects; major and minor influences; generalisability of findings

The various influences within each category operate in different ways: some tend to work positively to encourage use and access, whereas others tend to influence decisions in negative ways. The extent of impact and direction of relationships between the different influences are examined in the population survey and interviews that follow in later stages of the study.

The main aim of the focus group stage was to establish what the reasons for differences are, not to measure their relative significance. Nonetheless, and although statistical significance and generalisability were not claimed for the findings of this stage of the research programme, it is clear that certain topics are discussed more often, more widely and in more detail than others. Also, the expressive and conversational style and manner of participants indicates strength of opinion about reasons, along with the amount and nature of similarities and differences of opinion within and across groups. Therefore, whilst recognising the impact of sample, context and setting of this focus group study, it is reasonable to highlight different levels of importance in the reasons identified to explain differences in use of and access to services.(21;22;23) The main findings are discussed below in relation to the five main categories.

Experiences

In terms of both the quantity and content of the discussions, the professional's **experience of patients** and the patient's **experience of professionals** represent the most important influences on decisions to use or provide access to services. Together, the influence of people's approaches towards each other within what is described as the 'health care encounter' were both widely and comprehensively discussed, with many aspects discussed in great detail across the groups and by many participants.(25) Many of the experiential accounts of health care and health professionals were particularly vivid and powerful, representing narratives of significant events and people in the participants' lives.

The **expressive 'manner'** of the health professional was afforded great attention and frequently emphasised as of crucial importance in decisions by the public to use services subsequently. For several public participants, being treated respectfully, thoughtfully and as an individual was identified as more important than the professional's **instrumental skills** or expertise at treatment and/or diagnosis. By contrast, the professionals tended to recognise the impact of their manner on patients' subsequent use less often. Nonetheless, for some public participants, substantial and highly charged attention was given to treatment and diagnosis issues, particularly from those who have experience of what they perceived as ineffective or problematic treatment, late or wrong diagnosis, or bad service. For example, problems with drug side-effects or the perceived over-dependency of some doctors on prescribing medication, late diagnoses of malignancy and ineffective/inappropriate treatment were described by a few participants as major disincentives to using services.

Another important experiential issue relating to the professionals' approach (and seen as a reflection of their attitudes) links to concerns about **fairness**. Many participants, from across the groups, acknowledged how professionals are not always even-handed, with a variety of reasons suggested for this. Some reasons for providing differential treatment, such as empathy between user and provider, were seen as broadly acceptable and understandable, whereas others were discussed as problematic aspects of discrimination and prejudice. Associated with these fairness issues were concerns about over-generalisations and prejudicial assumptions, as well as standardised rather than individualised care.

The relative significance of the professional's manner and skill on public decisions to use services is tested statistically in the population survey. However, it is important to highlight that the emphasis on interpersonal-communication aspects is consistent with the literature regarding the nature and distribution of NHS complaints.(26;27;28;29)

Although discussed extensively within and across the sessions, the impact of the **user's approach** on the professional's behaviour was contentious. Some participants considered the attitude and behaviour of patients a big influence on professionals' decisions about providing access to services, whereas others were less convinced about its actual effect on professional action. On several occasions within the focus groups, participants described very different accounts of these influences.

As such, these various aspects of experience of the health care encounter are compatible with the notion of **'health career'**,(30;31;32) and in this context can be applied to both users and providers. Both the quality and quantity of past experiences influence future actions and expectations.

Finally, with regard to experiences, considerable attention was paid to issues relating to the **service context**: delays and difficulties getting appointments and treatments were often linked to resource levels, priorities and allocation. They were said to influence decisions to use or access services primarily with regard to having or sustaining levels of motivation.(30)

Knowledge

The 'possession' of **knowledge,** understanding and personal abilities was widely recognised as an important and generally positive influence on both use and access to services. Many different elements within the sub-categories were seen to influence strongly both public and professional behaviours, decisions and outcomes. For example, up to date and detailed knowledge of the system, about health and health care services and treatments, plus more general competencies and personal abilities were consistently recognised to affect people's ability to make informed and 'appropriate' decisions. For example, being able to communicate clearly and confidently, and share common languages were frequently identified as particularly important influences on both use and access to services.

Attitudes

Generally the role and influence of people's **attitudes** is hard to evaluate. There were as many positive as negative attitudes discussed, with general 'life and self' attitudes and health-specific attitudes discussed to widely varying degrees in the different groups and by the different participants. Overall however, people's attitudes were identified as very important influences on decisions to use and/or provide access, operating in complex and often contradictory ways: accounts and examples relating to attitudes were often vividly and elaborately presented. Variations in attitudes by gender, class, age and ethnicity were cited frequently in relation to both users and providers: they were seen as both informed and influenced by social and material circumstances and experiences. Many participants identified how people's **expectations** of the NHS are often linked to their attitudes and experiences, and recognised the relationship between expectation level and satisfaction as observed by Pichert et al. in their discussion of patient satisfaction.(32)

Poor mental state, be it with regard to low intelligence, substance abuse or more conventional notions of mental impairment and illness such as depression and schizophrenia, was recognised as an important barrier to use. It impacts on general motivational levels and/or abilities to understand potential benefits or engage with the service or its providers. Although this was sometimes discussed in terms of **'attitude'**, on other occasions it was identified as a **knowledge**-competence issue.

Socio-economic circumstances

Interestingly, and in contrast to the focus of much of the inequalities literature,(2;3;4;5;31;33) factors and issues relating to socio-economic circumstances were discussed less often than other topics. However, their role and importance emerged within the discussions regarding **inequality issues** and they were then discussed vividly and critically. Some aspects of an individual's circumstances were seen to influence directly use and access to services in terms of providing material opportunities and abilities, whereas others worked indirectly, via relationships to attitudes and/or experiences, and/or knowledge and skills. For example, car ownership or hours of work influence an individual's ability to get to an appointment. Long-term poverty and/or homelessness may result in decreased motivation and self confidence which reduce the inclination to approach a service or attend an appointment, as well as making it physically harder to do. Various different 'lifestyles' were described as influencing use of health care as well as need.

NHS context

The influence of the **NHS context**, in terms of the service level and organisational arrangements, was recognised and discussed by many participants across the groups. Some of the issues and ideas discussed were based on personal experience, whereas others were from impressions of the service, from sources such as the media.

Generally, the professionals were more preoccupied with **resource-related issues** of service availability and quality, whereas the public tended to focus on issues of access in terms of practical **arrangements**, such as opening hours, accessing appointments and location. Both discussed issues of discrimination within the system, whereby some population groups are served better than others, and several mentioned concern over waiting lists, queue jumping and the private sector.

Underpinning many of the discussions was an awareness that regardless of the extent to which an individual - public or professional - wants to use or provide a service, if it is not available then access will not happen.(3;34)

Conclusions

The focus group study successfully produced substantial data regarding understandings of reasons for differences in the use of and access to services.

The participants, from their various walks of life and relationships to the health service, fully engaged with the research topic to suggest a diverse range of influences on their own and others' service use, and the different patterns of health service use and access for different social groups.

By organising the data, the range of explanations have been categorised into those relating to the people involved (ie. users and providers) and those that relate to the service/system. People's attitudes, experiences, knowledge and socio-economic circumstances combine to influence whether they decide to use or provide access to services. The service context facilitates or impedes this process.

The focus group method provided an illuminating environment for lively discussions to take place and enabled a wide range of issues and priorities to be identified, considered and discussed in detail. The inductive method established what users/non users and providers of services consider influential on decisions to use and/or provide access to services.

The next stage

Using the results of the focus groups, the next stage in the research was to quantify the relative impact of different barriers and examine whether these differ systematically between different population groups.

Accordingly a quantitative postal survey was developed using the focus group results – the next section of this report will describe the survey and its results.

Stage Two - Postal Questionnaire Study

Introduction

The main aim of this second stage of the study was to build on the findings of the focus group study and to quantify the relative importance of the wide range of factors identified as influencing service use. The survey would also allow these factors to be quantified for a range of sub groups within the population studied.

We decided to conduct the survey on the population aged 50-94 for the following reasons:

- There is evidence that older people are more likely to experience problems with access to and utilisation of health care(35;36)

- Older people have a higher level of morbidity and a greater need for health care

- In a sample of older people we were more likely to obtain sufficient numbers both with and without significant ill health such that valid comparisons of service use could be made

- Older people are more likely to have experience of a greater range of health services than younger people(37)

- Older people have been shown to give a higher response rate to postal questionnaire surveys than younger people.(38)

Finally, the publication of the National Service Framework for Older People(39) made the study of this age group particularly relevant to the NHS.

Methods

From the five categories identified by the focus group analysis, a list of 36 separate factors as well as a range of health, social and economic variables were selected as influences on decisions to use health services. We then used these to construct the postal questionnaire instrument (see appendix 2).

The sections of the questionnaire were as follows:
Section A: Background Information
Section B: Your General Health
Section C: Using Health Services
Section D: Factors Affecting use of Health Services
Section E: About your Circumstances

For section D of the questionnaire, statements were developed to represent the 36 factors, and respondents were asked to indicate whether they agreed with each statement and to what extent it stopped or delayed service use. The survey instructions for section D and examples of two 'statements' are shown below:

Figure 4 Extract from postal questionnaire

Section D Factors Affecting Use of Health Services

In this section we are looking at factors that might encourage or discourage you from seeking help from health services when you have a health problem or illness.

Please read each statement.

- **If you agree with the statement** please tick (✓) the **"yes I agree"** column then tick (✓) one of the four boxes in the final column to show how often it stops or delays you using health services.
- **If you do not agree with the statement do not tick any boxes in that row.**

Statement	**Yes, I agree**	**This stops or delays me using health services:-**			
		Never	**Rarely**	**Sometimes**	**Often/ always**
I prefer to see a health professional of my own sex	☐	☐	☐	☐	☐
I have had bad experiences of using health services in the past	☐	☐	☐	☐	☐

Broad definitions of 'health professional' (including dentists, opticians, pharmacists, chiropodists) and of 'health services' (including primary and secondary care, screening services and alternative medicine) were used.

After local piloting with patients in a general practice, the postal questionnaire was sent to 6002 randomly selected residents, aged 50 to 94, living in Sheffield and identified from the Sheffield Health Authority records of general practice registration. The large size of the survey sample means that confidence intervals are narrow for the analysis. Thus, for example, a survey result of 50% has 95% confidence intervals of 48.5% to 51.5%.

Methods of Analysis

For each statement, service use was considered as influenced significantly if a respondent indicated that the issue sometimes, often or always stopped or delayed them using health services or consulting health professionals.

For each issue, the proportion agreeing with the statement and the proportion for which the issue significantly influenced service use was calculated. We then calculated the proportion of those agreeing with the statement for which the issue significantly influenced service use.

For the sub group analysis, crude odds ratios were calculated in respect of the following four variables

- Age
- Sex
- Material deprivation*
- Level of ill health**

As these variables may all influence service use, a multiple regression analysis was also conducted. The adjusted odds ratios were calculated by entering the four variables simultaneously into a logistic regression equation (using SPSS for Windows: version 10).

A factor analysis was also conducted to ascertain whether the 36 statements could be reduced to a smaller number of core issues.

* Initially we considered the relative impact of a range of deprivation variables (receipt of means tested benefits, car access/ownership, Townsend deprivation scores, private/council housing, employment status) on differential service use. From this, receipt of means tested benefits was found to represent a reliable proxy for material deprivation, and therefore has been used in the sub group analyses.

** Ill health was defined by more than one medical diagnosis selected from a list of 20 specific health problems listed on the questionnaire (since most of the respondents indicated at least one diagnosis from the list).

Results

After two reminders where necessary, the overall response rate was 71% (4274/6002), equivalent to 74% after adjusting for undelivered questionnaires.

Respondents were slightly more likely than non-respondents to be female, under 75 years old and to live in wards of above average affluence (Appendix 3). But the overall good response rate ensures that our results are not significantly influenced by response bias.

Main findings

For each factor, two independent characteristics have been identified. The first is how frequently they are recognised as influences on service use, the second how big a deterrent impact they have on service use. Thus, the following five combinations of characteristics emerged, leading to the identification of five types of barrier.

Table 2 Types of Barriers

Type of barrier	**Frequency (recognised as an influence)**	**Strength (experienced as a barrier)**
Common	Common	High deterrent impact
Moderate	Common	Medium deterrent impact
Hypothetical	Common	Low deterrent impact
Minority	Occasional	High deterrent impact
Weak	Occasional	Low deterrent impact

The most frequent issues within each of these types of barriers are shown below, illustrated by the underlying statements from the questionnaire.

- **Common barriers**
  - I worry about wasting health professionals' time if there turns out to be nothing wrong
  - I only see a health professional if I think my illness is serious
- **Moderate barriers**
  - I think doctors can talk down to you or be patronising
  - It can be difficult for me to get an appointment to see my GP
- **Hypothetical barriers**
  - I don't know about all the health services that are available
  - I prefer to see a health professional of own sex
- **Minority barriers**
  - My health professionals don't take me seriously
  - My GP's opening hours are not convenient for me

- **Weak barriers**
    - I have had an illness I was embarrassed about
    - I worry that health professionals might not keep my details confidential

For each of the 36 issues, the proportion of respondents agreeing with the statement and indicating that it had significantly delayed or stopped service use has been calculated. The rank order of results for all 36 issues is shown below in Table 3.

Table 3 Ranking of 36 issues according to overall agreement with a statement about the issue; deterrent influence on service use overall, and deterrent influence for those who agreed with the statement.

Statement of Issue	**A) Proportion who agree with the statement** **Rank** (%, 95%CI)	**B) Proportion for whom issue has a deterrent influence on use of services** **Rank (%)**	**C) Proportion *of those who agree with statement* for whom issue has a deterrent influence on use of services** **Rank (%)**
I only see a h.p. if I think my illness is serious	**1 (58, 56-59)**	**1 (24)**	35 (31)
I like to see the same h.p. every time	**2 (52, 50-53)**	**5 (20)**	33 (32)
I don't know about all the health services that are available	**3 (41, 39-42)**	**9 (14)**	36 (28)
I am worried about drug side effects	**4 (41, 39-42)**	**3 (21)**	23 (46)
My h.p's always seem very busy and overworked	**5 (38, 37-40)**	**4 (21)**	20 (47)
I prefer to see a h.p. of my own sex	**6 (37, 35-38)**	**8 (14)**	30 (35)
I worry that the h.p. will think I'm wasting their time if there turns out to be nothing wrong	**7 (35, 34-37)**	**2 (21)**	**9 (54)**
I don't know what I'm entitled to receive from the NHS	**8 (35, 33-36)**	12 (13)	34 (32)
I think doctors can talk down to you or be patronising	**9 (34, 33-36)**	**7 (18)**	14 (50)
It can be difficult for me to get an appointment to see my family doctor (GP)	**10 (31, 30-33)**	**6 (19)**	**2 (59)**
I know other people who have had bad experiences of using health services in the past	11 (28, 26-29)	14 (11)	29 (36)
Doctors prescribe too many drugs	12 (26, 25-27)	11 (13)	21 (47)
I find it hard to be assertive, or to stand up to doctors	13 (26, 24-27)	**10 (13)**	15 (50)
My h.p's do not explain things to me	14 (20, 19-22)	13 (12)	**3 (58)**
I don't expect to have good health	15 (20, 19-22)	20 (8)	27 (38)
I am frightened of hospitals	16 (19, 18-20)	15 (10)	19 (48)
It is difficult for me to travel to the hospital for an appointment	17 (18, 17-19)	16 (9)	12 (50)
I tend to blame myself if I get ill	18 (16, 15-17)	18 (9)	**10 (54)**
I don't have confidence in my h.p's	19 (16, 15-17)	17 (9)	**7 (56)**
My family doctors' (GP) opening hours are not convenient for me	20 (14, 13-15)	19 (8)	**5 (57)**
I feel guilty about using NHS resources	21 (14, 13-15)	21 (8)	**4 (58)**
I am less likely to see a h.p. if I think my illness can't be treated	22 (14, 13-15)	22 (7)	16 (48)
I have had bad experiences of using health services in the past	23 (14, 13-15)	28 (5)	28 (36)
I am frightened to see hps because I might get bad news	24 (13, 12-14)	25 (6)	18 (48)
It is difficult for me to travel to my family doctor (GP) surgery for an appointment	25 (13, 12-14)	24 (6)	17 (48)
I don't always like h.p's visiting me at home	26 (12, 11-13)	30 (5)	31 (35)
I have had an illness I was embarrassed about	27 (11, 10-12)	33 (4)	32 (33)
My h.p's don't listen to me	28 (11, 10-12)	23 (7)	**1 (59)**
I don't have a friend or relative who can help me when I'm ill	29 (10, 9-11)	29 (5)	22 (46)
My h.p's don't take me seriously	30 (9, 9-10)	27 (5)	**8 (56)**
It is hard for me to take time off work to see a h.p. when I am ill	31 (9, 9-10)	26 (6)	**6 (57)**
I will not seek health service help if I think I will have to have an operation	32 (9, 8-10)	31 (4)	24 (44)
I don't have good relationships with my h.p's	33 (9, 8-9)	35 (4)	25 (41)
I have to pay for my prescriptions but cannot afford the cost	34 (8, 7-8)	32 (4)	11 (53)
I don't think my h.p's are skilled enough to treat me well	35 (8, 7-8)	34 (4)	13 (50)
I worry that my h.p's might not keep my details confidential	36 (6, 5-6)	36 (2)	26 (39)

h.p. = health professional
Top 10 items by each criteria marked in bold and shaded in grey

Sub group analysis

Within the study population some factors were greater barriers for specific sub groups.

Examples of factors that show the greatest differences by sex, age, material deprivation and levels of ill health are given below in figures 5 (i-iv) (with their adjusted odds ratios and 95% confidence intervals). (See appendix 4 for further details)

Figures 5 (i-iv) Factors that show greatest differences by 4 sub groups

- **(i) Gender**

Barriers greater for women
I prefer to see a health professional of my own sex
(male: female, 0.46 95% C.I; 0.38-0.56)
I think doctors can talk down to you or be patronising
(0.66; 0.56-0.78)

Barrier greater for men
I only see a health professional if I think my illness is serious (1.28; 1.08-1.50)

- **(ii) Age**

Barrier greater for younger age group
I have had bad experiences of using health services in the past (50-64: 65+years, 2.93; 2.15-3.99)

Barrier greater for older age group (65+ years)
It is difficult for me to get to my GP's surgery for an appointment (0.68: 0.52-0.89)

- **(iii) Means-tested Benefits**

Barriers greater for those on means tested benefits
It is difficult for me to get to my GP's surgery (also hospital) for an appointment (on benefits: not on benefits, 1.09; 0.89-1.32)
I don't have good relationships with health professionals (2.14; 1.51-3.03)

Barrier greater for those not on means tested benefits
I have to pay for my prescriptions but cannot afford the cost (0.40; 0.23-0.70)

- **(iv) Levels of Ill Health***

Barriers greater for those with higher levels of ill health
It is difficult for me to travel to the hospital (also GP) for an appointment (more ill health: less ill health, 2.61; 1.98-3.43)

My health professionals don't take me seriously (2.43; 1.75-3.38)

* No barriers were found to be statistically significantly greater for those with lower levels of ill health

Symptom groups

In addition to the above sub group differences, some barriers were limited mainly to people with specific health problems. For example, delays or non-use of services because of the unavailability of help when ill were experienced especially by those with respiratory symptoms, and difficulties travelling to hospital were experienced especially by those with cardiovascular symptoms. Also, the generally 'weak' barrier relating to 'embarrassment' predominantly delays or stops service use among those with bowel or stomach problems.

Factor analysis

The factor analysis demonstrated that, although there were significant correlations between barriers, as expected, it was not possible to represent the 36 identified barriers by a smaller number of composite factors. The analyses were therefore conducted for each of the 36 individual barriers.

Discussion

The survey results show the wide range of different influences on health service use suggested by the focus groups are recognised across a large, randomly selected sample. These vary in terms of how often the factors are recognised as barriers, how often they are experienced, and whether they are barriers specific to identifiable subgroups.

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Different Types of Barrier

Common Barriers: commonly recognised issues that also have a high deterrent impact on service use

The most common barriers to accessing services were
"I only seeing a health professional if I think my illness is serious";
"I worry that the health professional will think I am wasting their time if there turns out to be nothing wrong";
"I am worried about drug side effects" and
"My health professionals always seem very busy and overworked".

The high level of agreement with these statements and their deterrent influence on service use suggests a common view of the health service as over-stretched and only able to cope with the most urgent or serious threats to health.

Hypothetical Barriers: commonly recognised issues that have a weak deterrent impact on service use

Some issues were commonly recognised, but did not have such a major impact on service use:
"I don't know about all the health services that are available" and
"I don't know what I'm entitled to receive from the NHS" were statements commonly agreed with, but do not seem to represent major practical barriers.

Despite lack of knowledge about services and entitlements, it may be that individuals feel they can access most services and information through their general practitioner.

Preferring to see a health professional of the same sex was another common preference, but was not seen as a major barrier to using services.

Minority Barriers: minority issues that have a high deterrent impact on service use when they are recognised

Other issues were barriers to using services for smaller proportions of respondents, but they are still important in terms of equality of access because, for those who recognised these issues as potential barriers, there is a major impact on service use. For example, for those who agree that health professionals do not listen to them or do not take them seriously, the majority indicated this issue had an impact on their use of health services. This group includes more individuals with multiple health problems.

The strongest barriers appear to be issues related to individual confidence in accessing health services (also including "I feel guilty about using NHS resources", "I worry that the health professional will think I'm wasting their time if there turns out to be nothing wrong" and "I don't have confidence in my health professionals").

In the age group surveyed (over 50 years old), issues related to taking time off work or payment for prescriptions are only relevant to a minority of respondents. However, where they did apply, they had a major influence on service use.

Weak Barriers: minority issues that also have a weak deterrent impact on service use

The statements fewest people agreed with were: "I worry that my health professionals might not keep my details confidential" and "I don't think my health professionals are skilled enough to treat me well". Although confidentiality was a barrier for a relatively small proportion of respondents, 2% of the population still represents a large number of health service users. Those with concerns about confidentiality were more likely to be younger respondents, and those on means-tested benefits.

Differences by group

Association of barriers with sex(40)

A number of barriers are significantly associated with sex. More males than females indicated that they "only see a health professional if I think my illness is serious", whereas issues around assertiveness (finding doctors patronising or finding it hard to stand up to doctors) and worry about 'time wasting' were more often barriers for females. Preferring to see the same health professional every time and preferring to see a health professional of their own sex were also greater barriers for women than men.

Association of barriers with age

Perceived barriers had a bigger impact for those between 50 and 65 years compared to those over 65. Generally the proportion agreeing that an issue discouraged service use decreased with increasing age. This was despite the finding that older people had more ill health and use health services more: adjusting for ill-health makes the association with younger age even more striking. This finding challenges common assumptions that older people find more barriers to accessing health services.(35;39) It may be that their expectations from health professionals and health services are lower and so they perceive fewer barriers to services use. It may also be related to older people having fewer competing priorities (such as work and family responsibilities), which sometimes make it difficult for younger people to prioritise their own health care.

Association of barriers with material deprivation

Material circumstances have an impact on use of services and those less well-off make less use of preventive health care (for example attending screening programmes).(2;5;41)

As expected, the barriers most strongly associated with means-tested benefits included practical barriers relating to difficulties travelling either to the GP or to hospital. Several of the commoner barriers associated with receipt of means-tested benefits related to: only attending if they thought an illness serious, preferring to see the same health professional every time and preferring to see a health professional of their own sex. Benefit recipients were also more likely to feel too many drugs were prescribed, that health professionals were very busy or overworked and that doctors were hard to stand up to. These issues may reflect both health care being a lower priority for the worse off and generally poorer relationships with health professionals.

Association of barriers with ill-health

It might be expected that those with multiple diagnosed health problems would find it easier to access services, through having more experience of services and a sense of legitimacy in using health services stemming from their medical diagnoses.(42) However, after adjustment for other individual factors, all the most commonly recognised issues and barriers experienced were significantly related to the presence of more than one medical diagnosis. This raises concern that those at most legitimate need of health services may perceive the most barriers to accessing services. These respondents are certainly identifying more concerns and barriers, which suggests they have been influenced by more adverse than positive experiences of health services in the past. As people with different types of ill health sometimes highlight different factors and issues as major barriers indicates how important it is to consider specific as well as general issues when organising and providing services.

Conclusions

The survey analysis has demonstrated that many of the issues identified previously from the focus group study are major barriers to service use. Many of these are even more common as barriers in the population groups that we would expect to use health services more: women, those experiencing material deprivation and those with multiple medical problems. Other issues are widely recognised but found to deter service use less often or strongly. A few issues are less frequently identified as influences on service use but have substantial deterrent impact for that minority.

The next stage

Using the results of the survey, the next stage in the research was to explore, in detail, individual experiences of the various types of barriers to health service use.

Accordingly an interview schedule was developed using the focus group and the survey findings – the next section of this report will describe the interviews and their results.

Stage Three - Depth Interview Study

Introduction

The main aim of this third stage of the study was to build on the findings of the focus group and questionnaire stages to explore 'lived experiences and views' about the various sorts of barriers to service use identified earlier. Through semi-structured, in-depth interviews, we examined in detail actual experiences of the wide range of factors identified as influencing service use and investigated underlying reasons for differences. In other words, by interviewing individual members of the public we could add to our understanding of the mechanisms and processes involved in patterns of service use.(21;23;43) In addition, this interview approach allowed us to gain a better idea of what changes could be made in healthcare organisation and delivery to help remove inequalities in use and improve access.

Methods

Recruitment

Purposive sampling was used to recruit 33 people.(23) We aimed for approximately equal numbers of males and females within the age range 50-94 years. Given the higher levels of morbidity and mortality of people from areas of socio-economic deprivation we also aimed for a greater number of participants living in those areas of the city.(3;5)

The electoral roll was used as the preliminary sampling frame – 1032 randomly selected names and addresses from all Sheffield postcode areas were obtained from Sheffield City Council.

Every 10th name was selected from the electoral roll for the first mailing and, after six further mailings, 33 individuals had been recruited from 42 responses, achieved from 128 invitation letters (= 32.8% response rate; 25.7% recruitment rate). Letters describing the project and inviting people to participate in an interview were posted with response cards and stamped addressed return envelope. Towards the end of the recruitment process, people invited were selected from the list to achieve an even sex-balance and sufficient numbers from areas of deprivation. Stamped addressed response cards indicating willingness to participate, age* and preferred location of interview were included with the recruitment letters (* we asked for volunteers over the age of 50).

Respondents were contacted by telephone and following exchange of further details and verbal consent, appointments were organised in the volunteers' preferred location.

Interview Process

From the survey analysis an interview schedule was developed: six question areas comprising 23 survey items were included to cover the common issues, major barriers and main inequalities. Laminated sheets indicating the discussion points were produced to be shown to participants and guide the interviews. The content of these sheets is shown below, followed by a key.

Figures 6 (i-vii) Interview question areas and key to fonts

i) Question area 1

- **I worry that the health professional will think I am wasting their time if there turns out to be nothing wrong** **
- **My health professionals always seem very busy and overworked** **
- **I only see a health professional if think my illness is serious** *
- I feel guilty about using NHS resources

ii) **Question area 2**

- **I think doctors can talk down to you or be patronising ***
- **My health professionals do not explain things to me**
- *My health professionals don't listen to me*
- *My health professionals don't take me seriously*

iii) **Question area 3**

- **I like to see the same health professional every time ***
- **I find it hard to be assertive or to stand up to doctors**
- I prefer to see a health professional of my own sex *

iv) **Question area 4**

- **It can be difficult for me to get an appointment to see my GP ****
- **It is difficult for me to travel to my GP's surgery for an appointment**
- **My GP's opening hours are not convenient for me**
- *I don't have a friend or relative who can help me when I'm ill*

v) **Question area 5**

- I don't know about all the services available *
- I don't know what I am entitled to receive from the NHS *

vi) **Question area 6**

- **I am worried about drug side effects ****
- I don't have confidence in my health professionals
- Doctors prescribe too many drugs
- I am frightened to see health professionals because I might get bad news
- I will not seek health service help if I think I will need an operation
- I don't think my health professionals are skilled enough to treat me well

vii) **Key**

Items within each question area are listed in order of overall ranking:

bold ** = top 10 issue, major deterrent effect;
bold * = top 10 issue, moderate deterrent effect;
bold = middle rank issue, major or moderate deterrent effect;
italics = low rank issue, major deterrent effect;
normal * = top 10 issue, minor deterrent effect;
normal = middle rank issue, minor deterrent effect, or
low rank issue, moderate deterrent effect.

The interviews were recorded on audio-tape and transcribed verbatim for subsequent analysis.

Methods of Analysis

As with the focus group data, transcribed interview files were prepared and data inputted to the Atlas.ti software programme.(24)

Transcript data for each interview were coded in various stages - firstly, in relation to the 23 set questions (as 'a priori' codes). Secondly, in relation to points which arose within the interview discussions (as 'emergent' codes 'grounded' in the data). All the set question data were then also coded in relation to whether the issue under discussion delayed or stopped their service use.(23)

In addition, transcripts were coded with the interviewee's biographical details, and categorised in relation to their levels of health services use and extent of criticism, health status and home situation. Referring to the interviewees' evaluations of the health service as 'criticisms' reflects recognition of the ongoing debates about problems with the notion and measurement of 'patient satisfaction'.(44;45;46;47;48)

Interviews were analysed in two ways: firstly, by examining the full dataset to identify the details of the individual factors and issues influencing service use; and secondly by investigating a small selection of cases to identify the relationships between personal, social, economic and health service factors.(21)

Findings

Characteristics of the 33 interview participants (Table 4)

The table below shows the composition of the sample achieved from the various biographical, social and health/health service related categories.

Table 4 The interview sample

Age	6 - 50 to 59yrs, 9 - 60 to 69yrs, 14 - 70 to 79yrs, 4 - 80+yrs
Sex	15 Females, 18 Males
Level of NHS Use	11 High, 14 Medium, 8 Low
Extent of Criticism	12 Limited 19 Moderate, 2 Substantial
Overall Health	2 Good, 19 Moderate, 12 Poor
Description of Area (from Townsend Scores*)	2 Very high affluence, 4 High affluence, 9 Affluence, 4 Deprivation, 3 High deprivation, 11 Very high deprivation
Living Arrangement	21 Lives with family, 12 Lives alone

*Townsend scores for Area descriptions
< -4 = very high affluence; -4 to -2 = high affluence; -2 to 0 = affluence
0 to +2 = deprivation; +2 to +4 = high deprivation; > +4 = very high deprivation

The table demonstrates that the achieved sample satisfactorily matched the sample mix intended.

Main findings

- Overall, the health service use of different individuals relates to a combination of health service factors, personal characteristics and socio-economic circumstances.
- As with the survey, the interview analysis shows that some issues are frequently involved in decisions to use health services. Again, however, only some of these issues delay or stop actual service use (see appendix 5).
- Although some associations between barriers experienced, 'types' of people and socio-economic circumstances are evident (e.g. age, sex, living arrangements etc) the small sample size associated with the qualitative method precludes claims of direct or causal relationships between them. However, common themes and issues within the individual discussions suggest links can be identified.
- Individuals' social and economic circumstances tend to be more influential on patterns of service use than (Townsend) area scores.
- Many of the factors influencing service use recur within the various types of barriers but vary in different contexts, showing the complex issues and processes involved in decisions to use

services. This explains why it is not possible to produce a simple or brief check-list of factors producing barriers applicable to all contexts (as indicated earlier in the factor analysis of the survey findings). (See appendix 6 for components within 10 main barriers).

Important issues involved in barriers

By searching for patterns and relationships between the various types of codes, several were found to frequently co-occur or overlap with each other. This shows the complexity of issues and range of factors that combine to produce barriers to service use.

The report will now describe the detail of some of the most important issues within the main barriers identified and illustrate them with selected quotations from the interview transcripts.

The seriousness of an illness

The most common barrier to service use links to a belief that a large proportion of the interviewees hold personally, and is discussed extensively in the interviews. A majority of the interviewees said they do not use services or delay using them, or stop using services prematurely because they feel they should only see a health professional if they think their illness is serious. This belief is found to involve a varying combination of concerns about:

- Being a nuisance, which for some people related to them worrying about wasting busy professionals' time in the context of an over-stretched service. This concern more commonly stopped the younger interviewees, the males, those with higher levels of ill health and those living in poorer socio-economic areas.

  > *MS …they are overworked.. SK Would it put you off going…? MS Well yes, unless it's really, really serious I don't want to go. I mean, the other year I sliced the end of my finger off and I stuck a plaster on, I didn't bother going, I put a plaster on. (Ref 31:35)*

  For some people 'being a nuisance' was described in terms of fears of being seen as a hypochondriac. This fear more commonly stopped the female interviewees, those living in poorer socio-economic areas and those with higher levels of ill health.

  > *SK Have you ever had that experience that the doctor is saying "Oh what are you worrying about that, there's nothing to worrying about". AW Well in a way. You think they are not taking much notice. I've got LS. It's an irritation between my legs, but for years I've been treated for thrush, but it had gradually got worse and lasted longer… After a while she decided to send me the hospital and they found out what it was. But there again, all I got was two sheets of paper and one was… an organisation belonging to the Health Service. So, I finally wrote and she was a good help… SK So were you feeling when you were going back that you shouldn't be going back? AW That's right, yeah. SK Because you were being a nuisance, or what? AW Yes, or perhaps it was something that I was imagining, although I wasn't. But them thinking it's something that's not important, that kind of thing. But it was. SK Do you think that was by the way they behaved, or did they actually say, "Oh there's nothing here". AW No they just, at first they just said it was thrush…But then it got that when they were giving me these different ointments I'd either have a reaction, it made me feel worse or, about 2 or 3 days it was right…but about 10 days or a fortnight after that, it just started coming again. And you felt you didn't want to go, because you felt as if you were being a nuisance. (Ref 22:175)*

  Leaving illnesses until they become urgent/emergencies was identified more commonly by the younger interviewees, and those with higher levels of ill health.

  > *LC I will wait now and I could make an appointment to see Doctor W again, but I don't think that is necessary because it isn't urgent, so I will wait until the next three monthly check or unless something else crops up, and I have to go. (Ref 2:377)*

- Not knowing what problems are appropriate for seeking professional advice or follow recommendations. Different people evaluated what is 'appropriate/serious' in different ways with more from poorer socio-economic areas seeming to expect, be resigned to, or accept ill health. Most, but especially the younger interviewees and those living in poorer areas considered the amount, duration or impact of symptoms. For many, the severity of pain was the most significant symptom in their evaluation. Other symptoms and their impact on daily life were less commonly highlighted. Some considered whether their illness is likely to be self limiting or can be self-managed, and a few indicated that being worried or uncertain about symptoms or their potential impact is sufficient to prompt professional help-seeking. This related especially to finding 'lumps'.

  > *RP I'd only go if I thought it was serious enough...If I found a lump or I'd got pains anywhere… SK So pain is one of the things, and lumps you see as serious? Anything else that might make you think "Right I'm going to go"? RP Very bad headache, nose bleeds, you know anything that I thought was serious. I mean, I wouldn't go with a sore throat until I'd had it a day or two and it got worse. SK So you'd wait a time? RP Yes, I would take pastilles or something for it? (Ref 13:266)*

- In addition, only going to see a health professional for serious illnesses is also influenced by the deterrent effects of various negatives past experiences of health care. Many participants described how they have been discouraged by health professionals who seem to rush and not take them seriously; have uncaring and patronising attitudes; behave abruptly and dismissively, or provide unsatisfactory explanations. Bad experiences with health professionals were identified as barriers more often by the younger interviewees, the females, those with higher levels of ill health and those in poorer socio-economic areas.

  > *SK Some people have said...they're worried they'll be told "What are you fussing about". RP Yes, that puts me off. Yes, I must admit that… SK So you think some doctors are a bit off-putting in that way? RP Yes, yes… SK So does that play on your mind, when you are feeling a bit poorly or worried about something? RP Well I mean, I've difficulty in going up stairs because I think I've got arthritis in my knees… and I have chronic asthma anyway. Whilst I was at the doctors I mentioned it and the reply was, "Oh well we all have aches and pains at your age don't we?" Which I thought "Well yes, course we do, but not so much that you can't walk up stairs". There's a reason isn't there? SK So that will put you off? RP That will put me off going anywhere else about it, yes, yes. (Ref 13:250)*

Several reported being deterred by problems getting GP appointments; not being able to see their preferred health professional; the length of hospital waiting lists, and prolonged waiting room times. These were barriers more often for those interviewees with higher levels of ill health, those in poorer socio-economic areas and young elderly people.

A few mentioned how they have experienced drug side effects and how this constitutes a strong disincentive to future service use as they anticipate medication as the treatment of choice for most doctors for most health problems.

As a consequence of various negative experiences and perceptions, many people have negative expectations of the health service and health professionals. This results in many only using the NHS in urgent or emergency situations, and for severely painful, long-established, or 'worrying' symptoms. Some give up on the NHS altogether and turn to the private sector, albeit reluctantly.

> *CH The first one I had to pay for because, I waited a long time and it was so bad I couldn't see a thing through it. And my optician, despite writing and the doctor writing as well, kept saying "You're still on the list, you've some months to go". SK So how did that make you feel, that you had to wait so long? CH Well, I was not happy when I knew that I was relying on one eye which was already fading…Eventually I asked the man in charge "Can you do it privately?" He said get in touch through my office…so I got in touch with Dr W at (private hospital) and he did it for me. (Ref 9:199)*

Transport, location and proximity of services

Another extensive area of discussion that links strongly to the decisions of many people to delay or not use services involves issues relating to transport, location and proximity of services. Decisions involve trade-offs between the costs and effort of the journey vs. the perceived necessity and usefulness of the appointment. Some of the problems highlighted were different for travel to GPs and hospitals, but many involved the same issues. Problems with transport were more commonly experienced by the female interviewees; those with higher levels of ill health, and those in poorer socio-economic areas. The interviewees provided with transport tended to be those with visible illnesses, be older, and live alone.

- Common issues include: the need to rely on friends/family; the ownership of or access to a car; the costs, frequency and proximity of public transport to health service facility;

- Hospital specific issues include: the availability and offer of an ambulance/medicab, the journey time, and distance of parking facilities.

  MS ..before I had operation for my hips I had hydrotherapy…to exercise my muscles, and when I used to get in there was nowhere to park…I had to park car on (road) and walk up...and when I got up there I was exhausted… and then I had to walk back again and that were it, I were done for the day. So I weren't keen on going, but wife nagged me to go, you know, but there were no benefit… I weren't so bothered. Well actually I did pack it up cos it got to that point like… I couldn't get in car, my joints were aching that much. I had to stand for ten minutes or quarter of an hour while my joints eased off. SK Did you explain that that was the reason you wanted to stop? MS Yes. Well I told them like that I was packing up like cos it was just painful. (Ref: 31:106)

- GP specific issues include: the absence of NHS transport services

  CH They've moved the Health Centre twice as far from where it was. I live at the very furthest point of the district. If the people haven't got a car, there is a once an hour bus comes round which goes somewhere near. I don't exactly know how near it goes, but anybody else has got real problems getting there. To get by car, it's one of those…It used to be just off BM Road. Well that wasn't too far, within walking distance …but now its right at the far side on BL next to the tram lines which means it's a good mile. Not beyond my walking range but not the kind of thing I want to do if I had to go, if I were feeling ill. (Ref: 9:229)

The availability of someone to help

Another big discussion area and substantial influence on service use for many people was whether they had anyone to help them if they were ill. For some, living with family or having friends available to help them when ill means they have the support and live in circumstances in which they can cope without external services. For others, having someone available means they get encouraged to seek professional advice or assistance getting to the service. Some of the older interviewees who lived alone preferred to struggle on and emphasised their desire to remain independent. Some spoke of 'being a nuisance' to their family or doctor, only 'giving in' and asking for help when there was no alternative. Others preferred support from neighbours and friends. Having friends/family to help when ill more commonly influenced the service use of those living in poorer socio-economic areas, and those with higher levels of ill health.

> *FF I don't want an operation if I can help it. SK What is it about the operation? FF Well I live alone, and the operation I believe, can leave you debilitated, whatever the word is, for a month or so, more than a month perhaps, I don't know. And that puts me off cos I live alone, and there's nobody to go and shop for me or anything, so er, that's one reason I don't have it done. SK So it's not the actual operation, it's the recovery from it? FF Yes, yeah, yes. (Ref 4:52)*

Concerns about Drugs

Another major barrier to service use for several interviewees was linked to worry about drug side effects. For some this was something experienced personally, and for others it related to a friend or relative's experience. Concern about drug side effects was more common for the female interviewees and those with higher levels of ill health. In addition, a few were generally fearful of drugs through information they had acquired, for example, from media sources. Sometimes a delay or stop in the use of services or reluctance to comply with medical recommendations linked to a general lack of confidence in health professionals' skill and knowledge. But for others it related to a belief that doctors tend to over-prescribe medication or do not explain adequately the need for, benefits of and effects of a drug. At other times a drugs-related reluctance to see a health professional or use a prescription linked to a general dislike of being dependent on medication for health and association with a stigmatising disabled identity. The association of drugs with dependency and illness identity was more commonly a concern amongst those interviewees with higher levels of ill health.

> *BF Another thing, I don't like taking drugs unless I really need to, because I nearly got... When I had toothache I took codeine. It wore off and I stopped taking them. He gave me these tablets cos I was in so much pain, and then of course it wore off, it had took pain away but then it came back again. Then I was out of it you see and they found me in the middle of the kitchen and then I wore it off after an hour. I took even more and I ended up as I though, I was going to be on them forever. SK So it's put you off tablets? BF Yes, I was only seventeen then so. So I decided at the time I wasn't touching anything unless I really had to. (Ref 15:263)*

> *KE It's not something I like but I do have a repeat prescription and I do not like that at all. SK What's the problem there? KE I think I don't like the fact that I have to take medication, I mean it is a blood pressure tablet, I was prescribed it because I was very conscious of my blood pressure. They said they will reduce it which I was quite pleased about but I don't like the fact that I'm dependent on them. SK So it's the dependency rather than the side affects? KE Well at the moment I haven't had any side effects. It's the fact that I don't like to think that I'm dependent. SK So what does this dependency stand for? What is the problem then? KE I don't like the idea of not being healthy, I don't like the idea of, I think to myself you know you can't do yourself any good in the long run, there's going to be some sort of side effect. SK So it stands for something that you don't like the idea? KE That's right. (Ref 17:235)*

Knowledge of services

A major barrier to service use for a smaller proportion of the interview participants connects to their knowledge of services. Some assessed the quality of their general practice and NHS generally in relation to the availability and range of information provided about established and new services and treatments, whereas others sought information for themselves. This often related to how assertive individuals were and how highly they prioritised their health and believed in the effectiveness of preventative and therapeutic health care. Not knowing about the availability of a treatment or test was a barrier more often than not knowing about what treatments involve or their effects.

> *SK So you don't use preventative health care because you don't think there's much available for you? AW You can only find out when it's been declared, but you look in the doctors on the pinboards and there's nothing up. There's quite a bit for women but for men, no. I haven't seen anything at all. I do understand that there's a big benefit from it...SK So do you feel that there is more out there but you just don't know what it is? AW Or where to get it from, yes. This preventative medicine, is it always available at your surgery or somewhere else? I don't know about that… SK So overall there's a certain element of you're not quite sure what's out there?...AW That's right...It isn't that you don't want to use it, it's that you don't know about it. (Ref 14:206)*

> *SK Do you feel there are services out there but you just don't know what they are? BF Well, I suppose so love, yeah. I mean, I don't go looking, rooting round. SK No, so even though you know there might be things out there, you'll not bother? BF Well I've never even thought about it…I don't like to ask and I don't like putting people out (Ref 15: 375)*

A few people said they did not use a service because they did not know if they were entitled to it. A lack of knowledge about services was not a barrier for any particular section of the population, but was most commonly identified as a problem by those interviewees with higher levels of ill health, and limited users of services.

Assertiveness

Issues relating to the influence of <u>assertiveness</u> represent the most extensive area of discussion in the interviews, but non-assertiveness does not always result in non-use of services. For example, for some people, being timid links to compliance with professional instructions whereas for others diffidence and worries about being a nuisance keeps them struggling on, coping on their own, or waiting until their illness is perceived as urgent or very serious. Non-assertiveness more often delayed or stopped the service use of the female interviewees; those who were younger; those living with others and those in poorer socio-economic areas.

> *SK You didn't ask? IB No, I never thought to ask... Husband She had to ask them to help her with the toilet. They think if you can walk to the toilet you can walk back without help. But she can't manage... IB It was night-time though... Husband And she rung the bell and she come, this lass, and said "What do you want?" And she said "Will you take me back to bed?" And she said "You've come, you can get back if you want". And she walked away and left her. IB And left me there all night, sat in that chair all night. And I never thought to complain or anything like that. Husband It was me that complained. IB I were thinking about it, err. SK Were you really upset, but you didn't like to say anything? IB No, I didn't like to say anything to 'em. (Ref: 27:375)*

> *SK Have you been given enough explanations to feel that they know what to do and why? BF No, not really, they just give you a prescription, a repeat prescription... SK So if you don't get an explanation, like about the treatment, or a referral for something, do you ask? BF No I don't, I just take it that. I take people at face value love, and believe everything they say. And I have been like that always, and it's, I've not just been let down by the doctors...and it's not when I'm in there but when I get out that I think 'Oh you should have asked so and so'... SK So what does that do the next time you're going to go? BF It just happens again, you know, but I don't go unless it's really necessary. SK So is that part of what's putting you off? BF Yes. (Ref 15:295)*

Confidence in health professionals

The importance of having faith and <u>confidence in health professionals</u> was also discussed extensively in the interviews but found to delay or stop use of services infrequently. Similarly, trust in the technical skills and knowledge of health professionals was highlighted as an important concern, but with little impact on service use. The expertise of health professionals tended to be assumed by most people on the basis of respect for the quality and extent of their training and level of qualifications. However, several participants mentioned how medical errors and fraudulent claims to qualifications exposed by the media do worry them, and increase their reluctance and delay them seeking advice. A general lack of confidence in health professionals was more common amongst those interviewees living in poorer socio-economic areas. Concerns about technical skills tended to be slightly more common for the female interviewees, those who were older and those living alone but especially for those living in more affluent socio-economic areas.

> *DM Well I'm very nervous about having the operation ... Who knows whether you are going to come out of it or what. Who knows, nobody knows, do they? ..Is it better being left alone? Is the doctor who's doing it really qualified to do it, that's another thing, isn't it? We've found out recently that a lot of these doctors haven't been qualified anyway... and I mean there's been a lot in the news about this doctor who killed all them babies isn't there? Negligence. We put our lives in the hands of professionals don't we?.. SK Do you have any personal experience of things going wrong, other than things reported in the press? Have you any friends or family who've had that situation? DM Oh yes, I have. SK So you are worrying justifiably? DM Yes, yes, I've got a relation who's been in hospital and she's a walking zombie, because of the things she's had done to her. I know a lot of people who've had operations on their knees who've come out not walking. SK So you have actually seen things that haven't gone very well? DM Yes, yes. And I always say that the operation depends on the person who's doing it. (Ref 29:372)*

Individual circumstances

Interestingly, the interviews have shown that individuals' social and economic circumstances have more impact on their patterns of service use than the socio-economic environment of the area in which they live. The importance of individual factors became evident in several interviews where interviewees described the role and influence of home situations.

Amongst those participants who live in areas coded differently from their individual circumstances, those coded as affluent, highly affluent or very affluent who described or demonstrated personal situations of relative poverty tended to highlight greater barriers to service use than affluent individuals living in areas of relative deprivation.

One of those who lived in an area more affluent than her own situation was one of the very few interviewees who was concerned about not over-using the health service partly in relation to its cost.

> *SK ..Some people have talked about delaying, or not going to see a doctor because they felt guilty in terms of using too much of the NHS resources for themselves. Would that ever cross your mind? AW Yes it would, because I always think, well if this gets serious, say like you can get cancer, they can't cure anything like that, but you need a lot of treatment. SK So you tend to think about resources? AW Yeah, you might need, if it's only a mild illness that's alright, but keep the money for if it gets really serious, say you'd been going lots and then they can't afford treatment. SK So it's sort of like you think you've got a quota? AW I think "Could I do more for myself than ask for prescriptions and things?"... SK So part of not going is cos you don't want...to take more than you feel entitled to? AW So that when you actually need it you've got more left for yourself. (Ref: 22:293)*

Problems for relatively poor individuals living in affluent areas were indicated in another interview. Service use is restricted to severe, enduring or disabling symptoms as getting to the GP was described as difficult because the bus service is poor and neighbours are not helpful. However, the family situation and determined attitude of this interviewee moderates his problems.

> *NB The only thing that puts me off from going to the doctors is getting there and getting back...The bus service is every half an hour and my doctors about a mile and a half away. If we come out the doctors and it's raining there's no bus shelter so we get wet through because we could have to wait half an hour. SK So it's not the actual surgery? NB No, nothing to do with the doctor, it's transport...that's the only problem we have... SK So that will put you off a little bit?.. NB Oh yes certainly...I mean I've got it now this earache but I mean it's no problem, you understand what I mean?.. SK Do you think that having a wife at home affects the way you use the health services?.. NB Well it's only since I've had a stroke that she's had to go to the doctors with me... because I couldn't get on and off the buses...SK What about if you were on your own?..Do you think you would turn to the doctors more readily for help?..NB I don't know, if I hadn't a wife I don't know. Nobody from on the road, because they don't do that sort of thing these days. I mean in my younger days neighbours came and helped each other, which they don't these days... SK So what would you do if you weren't quite able to be independent and hadn't got someone around to help you? NB Try and do it myself. I'm very independent, same as now, I couldn't walk and I knew I was going to walk...(and) I was determined I was going to get up stairs and that's why I've got on so well, determination that I can do things. SK So your first line of attack would be to struggle on independently? NB No, I think I'd ring my son up, my granddaughter, but even then, only as a last resort if I couldn't do it. (Refs: 19:241,304 and 315)*

Other influences

In appendix 5, the 10 pre-set topics discussed most extensively within the 33 interviews are listed in order of the number of code references. After this, the 10 pre-set topics associated with the highest proportions of Delay/stop service use references are listed in order, along with the number of interviewees that identified the issue as a barrier. Then, a third table (appendix 6) details the component elements of the 10 main barriers and co-occurring codes.

Conclusion

This first part of the interview analysis has demonstrated the following:

Believing the health service should only be used for serious illnesses involves a complex and varying combination of issues. These include: being a nuisance, or seen as a hypochondriac; not knowing what is appropriate; bad past experiences, especially of health professionals being either abrupt or overworked; and long waiting lists.

Transport is also a major factor in determining service use with difficulty getting to the GP found, surprisingly, to be a problem more often than getting to hospitals. A partial explanation for this finding may be that many hospitals are on bus routes whereas GP surgeries are often down back streets off bus routes.

Having help and support available is an important influence on the timing and extent of service use. However, once again this is very individual-specific in its effect.

The other major issues that operate as barriers were concerns about drug side effects, knowledge about services, and the assertiveness of individuals.

Next, in terms of the interview analysis, a selection of individual transcripts were examined in further detail to illustrate the influence of and relationships between issues involved in decisions to use services and barriers to service use and influence of individual circumstances. The main details identified from these case studies are described below.

Case studies

We examined four contrasting interview scripts for case studies. The individuals were selected from the first part of the interview analysis to help illustrate how different personal attributes and individuals' experiences, along with specific social and economic circumstances, interact with health service factors and experiences to influence the level and timing of current and future use of the NHS. Names have been changed to maintain confidentiality.

Figure 7 Summary of health and service use characteristics of four case studies

Case study	Health	Level of NHS use	Extent of criticism	Timing of use
1. Martin	multiple health problems	high	moderate	delayed
2. Beryl	some ill health	limited	substantial	delayed
3. Stella	multiple health problems	high	moderate	prompt
4. Derek	some ill health	high	substantial	prompt

Case study 1 Martin

In his 50s, Martin lives with his wife in a highly deprived area. He has had various and life threatening and ongoing disabling health problems and is a high health service user, but delays or stops use because of past experiences and perceptions of the health service and a reluctance to become 'medicalised'. He appears resigned to living with symptoms of ill health despite disliking his restricted life style and dependency on state benefits.

His delays mainly relate to perceptions of a very busy service with hospitals/health professionals only treating illnesses when symptoms are critical; experiences of dismissive attitudes and deferred treatment, and difficulties travelling to hospital appointments.

Martin is worried by the idea of being seen as a scrounger or hypochondriac, and believes his GP can look after his heart condition adequately. He interprets hospital care interventions as alarming indications of severity and does not want further tests or treatments. He takes a minimum of medication, despite limitations to his levels of activity because of chest pains, and prefers to struggle on, reliant on the help he gets from his wife.

Case study 2 Beryl

In her 70s, Beryl lives alone in a highly deprived area. She is an infrequent health service user despite various health problems, because of various bad experiences of health care and a belief that she should cope independently.

Her limited use mainly relates to experiences of drug side effects and inappropriate professional behaviour, and an upbringing that advocated self-help and an unchallenging attitude.

Beryl says she is annoyed with herself as she knows that she should have complained about her bad past experiences, but a lack of self-confidence meant she preferred to avoid future use of services rather than make a fuss. She believes strongly that she should not be a nuisance to others in her family and the health service. Beryl says she has a small circle of friends and neighbours who tend to provide help and support for each other. Since moving she has, reluctantly, had to change her long-term GP and transport to the new surgery is very difficult.

Case study 3 Stella

In her 50s, Stella lives with her husband in a highly affluent area. She is a high health service user and has had many health problems including some that were potentially life-threatening. She has several strong criticisms of some health care professionals.

Her continued use of services relates to an assertive manner and determination to get effective treatment; a supportive GP and husband; a family car, and a General Practice that is close to her home.

Stella believes strongly in the potential of medicine, and refuses to give up when she experiences uncaring professional attitudes, inaccurate diagnosis or ineffective treatment. She has used private health care when the NHS has been unable to treat her promptly.

Case study 4 Derek

In his 60s, Derek lives alone in a highly deprived area. He is a high health service user despite many criticisms based on bad personal/others' experiences of health care, including problems with drug side effects and ineffective treatments.

His concerns and criticisms also relate to perceptions of age-related discrimination and feeling 'fobbed off' by health professionals. He believes many staff mislead patients regarding their diagnosis or prognosis and/or ration their treatments, and relates this mainly to the problem of long waiting lists.

Despite problems and substantial discontent, Derek believes strongly in his entitlement to treatment and the potential of medicine, and has a determined approach to achieving a cure and 'beating the system'. Although generally pessimistic about the chances of treatments working well, he does not give up as he feels he has no alternative but to try. He has very limited contact with or support from his family.

Case studies conclusion

These four case studies illustrate how personal attributes and experiences, along with social and economic circumstances, interact with health service factors and experiences. Overall the interviewees identified a recurring range of problems with, and obstacles to, using the health service, but these case studies highlight how they constitute 'barriers' to service use to varying degrees because of individuals having different personal, social and economic resources. In addition to people having varying levels of 'need' for health care services, these internal and external factors influence the level and timing of current and future use of the NHS, and also the individual's expectations of a positive experience and outcome.

Discussion

The complexity of barriers

The interview analysis provides a greater understanding of the barriers identified earlier in the study and shows there are various reasons behind patterns of service use and inequalities in access. It reveals the detailed components of, and relationships between, the many issues and factors identified in the focus groups and population survey. Importantly, the interview accounts show there are many shared experiences and perceptions of health care and the NHS system, along with numerous personal, social and economic influences on service use. Through the two stages of the quantitative interview analysis we have been able to highlight the complex relationships between a range of common and specific factors to the under or over-use of health services (relative to clinical need), prompt or late use, and different extents of criticism.

The interview analysis also provides explanations for some of the more unexpected survey findings by revealing the complexity of the issues involved and the processes and mechanisms between them.

The analysis also indicates some of the reasons for variations in approaches to different types of health care (e.g. hospital, community and GP; medical, nursing and allied health professional). Additionally, the analysis shows how different health problems are often dealt with differently (e.g. painful/enduring/asymptomatic; acute/chronic; mental/physical).

'Appropriate' use and use in relation to 'need'

When taking into account the overall health status and level of service use of the interviewees, a few are found to be relative under-users and a few are relative over-users. However, most of the interviewees use services at a level broadly compatible with their health. 'Inappropriate' levels of service use tend to occur when people have personal attitudes and beliefs and socio-economic circumstances that make it difficult to accept or resolve problems experienced or perceived with the health service, or overcome barriers to service use. Whilst the health service cannot be expected to change individuals' histories and socio-economic circumstances, it is within the scope of its responsibilities to remove or at least reduce problems within its organisation that constitute barriers to service use and contribute to inequalities of access that exacerbate health inequalities. Arguably, it is also the responsibility of the NHS to be involved in the growing trend for 'joined up' public services to influence, for example, public transport provision, as this is shown in this study and elsewhere to play a major role in inequalities of access to health services.(49;50) That many of the interviewees identified similar problems - e.g. bad experiences with health professionals; uncertainty about what constitutes an appropriate reason to seek advice; difficulties getting to services; lack of knowledge or understanding about services available; worries about drug side effects, and difficulties and delays in getting appointments - provides the NHS with key areas on which to focus their attention, despite only some people being deterred or delayed by these factors.

Critical users

The interview analysis has shown that the relationship between health status and use levels is not always related to the extent of criticism about health services with, for example, some highly critical frequent users and some uncritical infrequent users. Notwithstanding the main relationship identified between health status and service use, the extent of criticism and service use are related as much to the individual's character and general approach to and expectations of life and their socio-economic circumstances, as to the type and amount of experience of the health service.

Level for analysis

Interestingly, the interview analysis has indicated that patterns of service use in relation to need and criticism of the health service are more closely linked to individuals' personal attributes and social and economic circumstances than the level of affluence or deprivation in their general area. This is particularly evident for those interviewees who were living in areas defined as more affluent than their personal situation. This finding contributes to discussions regarding the best 'level' for studies of health and health inequalities and the contrasting literature regarding the relative merits of individual, community and areas measures.(51;52;53;54;55) The mixed methods approach of this study allows both general issues and specific details to be examined.

Conclusions

Our understanding of the issues raised in the focus groups and quantified in the survey has been extended by the in-depth nature of the interviews and their two linked analyses. The interviews have demonstrated how the personal attributes of the individuals, along with their social and economic circumstances, interact with health service factors in determining patterns of service use.

Overall, the interview analysis has built on, confirmed and extended the focus group and survey findings and extended the understanding of barriers to health service use discussed elsewhere.(3;4;5;33) The different methodologies and stages have identified many common issues as well as shown some minor differences in emphasis. For example, the role of knowledge about services for service use was widely recognised in all three stages, but the interviews demonstrated the relationships between the various influences and issues involved, thereby explaining the diverse ways and varying extent of impact of knowledge for the different service use of individuals.

The next stage

Using the analyses of the focus groups, survey and interviews, the final stage in the research programme was to discuss the results with a range of health professionals. This was firstly to confirm that our findings concurred with their experiences; and more importantly, to get them to suggest practical steps to reduce the barriers to and inequalities in health service use.

Accordingly, a series of meetings were arranged – the next section of this report will describe them and their conclusions.

Stage Four - Follow-up Meetings

Introduction

The main aim of this final stage of the study was to get health professionals to suggest practical steps to reduce the barriers to and inequalities in health service use and confirm that our findings concurred with their experiences.

Methods

Recruitment

All the health professionals who had attended the focus groups and some doctors known to be interested in improving access to health care were invited to attend one of four meetings in March 2002. Twenty health professionals agreed to attend.

Meeting Preparation

From the survey and interview analyses, a meeting plan and the discussion areas to be addressed were identified. Handouts demonstrating the detail of seven discussion areas were produced. These comprised the main barriers along with their component issues and details of differences for various groups within the samples. Illustrative quotes from the interview transcripts were used to highlight in the issues.

Proposed discussion areas

- **Only using health services for serious illnesses**
- **Knowledge of services**
- **Availability of someone to help if ill**
- **Drug side effects**
- **Transport**
- **Effects of bad experiences**
    - **Plus, Alternatives to giving up**

Two pages of the handouts showing the first discussion area and one of its component issues plus quotes are shown below.

Serious illnesses only

Whilst many people said they don't go to see a health professional unless they think their illness is serious, most of these were living in poorer socio-economic circumstances; those with higher levels of ill health, and males.

Issues for discussion:

1. **Being a nuisance: worries about wasting professionals' time in context of busy doctors/service**

2. **Being a nuisance: worries about being seen as fussing or a hypochondriac**

3. **What is seen as appropriate/serious varies for different people: different criteria for seeking advice/treatment apply**

4. **Perceptions of NHS: busy services; waiting lists; treatment orientated vs. preventative approaches to health ? urgent/emergency use only**

Serious illnesses only 1: wasting busy professionals' time

Not using services unless an illness is serious, in relation to wasting busy professionals' time, more commonly stopped younger people; males; those with higher levels of ill health and those in poorer socio-economic circumstances.

KM I'm very concerned with the doctors being busy and not worrying them with trivial things, but I see other people and I think they're not bothered. (Ref 10:209)

AB Myself and my wife, we have been conscious of not abusing the service, and we kind of take that into account. We are aware that they are very busy. Certainly when you go to the hospital they're very busy. SK But that in itself doesn't put you off going? AB It doesn't put me off going if I thought that it, if something was serious enough to go. (Ref 12:244)

MS Yes, well, they are overworked.. SK Would it put you off going, knowing that they are quite busy? MS Well yes, unless it's really, really serious I don't want to go. I mean, the other year I sliced the end of my finger off and I stuck a plaster on, I didn't bother going, I put a plaster on. SK And part of that was because you knew they were busy? MS Yes. (Ref 31:35)

Pre-meeting briefing notes

A letter giving an outline of the meeting, its general aims and objectives and the seven discussion topics were sent to the health professionals two weeks prior to the sessions. Participants were informed that because of the length of the meetings and complexity of some of the issues, it was not anticipated that each meeting would be able to cover every topic. We emphasised that we wanted to get beyond superficial responses and have detailed discussions that could achieve more carefully thought-through suggestions.

The meetings

A slide presentation describing the various project stages, and a summary of their findings was presented by the researcher to each group. The participants were provided with the handouts described above. The proceedings of the meetings were recorded on audio-tape and notes were taken of the discussion by the project secretary.

Summary of Findings

The health professionals suggested that changes to the delivery and organisation of health care could be made in the following areas in order to improve access and use. Their recommendations can be grouped in the following general categories.

- Education and information
- Changes to primary and community care
- Professional approaches and attitudes
- Improving transport

Each of these will now be taken in turn outlining the main areas for attention.

Whilst school health education programmes have tended to concentrate on education about health and illness, it was suggested that benefits could be gained from more education about how to use the health service.(56;57;58) Thus, for example, education could address how to use the system and about the different roles of different health professionals. In addition, education should include how to recognise symptoms which warrant attention. Finally, such education programmes were seen to be of benefit not only to children themselves, but would also cascade upwards to other members of the family.

It was recommended that information should be particularly targeted, using varied and imaginative approaches to reach those sections of the population known as low users and/or at high risk. This process should tackle the low health expectations and low sense of entitlement of some population groups - e.g. the less well off, those with chronic/multiple illnesses, and men. Care should be taken with content and distribution, however, to avoid stigmatising people, and to avoid information overload.

Whilst targeted information was recognised as most important and effective, the professionals also emphasised the need generally to influence people's approaches and attitudes to healthy body/life/self.

Careful balance is needed to encourage self-help and appropriate non-use and to avoid making people over-anxious or illness-obsessed. However, it is important not to increase the under-use of health care of individuals and population groups recognised to have low health expectations, and those concerned about being a nuisance, as identified in this study and also by Tod and Gardner.(59;60)

▪ Changes to Primary and Community Care

It was recommended that there should be a decrease in the role of the General Medical Practitioner as the front line and 'gate-keeping' professional. This would mean increasing and improving non-doctor roles. For example, extending nurse practitioner/nurse consultant roles, extending the role of pharmacists, and improving receptionist training and scope. This process would require an enhancement of the clinical status and reputation of non-doctor health professionals and opening up of referral mechanisms.

The above would combine to decrease the burden for/dependency on GPs, to free up their time for better quality care of those who need their specific expertise and increase time for advice/education/preventative work.

In addition to the above, certain changes in the configuration of primary care were recommended. These included improving GP appointment systems by, for example, implementing 'Advanced Access',(7) and extending opening hours. Finally, the importance of size, distribution, and location of primary care facilities was emphasised as an area needing attention.

The professionals recommended increasing non-hospital health services and the range and targeting of health care and screening in different and/or less 'institutionalised' venues, for example on health buses, in supermarkets, working men's clubs, leisure venues/clubs, etc. Also, community initiatives need support and better advertising.

▪ Professional approaches and attitudes

The health professionals suggested health care students, qualified and unqualified staff should all receive better training in inter-personal communication skills, and be made more aware of the substantial impact of their attitudes assumptions and behaviour on patients' decisions to delay or not use services subsequently. Although it may be unpopular, some recommended introducing a contractual obligation for health professionals to regularly review these aspects of their practice.

To enhance compliance with professionals' recommendations, in particular the groups stressed the importance of two-way communication with patients, and of good quality explanations about the benefits of treatments prescribed and the need to provide clear information about drug side effects. They also recognised the need to follow up non-attenders sensitively to avoid exacerbating problems, taking care not to be heavy-handed or judgmental, or to remove patients' sense of autonomy, and to recognise the way that power is unequal in the traditional professional-patient relationship, and that this has a pervasive influence. The increased involvement of 'expert patients' in advice and support clinics was proposed.

The professionals also highlighted the need to improve teamwork and share ideas and information so as to avoid patients 'slipping through the net' of a large, complex and ever-changing system.

- **Improving transport services**

The professionals recommended increasing the range and supply of alternatives to ambulance services. For example, increase the number of medicabs; internal transport schemes within hospital grounds; 'Dial a Ride' taxis, 'and 'City ride' community bus services to local surgeries/clinics as well as to hospitals. Also they suggested increasing publicity regarding these various services in a wide range of health and non-health related venues, and, in recognition of socio-economic inequalities of access relating to transport, focus provision on the most deprived areas, and those areas with a high density of older people.

The professionals urged the advising of reception staff and health care professionals to avoid making assumptions about the availability of home support/transport (etc) and acceptability of relying on friend/family carer to patients. Service users should be informed routinely of transport options/services, with objective assessments for access to (NHS) transport services based on impairment and socio-economic factors.

- **General suggestions**

The professionals concluded from their own experience of working in the NHS and from our study findings that the NHS needs a combination of funding, organisational and attitudinal changes to reduce barriers to using the service and inequalities of access. They also identified the need for more open debate and decisions about roles and funding of the NHS.

The professionals highlighted a general need to tackle a widespread mismatch of expectations about the NHS at individual and collective; public and professional levels, and a need to improve communication in terms of both style and content. In particular, attention is needed to reduce contradictory and off-putting messages, as these exacerbate inequalities in use of services and health inequalities. The main media images of the NHS are of a busy, over-stretched service and as a sickness service, and these tend to deter or delay those at most need of the service. Also, there is too little emphasis on the NHS role in health improvement, maintenance and/or preventative orientations to health. These perpetuate the common belief that the NHS is for serious and acute illnesses only/mainly.

The growing importance of chronic disease management(61;62) and reduction of risk in those not particularly acutely or severely unwell makes this even more important.

The professionals supported national campaigns and work closer to home. They saw national level and PCT initiatives for general issues, e.g. general screening, and community/neighbourhood level initiatives for specific conditions/inequalities, and for areas/groups susceptible to specific conditions. They stressed the need for dissemination of information about new developments, good ideas and good practice, probably at the PCT level, including those that have not worked. They emphasised the need for care to integrate separate projects into networks to avoid replication and 'reinvention of the wheel'. They supported the use of email for messages and information sharing, being seen as less onerous than paper information.

Finally, the health professionals commended efforts working to increase the involvement of the general public in health care planning and delivery, with the greater use of local people in community networks and 'expert patients' in health initiatives.

Overall Summary and Recommendations

The intention of this study was to help the health service and its partners to reduce inequalities in access to health care. In particular, it is important to suggest practical steps that could be implemented which would improve access and reduce health inequalities. In this final part of the report we firstly summarise the four stages of the study and then make recommendations that have arisen from both health professionals and our own interpretation of the results.

What this study has established is the most important issues requiring attention as these now have the backing of rigorous research. Other ideas that have been suggested about what constitutes major barriers to access can, by the same token, be dismissed as far less important and of lower priority.

Examples of barriers that we have found to be of relatively minor importance are:

- concerns about confidentiality
- worries about health professionals' skills
- barriers to service use being greater for the very elderly

By contrast, our specific recommendations relate to the most important barriers generated by the triangulation of the main findings from all 4 phases of the project. The recommendations, set out below, relate to organisational issues as well as educational and cultural issues. If access is to be improved for all population groups, it is important that health professional and health service managers are made aware of the factors that influence service use.

This research programme has:

1. identified a wide range of factors that influence the way people access health services and interact with health professionals;

2. investigated how the importance of specific barriers varies with age, sex, socio-economic circumstances and individual health;

3. explored how barriers may operate for different individuals and explored the complex interaction between individual beliefs and experience and the decisions they make about accessing health care;

4. triangulated findings with the experience of health professionals and generated some specific recommendations for where health service providers could improve access by tackling some of the common and important barriers identified in this report.

Recommendations for interventions to reduce barriers to health care based on the evidence of this study are:

- ***Education and Information***

  Health education in schools needs to address how to use health care as well as how to recognise important symptoms and provide first aid.
  The health service needs to reverse the impression that it is always substantially overworked and that use must be restricted to serious or acute illness.
  The general public, patients and health professionals all need to be kept better informed about health services that are available and how to access them.

- ***Drug side effects***

  Health professionals and the pharmaceutical industry need to recognise the extent of public concern about the side effects of medication and its consequent barrier to service use. Better explanations and reassurance need to be provided.

- ***Encouragement and Empowerment***

  Certain specific groups, namely females, those from poorer socio-economic circumstances, and the younger elderly, have been identified as needing the most encouragement to use health services as they were found to be the least assertive and have the most limited access to resources that facilitate service use.

- ***Professionals' attitudes***

  Health professionals need to be made more aware of the impact of their attitudes and manner on decisions to use health services. More attention to communication skills should not only be provided as part of health professional training, but also included as part of Continuing Professional Development.

- ***Resources and service design***

  Health care needs to be delivered and organised in ways that reduce barriers to use. For example, the Advanced Access initiative in primary care(7) could be extended so that access to chronic disease management programmes becomes easier and that primary care is not just seen as something for serious and acute illness. In accomplishing this, primary care provision will need even more to be provided by health professionals other than general medical practitioners.

- ***Transport***

  Local health services such as primary and community care need better transport systems to be provided. These could include increasing both public and voluntary sector provision as well as better publicity about existing services. Access to hospital care was not seen as a major problem, but better internal transport within increasingly large hospital sites, (both indoors and outdoors) should be provided.

- ***Individual assessments***

  In interventions to reduce barriers to service use, everyone needs to beware of making assumptions about and applying stereotypes to people. Service providers should always treat people as individuals and assess potential barriers to those people's need of health care. For example, in drawing up a health care management plan, a specific assessment should take into account what potential barriers to service use might exist for that individual patient.

While the present research has not conducted a controlled trial of the benefits of these recommendations they do provide the basis for what would be useful further research, or for piloting in practice.

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Appendices

Appendix 1
Example of detail within focus group category: Experiences

1. Experiences of the public: of health and illness, health care and health professionals

1.1 Experiences of Health and Illness

- Significance - gender and pain tolerance [P5 public: 1409-1525]
- Significance – tolerance of symptoms and cultural differences
- Significance - need to use [P5 public: 1812-1845]
- Significance - cancer screening [P5 public: 894-918]
- Significance – type of illness - generational experience [P6 hospital & community profs & unqualified carers:1370-1401]
- Quality - severity of symptoms– major impact from illness
- Quality - severity of symptoms – minor impact/ illness, self-limiting condition
- Type – life threatening/social inconvenience or constraining
- Type - stigmatised condition
- Amount – frequency of ill health

Experiences of health and illness

- Significance – who involved; potential outcome; type of disease
- Quality/severity – major/minor symptoms
- Type – acute/chronic/ emergency conditions
- Amount – occasional/frequent ill health

1.2 Experiences of Health Care

- Quality of service – negative – vulnerability [P9 primary care meetings: 951-957]
- Quality – positive - care and outcome [P5 public: 976-988]
- Quality – efficient - thorough – prompt [P2 public: 828-840]
- Quality – variability – understanding – wariness [P2 public: 431-459]
- Quality – constancy – problems – diagnosis and treatment [P10 public: 1887-1915]
- Quality – constancy – good service - faith in outcome [P2 public: 350-372; 1691-1692]
- Process – complicated or simple
- Process - difficult – poor liaison/communication - deterrents to attend [P2 public: 599-606]
- Process - difficult – confusion – changes – deterrents to use [P5 public: 447-495]
- Significance – important relationship & fatal outcome – loss of faith [P10 public: 809-836]
- Significance – personally or closely involved or affected
- Quantity - duration – chronic conditions and long term care [P2 public: 377-425]
- Quantity – frequency – regular user
- Organisation – staffing - therapeutic relationships [P2 public: 848-864]
- Organisation – hurdles and hoops – access to specialists [P8 hospital profs: 1691-1703]
- Type - tests/treatments – fear [P5 public: 399-431]
- Type – emergency or planned/routine treatment
- Type – palliative or curative
- Type – preventative/screening
- Type – long or short term care
- Type - in/out patient setting - ward/hospital atmosphere
- Effect – cure
- Effect - failure/death

Experiences of health care

- Quality of service
- Process
- Significance – who involved; what outcome
- Quantity
- Organisation
- Type
- Effect
- Treatments
- Recency

- Effect – complicate/worsen – side effects
- Effect - ease
- Treatments – painful/pleasant
- Treatments - high or low tech equipment - frightening or awe inspiring
- Recency – recent or past occasion

1.3 Experiences of Health Professionals

- Relationship – continuity - locums' knowledge of individual [P10 public: 1164-1177]
- Relationship – caring [p5 public: 1120-1121]
- Approach – encouraging use – fairness and discrimination – rudeness [P2 public: 556-562]
- Approach - discouraging use, dismissive
- Approach – respectful – positive/assertive [P2 public: 610616]
- Approach – autocratic/authoritative/domineering
- Approach – insensitive – rude [P10 public: 2211-2234]
- Approach – patronising attitude and inefficiency – rushed deterrents to return [P1 non-user telephone data: 61-85]
- Approach – arrogance [P6 hospital & community profs & unqual carers:943-957]
- Approach – managing status – communication [P5 public: 1687-1704]
- Approach – gender differences – communication and compassion [P2 public: 1157-1164]
- Approach - gender – broadmindedness [P2 public: 1228-1237]
- Approach – professional encounter - isolation and fear [P2 public: 1887-1904]
- Approach – caring - encouraging - listening - explaining
- Approach – obstructive - deterrents to use/barriers to access - receptionist [P4 public: 686-707]
- Skill – expertise -
- Skill - effect

Experiences of health professionals
- Relationship – duration; quality
- Approach* – manner, status, gender, professional
- Skill – expertise/effect

2. Experiences of the Professionals: of patients, of assessing/ diagnosing, of providing treatments, of making referrals, of the system

2.1 Experiences of patients

- Difficulties – different expectations – appointment system [P7 community profs: 664-679]
- Inappropriate use – language & misunderstandings [P3 hospital & community profs: 1322-1340]
- Inappropriate or appropriate users - social not health problems - general welfare service - approachable community experts/professionals
- Home visits – relationships & fear [P6 hospital & community profs & unqualified carers: 842-855]
- Socio-economic variations - major and minor illness – caseload [P7community profs: 972-979]
- Individual variations – tolerance of symptoms [P7community profs: 1275-1281]
- Assertiveness - intimidation — chasing up delays and getting referrals [P7 community profs: 1430-1451]
- Faith – varying levels – different services [P6 hospital and community profs and unqualified carers: 927-941]

Experiences of patients
- Difficulties
- Appropriacy of use
- Home visits
- Socio-economic variations
- Individual variations
- Assertiveness
- Faith

2.2 Experiences of health care and other professionals

- Discrimination – follow-up - presumptions of non-compliance
- [P9 primary care meetings: 73-81]
- Misdiagnosis – communication [P6 hospital & community profs & unqualified carers: 1331-1336]
- Communication - team work - liaison and hand-over

Experiences of health care & professionals
- Discrimination
- Misdiagnosis
- Communication
- Willingness
- Motivation
- Involvement
- Effect

- Willingness - home visits - effort and risk
- Motivation - years working since qualified - energy & enthusiasm
- Involvement - detached or involved relationship with patient
- Involvement - long or short term relationship with patient
- Effect - success - previous referrals/treatments
- Effect - failure - previous referrals/treatments

Appendix 2

NHS

Sheffield Health Authority and University of Sheffield
School of Health and Related Research

CONFIDENTIAL QUESTIONNAIRE

Please answer all the questions that apply to you and return this form to the Department of Public Health in the envelope provided. Thank you.

Section A Background Information

A1. How old are you? .... years

A2. Are you **Male** ☐ **Female** ☐

Section B Your General Health

B1. Have you ever been told by your doctor or by any other health care professional that you have:
(Please tick all boxes that apply)

- Anaemia ☐
- Angina or heart disease ☐
- Arthritis or rheumatism ☐
- Asthma ☐
- Bowel problems ☐
- Bronchitis ☐
- Cancer ☐
- Dementia (e.g. Alzheimer's disease) ☐
- Depression ☐
- Diabetes ☐
- Dyspepsia (indigestion) ☐
- Epilepsy ☐
- Eye conditions (e.g. cataract or glaucoma) ☐
- Hearing problems ☐
- Had a heart attack ☐
- A hernia ☐
- Hypertension (high blood pressure) ☐
- Parkinson's disease ☐
- Had a stroke ☐
- Thyroid problems ☐

Section C Using Health Services

Have you used any of the following health services **in the past 12 months** for **your own health?**

For each service you have used, please tick (✓) one box to show the number of times you have used the service. ***If you have not used the service, please leave the line blank.***

	The number of times I have used the service is:		
	1-2 times	**3-6 times**	**7 or more**
Family doctor (GP)	☐	☐	☐
Community nurse e.g. practice or district nurse	☐	☐	☐
Community psychiatric nurse	☐	☐	☐
Advice from pharmacist (chemist)	☐	☐	☐
Dentist	☐	☐	☐
Optician	☐	☐	☐
Chiropody service	☐	☐	☐
Therapy service e.g. physiotherapist, occupational therapist, speech therapist	☐	☐	☐
Alternative medical worker e.g. homeopath, osteopath	☐	☐	☐
Health screening e.g. breast screening, over 75 checks	☐	☐	☐
Accident & emergency department (Casualty)	☐	☐	☐
Outpatient consultation (NHS)	☐	☐	☐
Outpatient consultation (private)	☐	☐	☐
*Inpatient hospital stay (NHS)	☐	☐	☐
*Inpatient hospital stay (private)	☐	☐	☐
*Day case operation (NHS)	☐	☐	☐
*Day case operation (private)	☐	☐	☐

* If you had an inpatient hospital stay or day case operation please say what it was for:-

In the next section we use the words **health professionals** and **health services** to mean any of the people and places listed on this page.

Section D Factors Affecting Use of Health Services

In this section we are looking at factors that might encourage or discourage you from seeking help from health services when you have a health problem or illness.

Please read each statement.

- **If you agree with the statement** please tick (✓) the **"yes I agree"** column then tick (✓) one of the four boxes in the final column to show how often it stops or delays you using health services.
- **If you do not agree with the statement do not tick any boxes in that row.**

Statement	**Yes, I agree**	**This stops or delays me using health services:-**			
		Never	**Rarely**	**Sometimes**	**Often/ always**
I prefer to see a health professional of my own sex	☐	☐	☐	☐	☐
I don't know about all the health services that are available	☐	☐	☐	☐	☐
I feel guilty about using NHS resources	☐	☐	☐	☐	☐
I will not seek health service help if I think I will have to have an operation	☐	☐	☐	☐	☐
I like to see the same health professional every time	☐	☐	☐	☐	☐
I think doctors can talk down to you or be patronising	☐	☐	☐	☐	☐
I don't know what I am entitled to receive from the NHS	☐	☐	☐	☐	☐
I don't expect to have good health	☐	☐	☐	☐	☐
I tend to blame myself if I get ill	☐	☐	☐	☐	☐
I don't always like health professionals visiting me at home	☐	☐	☐	☐	☐
I find it hard to be assertive, or to stand up to doctors	☐	☐	☐	☐	☐

Statement	Yes, I agree	This stops or delays me using health services:-			
		Never	Rarely	Sometimes	Often/ always
I only see a health professional if I think my illness is serious	☐	☐	☐	☐	☐
Doctors prescribe too many drugs	☐	☐	☐	☐	☐
I am frightened to see health professionals because I might get bad news	☐	☐	☐	☐	☐
I am worried about drug side effects	☐	☐	☐	☐	☐
I am frightened of hospitals	☐	☐	☐	☐	☐
I worry that the health professional will think I am wasting their time if there turns out to be nothing wrong	☐	☐	☐	☐	☐
I don't have confidence in my health professionals	☐	☐	☐	☐	☐
My health professionals do not explain things to me	☐	☐	☐	☐	☐
I have had bad experiences of using health services in the past	☐	☐	☐	☐	☐
I know other people who have had bad experiences of using health services in the past	☐	☐	☐	☐	☐
I don't have good relationships with my health professionals	☐	☐	☐	☐	☐
My health professionals don't listen to me	☐	☐	☐	☐	☐
My health professionals don't take me seriously	☐	☐	☐	☐	☐
I don't think my health professionals are skilled enough to treat me well	☐	☐	☐	☐	☐

Statement	Yes, I agree	This stops or delays me using health services:-			
		Never	Rarely	Sometimes	Often/ always
It can be difficult for me to get an appointment to see my family doctor (GP)	☐	☐	☐	☐	☐
My family doctors' (GP) opening hours are not convenient for me	☐	☐	☐	☐	☐
It is hard for me to take time off work to see a health professional if I am ill	☐	☐	☐	☐	☐
It is difficult for me to travel to my family doctor (GP) surgery for an appointment	☐	☐	☐	☐	☐
It is difficult for me to travel to the hospital for an appointment	☐	☐	☐	☐	☐
I have to pay for my prescriptions but cannot afford the cost.	☐	☐	☐	☐	☐
My health professionals always seem very busy and overworked	☐	☐	☐	☐	☐
I am less likely to see a health professional if I think my illness can't be treated	☐	☐	☐	☐	☐
I worry that my health professionals might not keep my details confidential	☐	☐	☐	☐	☐
I have had an illness that I was embarrassed about	☐	☐	☐	☐	☐
I don't have a friend or relative who can help me when I'm ill	☐	☐	☐	☐	☐

Section E About Your Circumstances

E1. What kind of accommodation do you live in? *(tick one only)*

Local authority (council) rented ☐
Housing Association or private rented ☐
Owner occupier ☐
Nursing/ residential home ☐
Other ☐

E2. Is there a car or van normally available for use by you or any members of your household? (Include any provided by employers if normally available for private use by you or members of your household).

Yes ☐ **No** ☐

E3. Which of the following best describes you? *(tick one only)*

Employed or self-employed ☐
Retired ☐
Unemployed/ long-term sick ☐
Other ☐

E4. What is your occupation? If you are currently retired or unemployed, please state your most recent occupation. If you have never had an occupation what is (or was) the occupation of the main wage earner in your household?

Please be as specific as possible:

E5. Are you or anyone else in your household receiving any of the following state benefits? *(please tick all that apply)*

Job seeker's allowance ☐
Income support ☐
State retirement pension ☐
Family credit ☐
Housing benefit ☐
Council tax benefit ☐

E6 What is your ethnic group?

e.g. White, Indian, Black Caribbean etc

Should you feel that answering any of the above questions has drawn your attention to problems which cause you worry or concern, you are advised to contact your GP

THANK YOU VERY MUCH FOR YOUR HELP
Please return your completed questionnaire in the envelope provided
NO STAMP IS REQUIRED

Appendix 3

Comparison of survey respondents and non-respondents

	Respondents %	**Non- respondents %**	**Chi squared**
Sex			
% male	46 (1945/4273)	52 (892/1729)	P<0.001
Age			
% 50-64	52	49	
% 65-74	26	22	
% 75+	22	28	P<0.001
Deprivation			
% Live in deprived wards (Wards with a positive Townsend score)	32	43	P<0.001

Appendix 4

Odds ratios for association of individual characteristics with barriers to using health services

Item	Age 50 to 65yrs		Sex = male		On benefits		Ill-health	
	Crude OR	Adjusted OR* (95% CI)	Crude OR	Adjusted OR* (95% CI)	Crude OR	Adjusted OR* (95% CI)	Crude OR	Adjusted OR* (95% CI)
I only see a hp if I think my illness is serious	1.05	1.26 (1.06-1.49)	1.12	1.28 (1.08-1.50)	1.36	1.50 (1.23-1.82)	1.09	1.28 (1.07-1.52)
I worry that the hp will think I'm wasting their time if there turns out to be nothing wrong	1.19	1.69 (1.44-2.00)	0.80	0.68 (0.57-0.80)	1.14	1.16 (0.96-1.40)	1.15	1.64 (1.38-1.95)
I am worried about drug side effects	1.18	1.75 (1.48-2.06)	0.83	0.73 (0.62-0.86)	1.10	1.08 (0.89-1.31)	1.22	1.98 (1.66-2.37)
My hps always seem very busy and overworked	1.20	1.85 (1.57-2.20)	1.02	1.07 (0.91-1.26)	1.24	1.31 (1.08-1.58)	1.23	2.05 (1.71-2.45)
I like to see the same hp every time	1.04	1.37 (1.15-1.64)	0.80	0.70 (0.59-0.83)	1.37	1.38 (1.14-1.68)	1.27	1.97 (1.63-2.37)
It can be difficult for me to get an appointment to see my family doctor (GP)	2.37	2.62 (2.21-3.11)	0.74	0.73 (0.62-0.86)	0.98	1.09 (0.89-1.32)	1.06	1.34 (1.13-1.59)
I think doctors can talk down to you or be patronising	1.79	2.03 (1.70-2.41)	0.67	0.66 (0.56-0.78)	0.93	0.93 (0.76-1.14)	1.32	1.59 (1.33-1.90)
I prefer to see a hp of my own sex	1.22	1.39 (1.15-1.69)	0.46	0.46 (0.38-0.56)	1.42	1.40 (1.13-1.73)	1.24	1.25 (1.02-1.52)
I don't know about all the health services that are available	1.41	1.59 (1.30-1.94)	0.89	0.90 (0.74-1.09)	1.06	1.06 (0.84-1.34)	1.36	1.52 (1.23-1.87)
I find it hard to be assertive, or to stand up to doctors	1.61	2.04 (1.68-2.48)	0.53	0.53 (0.44-0.65)	1.38	1.34 1.08-1.67)	1.73	1.96 (1.59-2.42)
Doctors prescribe too many drugs	1.37	1.62 (1.33-1.96)	0.95	0.97 (0.80-1.17)	1.36	1.34 (1.08-1.66)	1.51	1.65 (1.34-2.03)
I don't know what I'm entitled to receive from the NHS	1.32	1.56 (1.28-1.92)	1.11	1.14 (0.94-1.39)	1.20	1.17 (0.93-1.47)	1.64	1.82 (1.46-2.27)

(continued)

Item	Age 50 to 65yrs		Sex = male		On benefits		Ill-health	
	Crude OR	Adjusted OR* (95% CI)	Crude OR	Adjusted OR* (95% CI)	Crude OR	Adjusted OR* (95% CI)	Crude OR	Adjusted OR* (95% CI)
I know other people who have had bad experiences of using health services in the past	1.93	2.17 (1.75-2.70)	0.68	0.67 (0.55-0.83)	0.94	0.96 (0.75-1.24)	1.24	1.51 (1.21-1.89)
My hps do not explain things to me	1.42	1.65 (1.36-2.00)	0.96	0.97 (0.81-1.17)	1.17	1.16 (0.93-1.45)	1.48	1.66 (1.35-2.04)
I don't expect to have good health	0.94	1.23 (0.97-1.56)	1.01	1.09 (0.87-1.37)	1.87	1.70 (1.32-2.18)	2.42	2.39 (1.82-3.13)
I am frightened of hospitals	1.18	1.40 (1.12-1.74)	0.64	0.66 (0.53-0.82)	1.52	1.46 (1.15-1.85)	1.53	1.55 (1.23-1.97)
It is difficult for me to travel to the hospital for an appointment	0.60	0.83 (0.67-1.04)	0.82	0.91 (0.73-1.13)	3.13	2.63 (2.10-3.29)	3.17	2.61 (1.98-3.43)
I tend to blame myself if I get ill	1.26	1.57 (1.25-1.97)	1.09	1.14 (0.91-1.41	1.33	1.27 (0.99-1.64)	1.94	2.14 (1.66-2.76)
I don't have confidence in my hps	1.69	1.93 91.54-2.43)	0.91	0.92 (0.74-1.14)	1.19	1.23 (0.96-1.58)	1.32	1.52 (1.20-1.93)
My family doctors' (GP) opening hours are not convenient for me	2.65	2.80 (2.19-1.53)	1.24	1.23 (0.99-1.53)	1.18	1.40 (1.08-1.82)	0.86	1.07 (0.84-1.34)
I feel guilty about using NHS resources	1.26	1.45 (1.15-1.82)	0.80	0.81 (0.64-1.01)	1.00	0.96 (0.73-1.25)	1.54	1.70 (1,33-2.18)
I am less likely to see a hp if I think my illness can't be treated	1.84	2.17 1.67-2.82)	1.01	1.03 (0.80-1.31)	1.10	1.13 (0.84-1.51)	1.49	1.80 (1.37-2.36)
I have had bad experiences of using health services in the past	1.84	2.93 (2.15-3.99)	0.83	0.69 (0.52-0.92)	0.98	0.93 (0.66-1.31)	1.76	2.42 (1.75-3.35)
I am frightened to see hps because I might get bad news	1.29	1.50 (1.15-1.94)	0.82	0.84 (0.65-1.08)	1.36	1.34 (1.00-1.79)	1.45	1.53 (1.16-2.03)

(continued)

Item	Age 50 to 65yrs		Sex = male		On benefits		Ill-health	
	Crude OR	Adjusted OR* (95% CI)	Crude OR	Adjusted OR* (95% CI)	Crude OR	Adjusted OR* (95% CI)	Crude OR	Adjusted OR* (95% CI)
It is difficult for me to travel to my family doctor (GP) surgery for an appointment	0.49	0.68 (0.52 –0.89)	0.67	0.74 (0.57-0.96)	3.32	2.68 (2.07 – 3.48)	3.34	2.55 (1.83 –3.57)
I don't always like hps visiting me at home	0.87	1.04 (0.76-1.41)	1.12	1.18 (0.88-1.59)	1.76	1.66 (1.20-1.30)	1.65	1.56 (1.11-2.19)
I have had an illness I was embarrassed about	1.42	1.75 (1.25-2.44)	1.17	1.21 (0.88-1.66)	1.66	1.67 (1.18-2.37)	1.64	1.78 (1.24-2.56)
My hps don't listen to me	1.20	1.56 (1.21-2.01)	0.99	1.04 (0.81-1.33)	1.1	1.60 (1.22-2.09)	2.29	2.41 (1.79-3.24)
I don't have a friend or relative who can help me when I'm ill	0.76	0.91 (0.74-1.13)	0.71	0.83 (0.67-1.02)	2.10	1.70 (1.37-2.12)	3.32	2.23 (1.74-2.85)
My hps don't take me seriously	1.24	1.62 (1.22-2.14)	0.78	0.81 (0.62-1.07)	1.61	1.48 (1.10-2.00)	2.29	2.43 (1.75-3.38)
It is hard for me to take time off work to see a hp when I am ill	42.9	38.53 (17.03-87.16)	1.69	1.68 (1.27-2.22)	0.25	0.35 (0.21-0.59)	0.46	0.87 (0.66-1.16)
I will not seek health service help if I think I will have to have an operation	0.92	1.13 (0.82-1.54)	0.92	0.96 (0.71-1.30)	1.51	1.38 (0.98-1.93)	1.95	1.91 (1.34-2.73)
I don't have good relationships with my hps	1.39	1.81 (1.28-2.55)	0.95	1.00 (0.72-1.40)	2.16	2.14 (1.51-3.03)	1.81	1.87 (1.28-2.74)
I have to pay for my prescriptions but cannot afford the cost	62.97	64.4 (20.46-202.55)	0.78	0.74 (0.54-1.02)	0.31	0.40 (0.23-0.70)	0.76	1.44 (1.05-1.98)
I don't think my hps are skilled enough to treat me well	1.30	1.53 (1.10-2.12)	1.26	1.30 (0.95-1.78)	1.33	1.32 (0.92-1.89)	1.62	1.77 (1.23-2.54)
I worry that my hps might not keep my details confidential	1.77	2.16 (1.39-3.36)	1.45	1.18 (0.78-1.78)	1.63	1.70 (1.08-2.66)	1.53	1.73 (1.09-2.76)

* Adjusted for the other three factors in the table

95% CI = 95% confidence intervals hp(s) = health professional(s)

Appendix 5

Interview topics by amount of discussion (ranked by number of topic references*)

Interview topic	Number of topic references *
1. Assertiveness/difficulty standing up to doctors	155
2. I only go to see a health professional if I think it's serious	148
3. Confidence in professionals: trust/faith	137
4. Professional's skill/knowledge	102
5. Transport/location	98
6. Prefer to see the same professional	83
7. Problem getting GP appointments	75
8. Anyone to help if ill	73
9. Busy doctors/service	71
10. Explaining	63

* N.B. 33 of the 'total topic references' relate to being a 'set question'

Barriers to service use (interview topic ranked by % 'Delay/stop service use: Yes'/Total topic references)

Interview topic	Delay or stop: Yes quotes/ Total topic references (%)	Total number of topic references **	Number of topic references Delay or stop: Yes;	Number of participants identifying issue as a barrier
1. I only go to see a health professional if I think it's serious	62.8	148	93	30
2. Knowledge of services	40.0	55	22	12
3. Drug side effects	36.2	58	21	13
4. Anyone to help if ill	35.1	74	26	14
5. Transport/location	32.6	98	32	14
6. Being taken seriously	29.0	55	16	9
7. Prefer to see same professional	28.9	83	24	12
8. Busy doctors/service	25.3	71	18	13
9. Worry about wasting professional's time	25.0	52	13	10
10. Convenient opening hours	24.3	41	10	9

Appendix 6

Component elements and co-occurring codes of main barriers (a priori and emergent topic codes)

1. **I only go to see a health professional if I think it's serious** often co-occurs with being a nuisance, fussing/hypochondria, wasting professionals time, busy doctors/ service; involves pain/discomfort; self assess: serious/enduring/severe impact; self assess: self limiting illness; self assess: worried/uncertain; also involves self esteem, assertiveness, nervous/shy, approaches to life; struggle on/give in; expectations/limitations of treatment, urgent/emergency, effect of bad experience, no choice/alternative, getting GP appointments, professional's manner/attitude
2. **Knowledge of services** (NB some overlap/mix in with 'entitlement' coding); involves information- seeking, information sources, approaches to life, good general practice, media, assertiveness, effect of other's experience, check/follow up/preventative, effect of bad experience, criticism of NHS/system, priorities/valuing health/ health care, NHS Direct, preferential/ discriminatory treatment, age, travel/transport,
3. **Drug side effects** often co-occurs with compliance/non compliance, confidence in professional; effect of bad experience, explaining; professionals' skill/ knowledge, criticism of health professional, effect of others experience, denial/dislike illness label/ dependency; medication; (NB sometimes coding muddled in with 'over-prescribing')
4. **Anyone to help if ill** (NB this issue can work in either direction to ↑ or ↓ use); involves circumstances for coping, independence and coping, family, neighbour/friend, living alone, travel, being a nuisance, struggle on/give in, urgent/emergency, no choice/alternative, age,
5. **Transport/location** often co-occurs with circumstances for coping, independence and coping, family, neighbour/friend, anyone to help if ill
6. **Being taken seriously** often co-occurs with listening, effect of bad experiences, time, good health professional, criticism of professional, professional's manner/attitude/approach
7. **Prefer to see same professional** (NB this issue can work in either direction to ↑ or ↓ use); see long term patient/ continuity, effect of bad experience, patient-professional relationship, changing doctor/practice, assertiveness, sex of professional professional's skill/knowledge, caring: compassion/concern/ understanding; professional's manner/attitude/approach
8. **Busy doctors/service** often co-occurs with being a nuisance, wasting professional's time, fussing/hypochondria, only go to see a health professional if I think its serious
9. **Worry about wasting professional's time** often co-occurs with being a nuisance, busy doctors/service, only go to see a health professional if I think it's serious, fussing/hypochondria
10. **Convenient opening hours** often co-occurs with age; employment: hours/shifts/ autonomy