Consumers & Information:

An assessment of the health information needs of mental healthcare users and the role of the Internet.

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Abstract

Background

Significant resources are used to produce health information but little is known about consumer information needs, particularly in mental healthcare. The Internet is increasingly being used, particularly for mental health topics.

Methods

Literature reviews in the areas of health information needs and the role of the Internet in healthcare; in-depth interviews to explore the experience of mental health users with health information and with the Internet; and a population survey to investigate the interview findings and provide generalisable data on information needs.

Results

There is very little existing research in the area of mental health information needs. Much of the literature around consumer use of the Internet for health information focuses on issues of quality and access.

The most common information needs were: what the problem is; what treatments are available; how to help oneself; where to get help from; what has caused the problem; and the future course of the problem. The sources of information considered most accurate and most likely to be used were general practitioners and mental health professionals. The Internet was not ranked highly for accuracy, but was one of the sources likely to be used. The presence of mental health distress was significantly associated with the use of the Internet for mental health information, after adjustment for age, sex and educational level.

Another need is to hear about the experience of others, and this was a particular role for the Internet. This need can be subdivided into 'universality', 'installation of hope', and 'empathy and understanding'.

Conclusions and implications

Mental healthcare users are poorly served by current health information provision. The results provide support for a stronger practitioner-patient partnership. Policymakers should address the needs identified in this work, including the need to hear about other people's experience. Further research investigating health-related use of the Internet is required.

Contents

"Thank goodness I am not as mad as I thought I was."

(Interviewee 2)

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This research project was the idea of the author. The protocol was developed with the supervisors. All aspects of the project were undertaken by the author except where indicated in the text. This thesis is the work of the author.

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1. Introduction & background

1.1 Introduction: consumers, information & the Internet

Three of the main issues in western healthcare at the beginning of the twenty-first century are:

- consumerism, increasing user involvement in healthcare and patient empowerment;
- evidence-based healthcare and the dissemination of evidence-based information;
- the impact of new communication technologies on healthcare, particularly the Internet.

All are having significant impacts on the supply and demand of health services and all are leading to a substantial increase in the amount of information available to healthcare users. Additionally, this triad is contributing to the present challenge to healthcare professions, in particular the medical profession.[1,2]

The importance of information for users of healthcare cannot be overstated.[3] This includes public health information for prevention and health promotion, clinical information on specific conditions, information to support (shared) decision-making, and information on health services, such as performance measures.[4-6] Information is provided in the mass media, in books, leaflets and posters, in the practitioner-patient relationship, by family and friends, and by telephone and the Internet. Despite this growth in both supply and demand of health information, preliminary literature searches conducted prior to starting this project showed that surprisingly little is known about the information needs of healthcare users in general, and mental healthcare users in particular.

Meanwhile significant new developments in health information are taking place. In the UK, the National electronic Library for Health and NHS Direct Online have been launched.[7] There are also multiple health information websites run by commercial and voluntary organisations, and by individuals. At the start of this project Internet use by UK residents was growing by at least 10-15% per month.[8] Advances in digital television will further extend access to Internet-based information and other new developments may include clinical consultations via email.[9] There has been little research into the impact of this revolution in access to health knowledge,[10] in the preliminary literature search I identified a lack of rigorous qualitative work exploring users views and use of the Internet as a source of health information. Studies in this area have tended to focus on evaluating the quality of available information,[11] and on developing quality standards.[12] There has been little work aimed at exploring and understanding the user perspective. Understanding how patients use the Internet has been identified as one of the challenges for the Internet age.[13] Such work is important to identify the needs of healthcare users; to identify the barriers to the uptake of information; and to explore the impact of new developments on the practitioner-patient relationship.

This project focuses on the area of mental health, which is a current priority area for the UK National Health Service.[14] According to the World Health Organisation mental health problems are "among the most important contributors to the global burden of disease and disability".[15] Mental health encompasses a range of conditions, including severe chronic disorders which place a heavy burden on patients and carers. Mental health problems are very common (for example depressive symptoms have a point prevalence in the general population of 13-20%).[16] Many people with mental health problems are not seen by health services, arguably increasing the importance of the provision of health information in this area.[17]

1.2 Background

1.2.1 National policy context

In the UK, health information is a key issue for the NHS. Indeed, it has its own NHS Information Authority, shortly to be reconstituted as part of the Information Centre for Health and Social Care. The NHS Executive emphasises the importance of patient partnership in the future of healthcare in the UK, and the requirement for better informed patients.[18] The Patients' Charter (1991) included the right to information on treatment,[19] and the work of both the NHS Centre for Reviews and Dissemination and the Cochrane Collaboration include the dissemination of information to patients. One of the principles of the 1999 NHS information strategy document, Information for Health, is to provide the public with accurate and up to date information about health and health services.[20] Launched in 1998, the National Service Framework for Mental Health highlighted the importance of mental health service provision and announced a national Mental Health Information Strategy which states that *"people with mental health problems and their families, friends, carers and the public need information to: help them understand their illness and difficulties; explain what types of treatment and other help is available; tell them where and how they can get help in their locality; and promote mental health."*[21]

At the same time, NHS resources, including practitioner time, are under increasing pressure. The average length of a general practice consultation is nine minutes.[22] A better understanding of user information needs may lead to improved use of scarce resources.

1.2.2 Health information & individuals

Consumer health information is of increasing importance. Patients want more information about medical conditions and treatments, and users are becoming more involved in healthcare and in shared decision making.[6,23] Information services such as NHS Direct in the UK have been established to manage demand for health services,[24] and numerous independent sources of health information have been established on the Internet.

Coulter and colleagues describe four purposes of health information for patients:

- to prevent disease;
- to promote self-care;
- to support treatment choices;
- to improve the effectiveness of clinical care.[6]

Buckland describes four sources of consumer health information: (1) information provided as part of clinical management; (2) information services and helplines; (3) self-help literature and mass media; and (4) informal sources.[25] Traditionally, providers have delivered information to patients in the first of these: the practitioner-patient interaction. A survey carried out for the UK Office of Health Economics in 1994, found that the three commonest sources of health information for a representative sample of the UK population aged 15-64, were their general practitioner, newspapers and magazines, and television.[26] These three were also ranked as the most important sources. Surprisingly, information from family or friends rated fairly low on both lists. The same survey found that people in higher social classes were more likely to use a variety of sources than those in lower classes. A more recent survey, undertaken in 1999, of the Californian population, found that the public most often consulted their physicians for information, followed by family or friends, and then advice books.[27] These sources were more popular than the Internet, telephone advice lines and newspapers or magazines. The Californian survey found that the most trusted sources of health information were (in order) physicians, family or friends, and newspapers or magazines. These were followed by advice books, the Internet, and finally telephone advice lines. Most recently a study conducted in eight European countries again shows that doctors, and in particular general practitioners, are widely regarded as the most trusted source of health information.[23] The views on other sources vary by country. The UK arm of this study found that patients will also seek out information from a variety of supplementary sources, including leaflets, family and friends, and the mass media. This information particularly related to health service issues (such as waiting times, qualifications of specialists, and success rates of procedures) and details of procedures and medications (including side effects).[23]

Health information is therefore produced by a multitude of organisations, in various forms, and for several purposes. However it is notable that very few organisations have identified the information needs of users before producing materials.[28]

Information is particularly important in the area of mental health problems as they are common, are associated with considerable stigma and isolation, and those affected often do not present to health services.[16]

1.2.3 Health information & society

For some commentators, "informatisation" is now the defining feature of our age,[29] and information and its management are undoubtedly playing an increasingly important role in society. Some authors have gone so far as to forecast an information revolution with an impact to parallel that of the agricultural and industrial revolutions.[30,31] Others describe postmodern or postindustrial information ages.[32] In these critiques, the impact of new media and the Internet is often compared to that of the printing press on modernity. Knowledge and innovation rather than capital and labour are seen as the transforming resources of this information society,[33] with the Internet replacing the land. It is characterised by a predominance of information-based work, with large volumes of information flow, globalisation, and a new "information poor" underclass.[34]

Webster identifies five approaches to defining this new society.[32] This analysis is summarised in Table 1.1. Webster criticises each of these approaches as underdeveloped and imprecise. However there may be merit in considering elements of each of these categorisations in the concept of a new information society.

Table 1.1 Five ways to define the new information society.[32]

Approach	**Defining characteristic**
Technological	Spectacular technological innovation predominates
Economic	Economy based on knowledge goods
Occupational	Predominance of occupations based on information
Spatial	Dramatic changes in the organisation of time and space
Cultural	Massive expansion of the informational content of everyday life

Other theorists challenge the extent to which society is actually changing, and see the 'information age' as being another version of industrial capitalism, dominated by large multinational corporations, mass unemployment and economic and information inequity.[29]

Between these polarised views, Giddens describes an information-rich late-modern society, in which both healthy and ill individuals must negotiate and evaluate a confusing mass of competing messages.[35] The Internet facilitates cheap, accessible and widespread dissemination of information. In the area of health, this can empower individuals to become more involved in their own healthcare and to challenge expert opinion. The professional dominance of medicine is challenged by the "exposure of esoteric knowledge to public gaze", and by the availability of information on alternative approaches to health.[1] There is also increased awareness of patients' rights and reports of the fallibility of the medical profession, both as individuals,[36] and at a collective level in official performance data.[2,37]

1.2.4 Health Information & the Internet

"The Internet is at once a world-wide broadcasting capability, a mechanism for information dissemination, and a medium for collaboration and interaction between individuals and their computers without regard for geographic location."[38]

This quote highlights the fact that the Internet does not fit one simple definition. Technically, the term refers to an interconnected network of computers that exchange data via standard protocols. However this definition does not convey the dynamic, evolving nature of the Internet as a communication medium, nor its social impact on a global scale.

The Internet has certainly developed at a remarkable rate. It is estimated that 59% of Britons aged 14 or over currently use the Internet.[39] The average Briton has access to the Internet in at least two of: their home, work, school or library.[39] More than 11 million UK households have Internet access at home (46% of all households).[40] In 2002 the Office of National Statistics reported that the number of UK households online had increased by 18% in the previous year and had more than doubled in the preceding three years.[40] There are 420 million Internet users worldwide.[41] Estimates of the size of the world-wide-web vary, but it is likely that there are more than 10 billion pages of information,[42] and it is estimated that approximately 2% of all websites are related to health.[43] Based on these assumptions, there are now more than 200 million health-related web pages.

Difficulties that may be caused by the growth in online consumer health information include the problems of ensuring data confidentiality, of information quality control, of raising unrealistic expectations and demands on resource-limited health services, and of a possible increase in medical litigation.[44]

Coulter describes how the Internet is greatly increasing access to health information, but warns that much of the information is inaccurate or misleading, and that non-specialists face difficulties in identifying the best information.[45] There are concerns that there may be increased demands for inappropriate medical interventions.[23] There have been reports of the phenomenon of 'cyberchondria' or 'Internet-printout syndrome' which describe the bringing of Internet information to the consultation,[46] and its potential role as a third party in the practitioner-patient relationship.[47] There are also concerns about inequitable access to health information provided by this new medium.[23]

Robinson summarises the advantages of interactive health communication applications (including the Internet) as being: widespread availability and widespread dissemination, anonymity, peer information exchange and support, use as a tool to manage demand for health services, and to promote self-care.[48]

Accessing health information is one of the most frequent reasons for using the Internet.[49] Surveys consistently show that 60%-80% of world-wide-web users have used it to obtain health information.[50-52] A Harris poll found that of the 75% of USA adults with Internet access using the Internet to find health information, 21% do so at least 'often'.[51] Two-thirds of those using the Internet to find health information claim it has some impact on their healthcare decisions.[52] Consumers value the anonymity, convenience and quantity of information.[53]

Much of the limited evidence as to who the consumers of online health information are, and what they are looking for, comes from United States market-research surveys and web-usage statistics. Women are more likely than men to seek healthcare information online,[54] and the highest proportion of usage is in those aged between 30 and 64 years old.[53] Use of the Internet for health information declines with age.[55,56] Despite the much-discussed "digital divide" between the higher-income, more-educated "have-nets" and the lower-income, less-educated "have-nots," there has been little evidence of differences in online health information seeking by income group once they have Internet access.[57,58] Individuals most commonly access the Internet at home (76% of users do this), at work (35%), and at academic institutions (10%).[59] Newer developments including interactive digital television, web kiosks, mobile phone Internet access and cheaper home broadband connections, will further increase the availability of health information.

Interestingly, mental health issues appear to dominate as the most popular online health topics. In one US study, depression, bipolar disorder and anxiety problems accounted for 42% of the use of the Internet to find health information,[60] while another US survey showed that 21% of Internet users had used it to find information related to depression, anxiety or stress.[61]

1.2.5 Terminology

1.2.5.1 Consumers

Consumers have been defined as *"patients, past patients, prospective patients, long-term users of health services, relatives caring for patients or users, and people who speak for these primary consumers through local and national support and activist groups, community organizations such as community health councils, local and national coalitions of such groups, and international networks"*.[62] Terminology in this area is problematic,[63] and none of the alternative terms used to describe people who interact in some way with health practitioners or services (for example patients, users, clients) are value-free.[64] The term consumer was a pragmatic choice for this research, as information can be viewed as a product that is consumed, and 'consumer health informatics' is the current accepted term for work in this area.[65]

1.2.5.2 Information

Although information is a term that most people understand, it is hard to define. *A Dictionary of Epidemiology* describes information as *"facts (i.e. data) that have been* *arranged and/or transformed to provide the basis for interpretation and conversion into knowledge".*[66] There are two problems with the implicit assumptions of this definition, firstly that information always has a factual basis, and secondly that information is the intentional product of an organised process of production. In this project I am taking a wider definition of information to encompass anything that can be used to construct knowledge, whether or not it was created with that intention. My ontological position is one of subtle realism,[67] whereby information can exist independently of one's beliefs and understandings, but is only of use when the meaning is socially constructed as knowledge.

1.2.5.3 Mental health

I have used the definitions provided by the 2001 report on mental health from the US Surgeon General. This report describes mental health as *"a state of successful performance of mental function, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and to cope with adversity".*[68] Mental disorders are defined as *"health conditions that are characterized by alterations in thinking, mood, or behavior (or some combination thereof) associated with distress and/or impaired functioning".*[68] Mental health problems are signs or symptoms which do not have the intensity or duration to be classified as a disorder.

The report of the Surgeon General acknowledges that mental health is determined by individual values and bounded by culture. It is also difficult to divorce terms such as mental health and mental disorder (and illness) from their political context. Mental healthcare, the practice of psychiatry and the existence of mental illness have been questioned by various commentators as doing no more than providing an agency for the control of deviants in society,[69,70] and variations in diagnostic and management practices over time, and between cultures, support this argument. Others defend the advantages of a medical model of mental illness as conferring the rights and responsibilities of the sick role, and avoiding moral judgements.[71] In this research a pragmatic decision was taken to seek volunteers for interviews with experience of mental health services, rather than make any formal assessment or diagnosis regarding mental health. Where I refer to an individual's experience of mental disorder, this is based on self-reporting. Nevertheless, the findings should be considered in the context of how mental healthcare is practised in the UK at the start of the twenty-first century.

1.2.5.4 Internet

A technical definition of the Internet was given in Section 1.2.4 above. In this research the colloquial understanding of the term 'Internet' has been used, to describe the universe of webpages as viewed in a browser window, as a synonym for 'world-wide-web'. Electronic communication via email is a function of the Internet, but was not the focus of this study.

1.3 Plan of research

There are significant gaps in the knowledge base in relation to the health information needs of mental health users. The following research questions were identified:

With regard to the users of mental healthcare:

- What are their health information needs?
- What are their attitudes towards different sources of health information?
- What is the role of the Internet in mental healthcare information provision, from

the patient perspective?

Both qualitative and quantitative approaches have been used in order to explore and identify information needs and behaviour, and to gather generalisable data on these.

There are three stages to the research reported here. In the first stage [**Chapter 2**], I examined three questions using a critical literature review: what are the health information needs of consumers, particularly with regard to mental health; what are the issues for the Internet and consumer health informatics; and what models of information seeking and health communication could be used to explain the role of the Internet in providing health information?

In the second stage [**Chapter 3**], I used a qualitative approach. I undertook in-depth interviews with a purposively selected group of individuals who had experience of mental health problems, to explore their mental health information needs, and their attitudes towards sources of information. A qualitative approach allows the detailed exploration of the attitudes, beliefs and needs of information users, from their own point of view.[72] It was an appropriate approach for the first stage of the study as little is known in this area, and exploratory qualitative work was necessary to gain a better understanding of this topic. The research was inductive and grounded, and allowed the generation of hypotheses to be tested by the third stage of the study.

In the third stage of the study [**Chapter 4**], a descriptive cross-sectional survey was undertaken to allow more quantifiable and generalisable conclusions to be drawn regarding the mental health information needs of the general population, their attitudes and behaviour towards information sources, and the role of the Internet in meeting these. The cross-sectional survey design was informed by the findings of the literature review and qualitative interviews.

Finally, I have provided a critical summary of my findings and have drawn out the implications of this work for policy, practice and further research [**Chapter 5**].

Specific objectives of this project are shown in Box 1.1

Box 1.1 Objectives

1. To review the literature on the health information needs of healthcare users and consumer use of the Internet for health information, with special reference to mental health information.

2. To use in-depth interviews to investigate sources of information and the attitudes, beliefs and behaviour of individuals with experience of mental health problems with regard to health information and the Internet.

3. To undertake a descriptive, questionnaire-based cross-sectional survey to assess mental health information needs and the use of the Internet.

4. To analyse the data obtained, and to discuss the implications for policy, practice and future research.

5. To disseminate the findings to health professionals and the public via publications in the medical and lay press.

2. Literature review

2.1 Introduction

Based on my preliminary literature searches, my prior knowledge and discussions with the advisory group, three questions were identified for the literature review:

- What are the health information needs of consumers, particularly with regard to mental health?
- What are the issues for the Internet and consumer health informatics?
- What models of information seeking and health communication can be used to explain the role of the Internet in providing health information?

In this chapter I describe how the first and second of these topic areas were reviewed separately through systematic literature searching and identification of relevant articles (Section 2.2 and Section 2.3). I will then describe how the third topic area was reviewed through examination of theoretical literature identified through database searching, textbooks, and contact with experts in the relevant disciplines (Section 2.4).

Systematic searches of electronic databases were carried out in January to March 2001 and follow-up searching was conducted in August to October 2003 in order to identify studies which would contribute significantly to updating the material in this thesis. For each topic the same electronic bibliographic databases were searched. These are shown in Table 2.1. Databases were selected to cover the biomedical and allied health literature (Medline, Embase, CINAHL, PsycINFO, Cochrane Library, Best Evidence), the social science literature (IBSS, Sociofile), grey literature (SIGLE, HMIC) and the information sciences (LISA). Search terms used are displayed for each topic area in the relevant sections. In addition to standard citation searching of these databases, forward citation searching using a key (sentinel) article was carried out using the multidisciplinary Web of Knowledge databases (Science Citation Index Expanded and Social Science Citation Index, both 1981-present). This involves identifying a key early article on a topic area and using the "cited reference search" function to find subsequent published articles which referenced it.

Table 2.1: Bibliographic databases searched

Database	Date searched from (usually from database inception)	Description
Medline	1966	Comprehensive for main biomedical journals but has a North American bias and not all informatics journals included.
Embase	1980	Better than Medline for European biomedical journals and informatics journals.
Cumulative Index to Nursing and Allied Health Literature (CINAHL)	1982	Coverage of literature from nursing and the allied health professions.
PsycINFO	1967	Database for mental health and related areas. Includes many journals not indexed on Medline.
International Bibliography of Social Sciences (IBSS)	1951	One of the largest and most comprehensive social sciences databases.
Sociofile (incorporating Sociological Abstracts)	1974	Sociological literature. In addition to journal coverage, it indexes conference papers, dissertations, monographs & books.
System for Information on Grey Literature in Europe (SIGLE)	1976	Grey literature database including official publications, discussion and policy papers, technical or research reports, dissertations, and conference papers.
Health Management Information Consortium (HMIC) contains DH-DATA, Kings Fund, and Nuffield/Helmis databases	1983	Catalogues a range of UK grey literature, particularly policy documents.
Library and Information Science Database (LISA)	1981	Database for the information sciences.
Cochrane Library (Cochrane Systematic Reviews, Database of Abstracts of Reviews of Effectiveness, Cochrane Controlled Trials Register)	1996	Collection of high quality primary and secondary studies. Useful for identifying intervention studies.
Best Evidence (incorporating ACP Journal Club)	1991	Evidence-based health database containing critically appraised abstracts and commentaries.

In addition, the reference lists of key articles were searched and a hand search of key journals* was carried out for the last five years. The Internet was searched in 2001 using Google, AltaVista and NorthernLight search engines which were recognised at the time as having greatest coverage of academic sources, and this search was repeated in 2003 using Google. Requests for information (particularly for grey literature) were sent to academic mailing lists in 2001. Contact was also made with experts and relevant organisations by telephone, email or in face-to-face meetings. These included meetings with experts at UK academic centres with Health Informatics departments (including University College London, City University, Plymouth University, Manchester University, Sheffield University), and correspondence with the Centre for Global eHealth Innovation at the University of Toronto and the Department of Cybermedicine Research at the University of Heidelberg. I also met with policy experts at the UK Department of Health and the NHS Information Authority.

2.2 The health information needs of consumers

2.2.1 Method

The literature identification strategy outlined in Section 2.1 was followed. Box 2.1 indicates example search terms used for health information needs in the electronic bibliographic database searches. Box 2.2 indicates the search terms applied to limit the search to the area of mental health. The search terms were developed through exploring potentially relevant MeSH terms and keywords with each database and examining the

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* Bulletin of the Medical Library Association, Health Expectations, Health Information and Libraries Journal (formerly Health Libraries Review), Human Communication Research, Journal of Health Communication, Journal of Medical Internet Research, Journal of Online Behavior, Patient Education & Counseling, Social Science and Medicine, Sociology of Health and Illness.

MeSH coding of relevant articles. The literature review described here is based on a systematic search undertaken in 2001. New studies published since that time which contribute significantly to knowledge in this area have been added to this review.

Box 2.1 Search terms used for health information needs (MeSH and equivalent in capitals; * indicates truncated term)

"Need" concept e.g.
HEALTH-SERVICE-NEEDS-AND-DEMANDS
NEEDS-ASSESSMENT
Need*
AND
"User" concept e.g.
Consumer*
Patient*
User*
Carer*
AND
"Information" concept e.g.
Informati*
Communicat*

Box 2.2 Search terms used to limit to mental health studies all combined with OR operator (MeSH and equivalent in capitals; * indicates truncated term)

MENTAL-HEALTH
MENTAL-ILLNESS
MENTAL-DISORDER
PSYCHIATRY
PSYCHOLOGY
DEPRESSION
SCHIZOPHRENIA
ANXIETY
DEMENTIA
Mental*
Psych*

2.2.2 Results

2.2.2.1 What are information needs?

"People need information about health and healthcare in many different circumstances. Patients want to know more about what is wrong with them and how they can best look after themselves. Carers or relatives or friends seek information on behalf of others. Interested members of the public wish to contribute to the debate about local healthcare

services. The provision of public information should be sensitive to the different needs of different groups and the various ways people seek and use health information." Information for Health, an Information Strategy for the Modern NHS 1998–2005.[20]

The NHS information strategy is typical of the literature on consumer health information needs – it accepts that users should be given information and more of it, but provides no evidence of the benefit of doing this.[20] There is a strand of thought highlighted by the user involvement/patient empowerment literature, that anything that gives users more information is desirable of itself, i.e. *a good thing*. The discipline of information seeking research which has its roots in the disciplines of information science and communication studies supports this approach. Health information needs are conceptualised, as summarised by Nicholas, as arising "when a person recognises a gap in his/her state of knowledge and wishes to resolve that anomaly".[73] This definition depends on the *recognition* of the need by the individual - i.e. a *felt need* in the health services research categorisation - need is only a need when it is recognised. It also includes the satisfying of curiosity, with no requirement to provide (health) benefit for the individual, filling a knowledge gap is sufficient.

Numerous studies show that consumers *want* information,[5] and that lack of good quality information is the most frequent complaint of consumers.[74] Some studies suggest that consumer empowerment is achieved by information giving.[75] "Information, communication and education" are said to constitute one of the dimensions of how both inpatients and ambulatory patients define quality of care.[76] But if healthcare need is defined as 'ability to benefit', do users *need* information? Is the fact that they want and demand it reason enough for a health service with limited resources to provide it?

What sort of health gain benefits might be expected from health information? An increase in self-care; more appropriate use of the health service; and increased effectiveness and efficiency have all been suggested. Studies have shown that information giving can (but not always) increase patient concordance;[77,78] reduce length of stay;[79] reduce anxiety;[80] and a systematic review found that more effective practitioner-patient communication improved physiological outcomes in 16/21 studies.[81] The Toronto consensus statement on doctor-patient communication concluded that lack of information can lead to patient anxiety and dissatisfaction, and patients with serious illness have lower levels of psychological distress when they perceive themselves to have received adequate information.[82] However the evidence from one particular area of information giving, that of shared decision-making, suggests that while knowledge is improved and patients are stimulated to become more involved in decision-making, decision aids have little effect on satisfaction and no consistent effect on outcomes.[83]

Olszweski and Jones see two main motivations for providers giving information.[4] Firstly to avoid the consequences of not giving information (increased patient anxiety, reduced compliance, and increased chance of litigation) and secondly to create more effective and efficient services.[4] This analysis contends that the providers are more concerned with benefits to services, than to patients. This is also an argument in the shared decision-making literature[84] - that evidence-based patient choice has utilitarian aims, and is not just to foster user involvement or empowerment. If consumers learn about and choose the most effective treatments, then this will benefit services and reduce litigation. This leads to a possible tension – between effective and efficient healthcare on the one hand, and patients' further demands for more information which does not have obvious health gain or other benefit for the provider.

2.2.2.2 The health information needs of health service users

The research on the health information needs of users is characterised by several tendencies. It has generally been of low quality with small, often non-peer-reviewed studies which have assessed the expressed demands of current patients rather than needs more generally.[6] In addition, the North American literature is dominated by the needs of users for information to help them choose healthcare providers, which has little relevance to a UK/NHS context. Most of the work has been undertaken in the area of cancer information, with some on patients undergoing surgery.[25] Practically no work in the area of mental health information needs was identified. It is likely that information needs will differ by disease type, and that the findings from one specific area of healthcare cannot necessarily be generalised to other areas that have their own particular issues.

Three reviews of user health information needs (not restricted to one disease area) were identified.[4,5,25] However none was systematic or peer-reviewed. In the most recent and comprehensive of these, Olszweski and Jones summarised the reasons for patients seeking health information.[4] These are listed in Box 2.3.

The implication from Box 2.3 is that the motivation for seeking health information (which in general relates to clinical matters of diagnosis, prognosis, treatment, investigations)[4] is frequently not to make an informed choice, but because in some way information helps patients manage the social, psychological or financial burden of illness.

Box 2.3 The reasons for patients seeking health information (from Olszweski and Jones, 1998)[4]

1. To legitimise their illness and reason for not functioning socially/physically/economically. Information gives the illness a name and legitimises the symptoms as illness. Patients therefore avoid being seen as a hypochondriac and/or a waste of health resources.
2. For reassurance that their doctor has listened and understood and applied his/her expert knowledge.
3. To enable patients to make the necessary mental adjustments to their condition.
4. For patients to learn what agents should be avoided that would cause/worsen their symptoms/illness.
5. To enable people to contribute to their own treatment and care through following treatment regimes.
6. For people to interpret the significance of their symptoms and know who to consult.
7. To allow individuals to plan their social and economic functioning around their symptoms and treatment; and access material and financial assistance.

This analysis is supported by the other reviews in this area,[5,25] and by a subsequent focus group study which found that patients need information not only to understand their condition, the prognosis and the likely tests and treatments, but also to learn about available services and sources of help, to gain reassurance and help to cope, to help others understand and to give legitimacy to their help-seeking and individual concerns.[6,28] This study also identified the need for information to assist self-care, to identify further information and self-help groups and to identify the 'best' healthcare providers.[6,28] The list of needs identified in this qualitative study, which the authors see as pre-requisites for consumers taking an active role in their healthcare, is shown in Box 2.4, and echoes many of the summary points provided by Olszweski and Jones.

Box 2.4 The reasons for patients seeking health information (list from Coulter, 2002,[64] citing Coulter, Entwistle and Gilbert, 1999)[28]

1. To understand what is wrong.
2. To gain a realistic idea of prognosis.
3. To make the most of consultations.
4. To understand the process and likely outcomes of tests and treatments.
5. To assist in self-care.
6. To learn about available services and sources of help.
7. To provide reassurance and help to cope.
8. To help others understand what they're going through.
9. To legitimise help-seeking and concerns.
10. To identify further information and sources of support.
11. To identify the 'best' healthcare providers.

Another need identified by Thornton, writing as a consumer herself, is the need for information in order to contribute to wider health service debates, for example around population screening.[74]

A recent population survey and focus group study across European countries, undertaken by the UK Picker Institute and collaborators, showed that there are widespread demands for more health information, and for more of a partnership between patients and practitioners.[23] Patients indicated a need to have more information to allow them to make choices regarding treatment options and choice of healthcare provider. This European study shows that there are gender differences in health information behaviour, with women more likely to seek and express a desire for health information. This study showed that patients often exchange experiences with other patients.

Cancer is the only health topic area with a significant body of specific information needs research. A methodologically rigorous review of the literature on information, communication and shared decision-making in cancer care, undertaken for the NHS Centre for Reviews and Dissemination, found that the most common complaints made by patients with cancer relate to communication and information.[85] This review of the cancer information literature identified the needs of patients for information tailored to the patient's educational background, cultural orientation and general level of comprehension. They found that patients find personalised information more useful than generic, and recommended that the health service should help patients to access and understand relevant and appropriate information.[85]

In a review of the literature on the information needs of women with breast cancer, Rees *et al.* found that information needs change over time.[86] At the time of diagnosis the needs are for information on the likelihood of cure, the treatment options, and the stage of disease. At the start of treatment women need additional information – on the likelihood of recurrence, and about further investigations. Later on, information is required on self-care and the risks of cancer in family members. Leydon *et al.* also found that information needs of patients with cancer vary with the stage of illness, and that patients prefer information which is personalised.[87] They identified three shared attitudes of patients which limit their demand for information: faith in the doctors' expertise, a feeling that hope can be sustained by avoiding bad news, and a charitable recognition that with limited resources, information is inevitably scarce. This study showed that men were less likely to access additional information, or use health information services.[25]

At the start of this research project there had been very little research on Internet-based health information needs. Most of the published articles in this area were either based on opinion or were extrapolations from the findings of studies on general health information needs. One exception was a semi-structured interview study with representatives of patient associations in Sweden which identified four characteristics of patients' online information needs: (1) they are heterogenous; (2) the information should be of high quality; (3) the information must be easily accessible (including readability and comprehension); and (4) patients expressed a desire to share experiences with each other.[88] The authors acknowledge that this was just a small preliminary study, with only seven interviewees.

2.2.2.3 The health information needs of the users of mental healthcare

There was very limited literature in this area. The NHS Mental Health Information Strategy identifies that users and carers are *"commonly unaware of the range of treatment and support opportunities available",*[21] but this is based on expert opinion rather than empirical research. Most statements on mental health information needs are based on the views of professionals rather than on empirical work. In devising the Camberwell Assessment of Need for people with serious mental illness in the community, an instrument designed to support the general medical and social assessment of severely ill individuals, Slade *et al.* identified "information about condition and treatment" as one of 32 domains of general need.[89] There is some evidence that, as for other areas of healthcare, significant numbers of psychiatric patients report dissatisfaction with the current level of mental health information provision.[90,91,91,92]

Both psychiatric patients and their relatives benefit from learning about mental illness and how to cope with it,[93] but the specific interests of these consumers remain unclear. I identified three published studies which had considered mental health information needs from the user perspective, in a Western context. In a qualitative interview study of 33 inpatients with bipolar affective disorder, Pollack identified six conceptual areas of information need, concerning: (1) self management of the disorder; (2) understanding the disorder; (3) managing daily life; (4) living in society; (5) relating to others; and (6) relating to self.[94] A US study used a questionnaire survey to question a sample of patients with schizophrenia and affective disorder and their relatives about their specific educational needs. They found a widespread desire among patients and relatives to learn more about psychiatric illness and about strategies for coping with common problems.[95] In a small retrospective analysis of case-notes, Llewellyn-Jones *et al.* investigated the questions psychiatric outpatients asked at the end of consultations.[96] Of course, this will be influenced by the quality of the preceding interaction. The authors found that most questions asked by this population (who tend to have chronic conditions) related to medication issues - about stopping, reducing or side effects.

Finally, I identified an unpublished North American doctoral dissertation which describes the design of a website for people with depression.[97] As part of this study the author asked visitors to the website to complete an online questionnaire concerning the information they were seeking. This was therefore a self-selected sample of Internet users, who were already seeking information from a website, asked to identify the topics of most interest to them. The results show that among all respondents, the topics of greatest interest were: 'causes of depression'; 'recent research on depression'; and 'helping yourself if/when you are depressed'. The topics of greatest interest to the subgroup of people who were seeking information about themselves were 'helping yourself if/when you are depressed'; 'feelings of hopelessness/helplessness'; and 'causes of depression'.

There was no literature on the mental health information needs of the vast majority of service users who have mild to moderate mental health problems in the community.

2.2.3 Conclusions: what is not known, what questions need answering?

There has been work in the area of user health information needs, but in general it has focussed on user demands, is of poor methodological quality and mostly has been concerned with cancer information. There are suggestions of differences in information needs by personal characteristics such as gender but this has not been fully explored in the research to date. The very limited research undertaken into mental health information needs suggests that significant numbers of consumers are dissatisfied with information provision, and in particular several areas of need have been highlighted but not explored, including information on self-help and on treatments.

It was clear from this review of the literature that the research question "what are the health information needs of mental health users?" has not been answered.

2.3 The Internet and consumer health informatics

"The Internet is transforming health care. It is creating a new conduit not only for communication but also in the access, sharing, and exchange of information among people and machines." Jadad, 1999.[13]

2.3.1 Method

The literature identification strategy outlined in Section 2.1 was followed. Example search terms used in the systematic search of electronic databases are shown in Box 2.5. The broad strategy was: "e"-concept AND ("user" concept OR "health communication" concept). The search terms were developed through exploring potentially relevant MeSH terms and keywords with each database and examining the MeSH coding of relevant articles.

Box 2.5 Example search terms used for the Internet and consumer health informatics. MeSH and equivalent in capitals. * indicates truncated term.

"e"-concept e.g.
INTERNET
ELECTRONIC-MAIL
E-MAIL
ELECTRONIC-COMMUNICATION
COMPUTER-APPLICATIONS
COMPUTER-SEARCHING
COMPUTER NETWORK
COMPUTERS
MEDICAL-INFORMATICS
ehealth
e-health
Internet
email*
e-mail*
worldwide-web
www
cyber*
comput*
virtual
AND
"user" concept e.g.
CONSUMER
CONSUMER-ATTITUDES
CONSUMER-BEHAVIOR
consumer*
user*
patient*
OR
"health communication" concept e.g.
INTERPERSONAL-COMMUNICATION
MEDICAL-INFORMATION
PATIENT-INFORMATION
INFORMATION-SEEKING
EXPLORATORY-BEHAVIOR

2.3.2 Thematic coding of identified literature

Following the searches I reviewed approximately 10000 titles and/or abstracts for relevance. From these I identified 1300 articles in the broad area of the Internet and health information. In this review I consider issues related to health information provided for consumers on the Internet. I do not address wider ehealth issues such as electronic patient records or telemedicine.

The abstracts or full text versions of all 1300 articles were read and thematic categories identified. This process was undertaken with collaborators at Warwick University (Professor Margaret Thorogood, Dr Frances Griffiths, and Dr Pamela Lowe). Three collaborators each read a randomly selected sample of 50 to 100 abstracts and independently identified themes. This process was supported by the use of Procite citation management software which facilitates the coding of articles into 'groups'.[98] The four of us then met to discuss and agree our coding. I took the lead role in this process.

There was good consistency in the themes identified and broad agreement was reached that the literature in this area can be considered under five main headings:

- Quality of online health information
- Consumer use of the Internet for health information
- The impact of the Internet on the practitioner-patient relationship
- Virtual communities and online social support
- The online delivery of information-based interventions

Having reached joint agreement on coding, I reviewed the literature identified under each theme.

2.3.3 Results

Each theme will be discussed in turn.

2.3.3.1 Quality of online health information

Much of the research into electronic consumer information has addressed the issue of information quality. Indeed there seems to be an obsession with the quality of health information on the Internet in the biomedical literature. With colleagues, I carried out a systematic review of the literature in December 2001. I jointly undertook paper identification and data extraction with the first author (Dr Eysenbach). We included studies where the authors had searched the Internet for information on a specific health topic, and had then evaluated the quality of the information found in a systematic way (for example, a scoring system based on characteristics such as medical accuracy, currency, and readability). Seventy-nine studies in eight languages met our inclusion criteria.[99-183] We found that the studies varied markedly both in their methodological rigour and in their findings. Many studies were themselves of poor quality, evaluating small numbers of webpages. Few authors had used more than one quality assessor or had tested the reliability of their measures. Most strikingly only three of the 79 studies showed any evidence of attempting to replicate what consumers actually do when they search for information. For example, it is unlikely that many consumers would use search terms such as “gastroschisis and omphalocele" or "pectus excavatum”,[107] or “ambiguous genitalia”.[168]

Our findings showed that the quality of information had been evaluated in various ways, studies either used formal evaluative tools or compared information with that from other sources (although only rarely with an evidence-based gold-standard). The majority of authors came to negative conclusions about the quality of online health information. The main criticisms were of lack of completeness and difficulty in finding good quality sites. Completeness was often taken as a proxy for, or as an element of, accuracy. However, as we highlighted in the article, completeness is a criterion of questionable validity. Websites may intentionally focus on a single topic rather than aiming for comprehensiveness, possibly providing links to further information, but may therefore score low for a quality criterion based on completeness despite providing reliable information on a narrow area. Authors have also highlighted the lack of an editorial review process and the scarcity of information that is explicitly evidence-based.[112,113] Others have warned that inaccurate information can sometimes be deceptive,[184] or even harmful.[185]

I repeated the systematic searching and review of abstracts for this thesis in January 2004 and found a further 82 peer-reviewed studies published since we completed the original review which would fit our inclusion criteria.[186-267] The majority of these studies are still small, of poor quality, continue to use a variety of methods to measure quality, and rarely make any attempt to replicate consumer information behaviour. At most, what these studies demonstrate is that the quality of online health information varies. There are now over 160 studies which reach this not very surprising conclusion.

It is clear that many of the shortcomings detected are not specific to the Internet and are also present in other media. Coiera questions whether there is anything new about the poor quality information on the Internet, and whether the quality differs from the information provided in other, more traditional, media.[10] Printed materials are often of poor quality, inaccurate and frequently omit relevant information.[6] In our paper we reviewed several other studies which have investigated the accuracy of information in other media and these are summarised in Table 2.2.[11]

Table 2.2 Accuracy of health information found in traditional media (Adapted from Eysenbach, Powell, Sa and Kuss, 2002)[11]

Study	**Findings**
Smith *et al.* (1972)[268]	70% of health information broadcast on television was inaccurate, misleading, or both.
Frazier *et al.* (1974)[269]	76% of the information about oral hygiene on television, 53% from magazines, and 12% from newspapers was inaccurate.
Canto *et al.* (1998)[270]	20% of the information on oral cancer in the popular press was a "mix of accurate and inaccurate information"
Paskoff (1991)[271]	Enquiries by telephone to libraries yielded a rate of inaccurate information of 3.6%.
Institut für Ernährungswissenschaften der Universität Wien. (1998)[272]	Proportion of inaccurate press reports on healthy eating was found to be 55% in free advertising newspapers, 28.9% in life-style magazines, 29.9% in general interest magazines, and 17.5% in health magazines, and 14.1% in newspapers
Molnar *et al.* (1999)[273]	50% of the advice in newspaper advice columns was rated inappropriate, with critical issues only partially covered or not covered at all in 76% of the articles, and 58% were unsafe or potentially dangerous.

Table 2.2 shows that the problem of accuracy is not confined to the Internet. I believe that the obsession with the quality of online health information misses the point – poor quality or incomplete information has always existed, the difference that the Internet makes is one of accessibility not of quality, and the key question for researchers is "How do consumers use all the online health information that they now potentially have access to?"

The obsession with quality has also generated much endeavour in the production of quality rating instruments and exercises in kite-marking. The formal tools used to evaluate the quality of consumer health information have been reviewed.[3,12] These incorporate various measures (including accuracy, completeness, readability, and explicit details on authorship, sponsorship, and knowledge sources). The European Union has recently published a report, based on two years work, describing a new quality rating system for online health information.[274]

Regarding mental health, two studies (by the same authors) have assessed the quality of online information about depression,[100,193] The first of these studies was criticised for its method of selecting sites to evaluate.[275] Other small studies have examined the quality of information about Alzheimer's disease,[260] chronic fatigue syndrome,[218] and schizophrenia and Attention-Deficit Hyperactivity Disorder.[255] All of these studies showed that while some useful information was available on these mental health topics, the overall quality was poor and there was little concordance with evidence-based guidelines.

2.3.3.2 Consumer use of health information on the Internet

There is evidence that consumers want and use health information on the Internet,[276-278] and that certain characteristics of web-based information are valued by users. These include convenience (ease of access and 24 hour availability),[53] anonymity,[279] and personalisation of information.[280] Umefjord *et al.* investigated the motivations of users of their Internet 'Ask the Doctor' service.[281] In a cross-sectional survey, with a relatively low response rate (36%), they found that the major reasons for choosing to consult online were convenience, anonymity, problems with finding time to access health services, and feeling uncomfortable when seeing a doctor in person.

The Pew Internet and American Life report of two surveys (total 15000 people, 50% were Internet users) found that most users of Internet health sites do so for research and reference purposes.[53] Few use them to communicate with health services (9%) or to purchase pharmaceuticals (10%). The majority (54%) were looking for information on behalf of someone else (usually a relative), and generally this followed consultation with a doctor. Forty-three percent were looking for information for themselves, and in this case Internet use occurred more often *before* medical consultation. Usually information was being sought for a specific medical problem.

The 'Health e-People' report from the California Healthcare Foundation used the results of three surveys to consider the behaviour of what it categorised as three types of online user: (1) the well, (2) the newly diagnosed, and (3) the chronically ill and their care-givers.[282] These groups were found to use the Internet for information in different ways. The well group carried out episodic searching for information relating to short-term medical conditions, pregnancy, and prevention issues. The newly diagnosed carried out very intensive searching for specific information, valuing the ease of access and broad range of information. The chronically ill and their care-givers carried out regular searching for information related to new treatments, nutrition advice and alternative therapies. In addition, the latter two groups both valued and used online communities and chatrooms, a common finding in studies of Internet users.[276,283-287]

Three broad approaches have been taken to investigate consumer use of the Internet for health information. These are cross-sectional surveys, content analysis of website usage, and in-depth qualitative work. The first of these methods has involved surveys with patient groups (or the public). When this research started there were very few, if any, studies with this approach but now there are multiple studies quantifying the prevalence of Internet access in certain populations. A high quality systematic review article has identified 24 separate surveys published since 2000 which provide data on the proportions of Internet users among patients with cancer.[288] It is interesting that the predominance of the topic of cancer in the literature on traditional information seeking is now being replicated in the research on Internet use. The review article showed that (in the developed world) 39% of patients with cancer use the net, and a further 20% do so indirectly via family and friends. The author identifies four purposes of Internet use for cancer patients: communication (via email); community (in virtual support groups); content (factual information); and commerce (online purchasing of products and services). Of the other studies that I identified, most are based on clinic populations and consistently show that many patients (between 10% and 50%) are now using the Internet to find information related to their condition.[289-307] In a UK context, a survey of a primary care population in Oxfordshire found that 42% of respondents with Internet access had used it for health information.[308] Despite systematic searching I did not identify any surveys of the use of the Internet for mental health information.

An alternative approach to researching consumer use of the Internet for health information has been to investigate requests that members of the public make to Internet-based sources of health information. Not all such studies are of great value, for example an analysis of searches on an orthopaedics website found that the most frequent reasons for seeking information were to obtain information and advice about a condition (and its symptoms) and information and advice about its treatment - not very surprising or enlightening results.[309] Hiller analysed requests from cancer patients and carers sent to the German Cancer Information Service.[310] He found no difference in the content of telephone requests compared with email, suggesting that web-based consumer information needs are similar to information needs from more traditional sources. Hiller also found that users value the Internet for providing access to professional-oriented information, in particular information on treatments, which is difficult to obtain from other sources. Users still value the opinion of the information service in interpreting information found on the Internet. Eysenbach *et al.* looked at expressed consumer needs identified by analysing emails sent to their dermatology website.[311] Many users of this website were seeking second opinions, with 17% identifying frustrations with traditional consultations. In a separate study the same investigators tested the health knowledge of users of an eczema website to identify gaps in knowledge.[312] The findings show that there are common misconceptions among the website users concerning the cause and treatment of their conditions. However in the absence of any control group it is impossible to say whether these gaps in knowledge were related to the information seeking behaviour of these users. Widman and Tong also analysed the content of email requests for health advice (in relation to cardiovascular disease).[313] They concluded that there is a 'widespread unmet need for objective medical advice', but this study again lacks a control group. Their service may have created supplier-induced demand which would be an alternative but equally valid conclusion.

At the time when this project began I did not identify any studies that had undertaken in-depth interviews with health service users to specifically investigate their use of online health information. I am still only aware of one study which did this,[314] while one study analysed interviews collected for another purpose,[315] although others have identified the use of the Internet as one theme emerging from broader investigations of information use and needs.[316-320] The interview study was with a purposive sample of ten individuals living with HIV/AIDS. It found that these individuals use the Internet for four main reasons: (1) finding information; (2) making social connections; (3) advocating (letting one's voice be heard); and (4) for escaping. An analysis of 175 illness narratives conducted for the Oxford-based DIPEx project (Database of Individual Patient Experience) showed that cancer patients used the Internet at all stages of their illness to "find second opinions, seek support and experiential information from other patients, interpret symptoms, seek information about tests and treatments, help interpret consultations, identify questions for doctors, make anonymous private inquiries, and raise awareness of the cancer".[315]

Two focus group studies have investigated how consumers search for and appraise online health information.[321,322] Both of these showed that while consumers report scepticism about the quality of online information, and consider it important to check the source of all information found, in practice they were much less discerning than this and very few actually make any assessment of the credibility of the source.

Coiera points out that despite case reports of individuals coming to harm from poor quality online information or from drugs or devices purchased from the Internet,[323-326] no study has yet shown that the Internet has a positive or negative impact on public health outcomes.[10] A protocol for a systematic review of the 'use of interactive communication for consumer health education and the impact of the Internet on public health' has been registered with the Cochrane Collaboration but has not yet been undertaken. A high quality systematic review of cases of harm associated with the use of health information on the Internet identified only three case reports.[327]

It has been speculated that Internet use itself can lead to depression and social isolation.[328] McKenna has challenged this view, arguing that the majority of evidence does not support it, and that in this regard the Internet should simply be viewed as another mode of communication like the telephone or television.[329] The relationship between Internet use and depression is more complex than a one-way causal pathway.[330,331] There is also substantial evidence of the phenomenon of Internet addiction,[332] which although not particular to health information users, is an increasing public health problem with reports of rising numbers of people addicted to chatrooms, purchasing online, and gambling online.[333,334] There is also rising concern about the number of cases of sexually transmitted infections linked to high risk sexual behaviour facilitated by Internet dating.[335-340]

2.3.3.3 Impact of the Internet on the practitioner-patient relationship

The potential impact of the Internet on the practitioner-patient relationship is being increasingly debated. Several authors see the Internet as a key influence in changing the balance of knowledge and power between healthcare professionals and the public, empowering patients to become more involved in healthcare decision-making and contributing to the deprofessionalisation of medicine.[1,13,47,341,342] The more optimistic commentators see this as bringing benefits across the health system - with improved consumer education allowing better informed patients to take more control over their health and healthcare; web-enabled disease management improving the care of patients with chronic diseases, bringing likely cost-savings; real-time decision support reducing the risk of medical errors; email improving the communication between patients and practitioners; and improvements in health service administration.[47,343,344] There are some examples of the positive benefits that the Internet can bring to the practitioner-patient relationship, with case reports of individuals finding information that has helped their healthcare.[342]

However others take a less positive view. A semi-structured interview study of the experience of Swedish patient organisations concluded that health services and the medical profession were badly prepared for these changes in the doctor-patient relationship.[88] There have been similar statements about the lack of preparedness of individual physicians and their organisations in the US.[345] A survey of UK obstetricians and gynaecologists found that 40% feared that having patients better informed might damage the doctor-patient relationship.[346] A survey of American oncologists found that 9% of respondents reported that they sometimes or always felt threatened when patients brought Internet information to discuss.[347] Physicians seem to have particular concerns about the quality of information that might be found by patients (see Section 2.3.3.1 above) and the potential difficulties they could face if they were to communicate via email with their patients, including ethical and workload problems.[344,348-350]

Certainly patients are increasingly using information found on the Internet in their consultations with professionals. A US telephone survey of a representative sample of over 3000 members of the public found that 50% of those who had used the Internet to find health information relevant to themselves had taken this information to their physician.[351] In general this was perceived as a beneficial exercise - 83% of those who had taken information to their doctor reported that they felt more in control in the consultation, and 78% felt more confident.[351] While this survey was conducted in the US, a survey by Datamonitor suggests the prevalence of taking Internet information to the doctor is similar in the UK (and other Western European countries).[352] In an in-depth qualitative study of households, Hardey found that online health information was being increasingly used not only to find out more about a course of treatment, but also to challenge the professional who had recommended it.[1]

Other studies confirm that the majority of doctors have experienced patients bringing information to the consultation which had been found on the Internet. A Norwegian study found that three-quarters of practitioners had experienced this,[353] while a US survey found it was reported by 85% of their physician respondents, although it was still only an occasional occurrence.[354] This latter study, a postal survey of 2000 physicians with a 53% response rate, examined the impact of information-bringing on the physician-patient relationship. The authors found that the accuracy of the information again mattered to professionals, who considered that poor quality information was harmful and could damage their relationships with patients. Only a minority of physicians in this study (17%) reported feeling challenged by patients bringing information to the consultation.

Inevitably research in a rapidly changing area such as this will yield changing results. There may well be secular and temporal effects and physicians may feel less challenged as the Internet becomes more familiar and more widely used. It seems that the phenomenon of 'cyberchondria' or 'Internet printout syndrome' with patients bringing printouts to the consultation is happening but is not overwhelming physicians in the way feared by some early commentators.[46]

While the widespread dissemination of consumer health information on the Internet has the potential to empower consumers and to counter the information asymmetry of the doctor-patient relationship, it is clear that certain population groups may be excluded. A key component of quality in health services is fair access. Concern has been expressed that Internet based health information could create a 'digital divide' between the *have-nets* and the *have-nots.*[57,355] The latest figures from the UK show that users tend to be young (48% under 35, only 11% over 55), affluent and employed.[59] A pilot study on the use of web kiosks provided at hospitals in the UK, in an attempt to remove barriers to access, shows that the majority of users were still under 35.[356] Forty-five percent of UK Internet users are women.[59] The 2000 Pew Internet and American Life report found that in the USA women are much more likely to seek online health information than men.[53]

The groups most likely to be excluded from the Internet revolution are those groups who suffer exclusion from other types of healthcare – especially the poor, the homeless, the illiterate, the elderly,[357] and people with disabilities.[358] Korgen *et al.* showed that even after controlling for home computer ownership, White and Asian American college students use the Internet more than their Hispanic and Black American colleagues, although all have free Internet access, again suggesting that barriers to access are not simply economic.[359] Recent USA surveys show that the Internet is reaching lower income, less educated and minority community Americans, although lower income Black Americans still have poor access.[57] However extrapolating data on Internet usage from America to other countries can be problematic.[360]

Jadad commented on the paradoxical effect of the spread of easy access to Internet information causing a widening gap between those who do or do not have good access.[13] Information poverty can also operate at a population level. Horton and others have highlighted the information gap that exists in less developed countries,[361] and Donald points out that despite the expansion of the Internet and the removal of barriers to information and technology transfer, the distribution of health technologies is more unequal than ever.[362]

2.3.3.4 Virtual communities and online social support

Internet communities provide users with information and a platform for peer-to-peer communication that may be synchronous (such as in chatrooms) or asynchronous (such as on messageboards). Previous descriptive studies of health-related online communities have suggested that they can provide support to diabetes patients,[287] women with endometriosis,[285] people with HIV,[283] and alcoholics.[286] They can counter social isolation of elderly people,[363] and can help people cope more effectively with their disease.[364] Support seeking online is highest among those with the most stigmatising problems – including mental health problems.[365] In a review article of descriptive studies, White and Dorman highlight the fact that anonymity and convenience can facilitate use by those with stigmatising and disabling conditions.[366] These authors also discuss the possible disadvantages of online social support, including the exclusion of certain groups through the 'digital divide'; the misinterpretation of online messages which lack visual or aural cues; and the dissemination of inaccurate information.

There are few good quality intervention studies of health-related virtual communities. Much of the published work concerns pilot programmes or feasibility studies. I undertook and co-authored a systematic review of this literature with collaborators in

Canada.[92] In this review we identified 37 distinct studies in 44 publications which evaluated the effectiveness of peer-to-peer communication in virtual communities.[367-410] However only six studies evaluated peer-to-peer communities as stand alone interventions.[367,384,391,392,396,401] All six used a before-after design without a control group, therefore constituting a low level of evidence. Five of these studies had some level of health professional involvement within the community,[367,384,392,396,401] and there is some evidence of differences in how virtual communities are used depending on whether they are moderated or unmoderated.[411] Studies that have employed better quality designs such as randomised controlled trials have all assessed the effects of complex interventions which include peer-to-peer communication as just one component, usually combined with some health professional involvement. This may reflect commercial interests in the intervention under study, for example the 'CHESS', 'ComputerLink', and 'StarBright World' interventions. The lack of commercial potential may explain why peer-to-peer support in isolation has not yet been the subject of a good quality randomised trial. The most frequently measured outcomes in these evaluations of virtual communities have been depression and social support measures, and the majority of studies have failed to show positive effects.[92] It is clear that further research is needed to explore the effectiveness of peer-to-peer support in good quality randomised trials of stand-alone interventions.

Four descriptive studies have investigated Internet depression communities.[412-415] These studies showed that four out of five users were female and that many users found it easier to discuss mental health topics online rather than in person. The prevalence of major depression among users was high, and there was evidence that many users were turning to online support groups without being in touch with formal health services.[415]

Users of Internet depression communities reported benefits in terms of information, social support and contact.[412-415] However the only study to include a formal measure of social support found no change over six to twelve months.[413] Some users reported revealing their depression on an Internet community having not disclosed it elsewhere.[412,415] The relative anonymity and privacy of Internet support groups for mental health problems can offer particular benefits for those affected by stigma, as can the convenience of twenty-four hour home access.[416]

2.3.3.5 The online delivery of information based interventions

The Internet is increasingly being utilised for healthcare delivery. Specialties which have used telemedicine for remote diagnosis and asynchronous communication can now explore the enhanced possibilities of the Internet – for example to provide 'virtual outreach' consultations in areas with poor access to conventional services.[417,418] There are also an increasing number of Internet-based interventions which offer the possibility of overcoming existing barriers to accessing certain interventions, as well as reducing the need for health professional input. Studies in this area have tended to fall into one of three categories, usually evaluating: (1) health education or health promotion programmes; or (2) the online delivery of psychosocial interventions; or (3) web-based interventions to support chronic disease management. Inevitably many of these studies have been pilot work and this is an area likely to see rapid development in the coming years.

Studies of online health education and health promotion interventions have shown that the Internet is a feasible and acceptable method for their delivery, but the effects on health outcomes have been inconclusive. Studies of complex interventions which include behavioural counselling and self-monitoring to encourage physical activity and weight loss have shown the most promising results.[385,386,402,410] Other studies have shown the potential of web-based smoking cessation programmes,[369,419,420] nutrition and dietary education,[144,421] and sexual health education,[422]. The majority of evidence supports the Internet as a tool for health education with equivalence to more traditional methods, but there is no evidence for Internet based interventions being more effective.[423] The Internet may have advantages in facilitating the targeting of certain groups, such as teenagers in a sun safety campaign.[424]

Regarding psychological interventions, stand-alone computer programs have been used to successfully deliver mental health interventions in the past,[425] and there are now an increasing number of reports of psychological interventions being delivered successfully via the Internet.[426-433] Some of these interventions have simply provided web versions of psychoeducational materials which were previously available in print form. Others are more elaborate, using the interactivity of the Internet to develop online therapy, usually based on cognitive-behavioural approaches. For example, there are promising results with early studies of Internet-based Cognitive Behaviour Therapy (CBT) showing reduced frequency, duration and intensity of panic attacks in panic disorder;[426] improvements in depressive symptoms;[433] reductions in tinnitus-related distress;[428] improvements in symptoms of posttraumatic stress;[434] improvements in body image in eating disorders in a group-based intervention;[379] and improvements in recurrent headache symptoms with an intervention based on problem solving and applied relaxation.[429] However there have also been several studies showing little or no effect compared with control treatment (although these have tended to have poor rates of concordance with the intervention).[430] This is a developing area and systematic secondary research examining the effectiveness of online CBT is needed.

Finally, studies of web-enabled chronic disease management demonstrate one way in which the Internet can be used to allow patients to take more control over their healthcare. Again, this is an emerging area with most of the evidence coming from small pilot studies of Internet-based chronic disease management tools supporting a range of chronic health conditions, for example diabetes,[400,434,435] asthma,[436] HIV/AIDS,[437] heart failure,[438] and chronic wounds.[439] The potential of these chronic disease management tools may be more fully realised when they are linked to patient-held electronic records, supporting self-management of chronic conditions within the patient pathway. They have the potential to provide a cost-effective way to improve health and enhance patient-provider communication.[440]

2.3.4 Conclusions: what is not known, what questions need answering?

The Internet is undoubtedly having a major impact on healthcare. There is a wealth of research showing that health information on the Internet is unregulated and often of poor quality. There is also evidence of a 'digital divide' of inequality in access to online health information. The work on consumer use of online health information has generally been quantitative, describing frequency of use by different groups or content of consumer requests. Surveys examining Internet use have tended to be short, market research style projects and have not been grounded in preceding qualitative work. No work was identified that looked exclusively at the use of online mental health information. Many questions concerning 'how do consumers use the Internet for health information?' remain.

2.4 Models of information seeking and health communication

2.4.1 Introduction

Three major categories of models examine the relationships between health information, knowledge acquisition, attitudes and beliefs, and health-related behaviour. These are models of mass communication, models of health behaviour and models of information seeking. These have mainly arisen in the disciplines of media and communication studies, health education, psychology, and library and information science. The aim here is to describe the key points of the relevant theories in order to give an overview of this area, rather than provide a comprehensive synthesis. Conclusions are drawn and a conceptual map constructed which was used to guide the primary research.

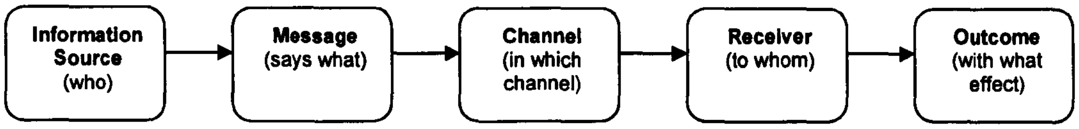
2.4.2 Models of mass communication

McQuail summarises four approaches to the study of public communication: (1) transmission models; (2) reception models; (3) ritual/exposure models; and (4) communication as display and attention.[34] The latter two approaches are concerned with communication as performance (as in the arts) and communication solely to generate publicity, and these will not be discussed further here.

2.4.2.1 Transmission models

The transmission approach sees the process as analogous to a radio transmitter, and is exemplified by the Lasswell formula.[441] Lasswell was one of the earliest theorists to attempt to explain the process of mass communication. He described a linear five step process consisting of (1) Who? (2) Says what? (3) In which channel? (4) To whom? (5) With what effect? This is shown in Figure 2.1.

Figure 2.1 The Lasswell Formula[441]



Many of the mass communication models have their origins in the Lasswell formula.[442] Shannon and Weaver added the influence of 'noise' that might disrupt the message.[443] Braddock identified the importance of the circumstances under which the message is sent, and the reasons for the communication.[444] DeFleur added a feedback loop from the effects of the received message to the transmission,[445] and Osgood and Schramm went further in seeing the process of mass communication as a circular one from transmitter to receiver and back again.[446] Westley and MacLean added subjectivity to the process: in their model mass communicators choose to relay their own account of information, shaped by the feedback received from the audience.[447] In Maletzke's model of mass communication, the characteristics of the medium are emphasised, as are the self-image, personality and social environment of both communicator and receiver.[448]

2.4.2.2 Reception models

These have their origin in semiology, critical theory and discourse analysis. They challenge the transmission approaches for not taking into account the way that the audience constructs meaning in a message. Meaning is embedded in the message by the communicator (through encoding), and then decoded by the receivers depending on their own ideas and experience. Importantly, messages do not always convey the intended meaning, as encoded and decoded messages do not necessarily correspond.[34] McQuail points out that the transmission and reception approaches are not necessarily incompatible.[34] Both can be useful in understanding the communication of information.

2.4.3 Models of health behaviour change

These models have been developed in psychology and health education. The main theories are summarised in Table 2.3. There is not room here to provide a detailed critique of each. In general these are North American models that have been developed and applied to the understanding of how health education can bring about change in individual health behaviour. They highlight the importance of knowledge and beliefs about health and how these influence behaviour. Also important is self-efficacy, the belief in one's own ability to take action. These models take rational approaches to human behaviour, and little attention is paid to individual identity or to the socio-economic and environmental conditions in which health behaviour change occurs.[449]

Table 2.3 Main theories of health behaviour change

Theory	Key features
Cognitive Consistency (e.g. Festinger)[450]	Behaviour or attitudes that are at odds with an established attitude demand change. Change takes the form of altering an attitude or the behaviour in order to reduce the level of dissonance. If this does not happen, dissonance leads to discomfort and impairment of thoughts and actions. The mechanism of reducing dissonance includes modifying one's behaviour or modifying one's attitudes.
Health Belief Model (Rosenstock)[451]	The likelihood of an individual taking action depends on their perceptions of their susceptibility to a problem; the seriousness of the problem; the benefits of taking action; and the barriers to taking action. Individuals will take action if the perceived benefits outweigh the perceived risks. Ultimately behaviour occurs depending on 'cues' to take action.
Social Learning Theory/Social Cognitive Theory (Bandura)[452]	The basic tenets of social learning theory are that (1) the consequences of behaviour influence the likelihood of repetition; (2) humans can learn vicariously (by observing others); and (3) individuals are more likely to model their behaviour on that of others if they identify with them. Bandura has developed his version of social learning theory as social cognitive theory, because of the emphasis on cognition in his model. He describes a triad of reciprocal and complex relationships between individuals and their behaviour; individuals and their environment; and the environment and behaviour. These relationships determine an individual's behaviour.
Health Locus of Control (Rotter)[453]	This construct was derived from Social Learning Theory. It is a measure of an individual's belief in whether their health is, or is not determined by internal (i.e. under personal control) or external factors (i.e. by powerful others or by chance). Individuals with a high internal locus of control are more likely to take action when presented with information, while those with a high external locus are less likely to act, as they feel that this will not influence the outcome.
Theory of Reasoned Action/Theory of Planned Behaviour (Ajzen & Fishbein)[454]	This theory assumes that human beings act rationally, making predictable decisions in defined circumstances. Behaviour follows an intention and will not occur without it. The influences on behavioural intentions are: attitudes (including behavioural beliefs and evaluation of the predicted outcome of behaviour); subjective norms (beliefs about the views of others); and perceived behavioural control (this latter influence was added in the Theory of Planned Behaviour model).
Protection Motivation Theory[455]	Explains the cognitive appraisal processes which mediate attitude change in terms of 'threat appraisal' and 'coping appraisal'. The former is an appraisal of the severity (or utility) of a specified event and the likelihood of its occurrence. The latter relates to both self-efficacy and the effectiveness of the response. This theory is primarily concerned with the effects fear has on attitude change.
Transtheoretical approach/Stages of Change (Prochaska & DiClemente)[456]	Describes stages of change that an individual will go through in adopting a behaviour. It also describes the processes underlying these changes. The 5 basic stages of change are: precontemplation, contemplation, preparation or determination, action, and maintenance. Individuals appear to move in a predictable way through these stages but at different rates, and sometimes do not progress beyond a stage. The processes underlying change are: consciousness raising (for example through information provision), social liberation, emotional arousal, self-reevaluation, commitment, countering, environmental control, rewards, and helping relationships.

2.4.4 Models of information seeking

Information seeking models have generally arisen from the field of library and information science, sometimes incorporating psychological theories. Several models have been proposed to explain information seeking and a recent book by Case has summarised this area.[457] In general these describe a sequential process, usually outlined in flow chart terms. They have often been developed to describe information seeking by groups of professionals, and often in a library setting. I will consider the theories that have relevance to consumer health information seeking.

One of the principle theorists is Wilson.[458] His model of information seeking has evolved in several key publications over the last 25 years.[459] He sees information seeking as starting at a point of uncertainty for an individual, which leads to successive goal-seeking behaviour to satisfy needs, which may be cognitive, affective or physiological. Wilson describes four modes of information acquisition: (1) passive attention (when seeking was not intended); (2) passive search (one type of behaviour incidentally results in acquisition); (3) active searching; and (4) ongoing active searching. The results of these activities provide feedback to the state of uncertainty, leading to more or less uncertainty and influencing further information seeking behaviour.

Wilson acknowledges the importance of both personal and environmental factors in influencing the whole process. In the Revised General Model of Information Behaviour, he describes how various psychological theories can be used to explain the influences on the process of information seeking.[459] Information uncertainty (the information need) arises in a particular context, and Wilson draws on Stress and Coping research to explain how information seeking is a mechanism to reduce the stress caused by uncertainty in that situation. Information seeking behaviour is therefore 'activated' by a particular level of stress or uncertainty. This process may be influenced by various 'intervening variables' which include those intrinsic to the individual such as their personal psychological characteristics, demographic factors, and factors related to their social role; and variables which are extrinsic, including environmental resources available and the characteristics of information sources (such as accessibility). Once information seeking behaviour is activated, Wilson identifies two mechanisms for it being sustained. The first draws on Risk and Reward Theory, from consumer research. Information seeking is sustained if the potential reward of finding information outweighs the potential risk of seeking it. This clearly has similarities to the Health Belief Model. The other mechanism described by Wilson also relates to the theories of health behaviour change described above, namely Social Learning Theory and the concept of self-efficacy. This is the importance of the belief in one's own ability to find and use information.

A theory of how individuals assimilate new information presented by the mass media is provided by the synergy model of Schooler *et al.*, as described by Napoli.[460,461] This model was based on experiences in the Stanford Five-City Project, a long-term trial of community-wide cardiovascular risk reduction. It has similarities to both the two-step flow hypothesis of Lazarsfeld *et al.*[462] and Rogers's diffusion of innovations.[463] This latter theory holds that new innovations (including new information) are adopted depending on the characteristics of five factors: the innovation; the adoptees; the rate of diffusion; the communication channels; and the social system. New information is more likely to be adopted if it is perceived as better than preceding ideas ('relative advantage'); if it is consistent with existing attitudes; if it is perceived as easy to understand and use; if it can be experimented with on a trial basis before total adoption; and if the effects of the innovation can be witnessed. The synergy model holds that individuals are alerted to new information by the mass media, and that if this creates awareness they will attempt to modify their behaviour accordingly.[461] If they face barriers as a result of attempts to change behaviour, they turn to their interpersonal network for information, support and feedback, and consult the mass media for further information. This model therefore implies that information can operate at different levels and times in the process.

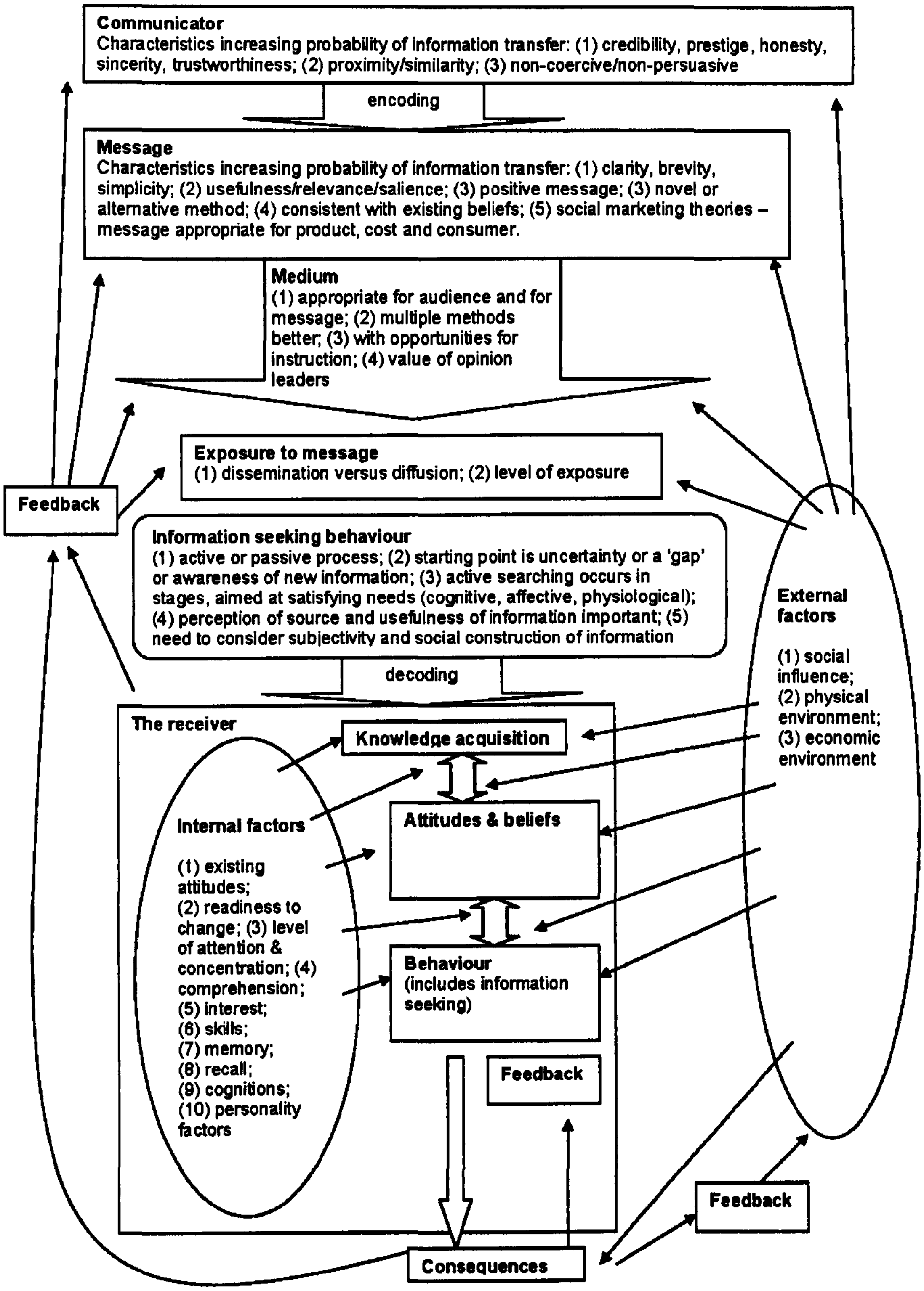
In the area of cancer information, Johnson and Meischke have developed their Comprehensive Model of Information Seeking (CMIS).[464] This model synthesises the Health Belief Model with evidence from Uses and Gratifications research and research into media exposure and appraisal.[461] The Uses and Gratifications approach is concerned with how people use the media to gratify their needs, which may be related to surveillance (of the world around us), personal identity, personal relationships, or diversion (i.e. escapism).[465] The CMIS therefore considers the causal factors related to information seeking and source selection from this perspective. Like Wilson, Johnson and Meischke acknowledge that information seeking may be driven by cognitive or affective needs. Their theory states that four health-related factors (demographic factors, previous experience, salience, and existing beliefs) determine the perception of the information source and the perception of the usefulness of the information, which (as in the Health Belief Model) lead to information seeking behaviour.

An alternative perspective is provided by Sense-Making Theory which concentrates on the process of information seeking and the social construction of knowledge.[466] It has the core assumptions that: human reality is discontinuous and filled with fundamental 'gaps'; and that information does not exist independently of human beings but is a product of observation and therefore subjective. This theory posits that humans try to make sense of the 'gaps' in their reality by seeking 'bridges', and that information seeking is part of this construction. Sense-Making studies show that individuals first go to information sources that are closest and most convenient, regardless of credibility. Individuals also value a diversity of information sources.

2.4.5 Synthesis

Both transmission and reception models of mass communication provide useful frameworks for studying public information. Characteristics of the communicator, the message, the medium, the audience and the environment are all important, including the perceptions of both communicator and audience, and the encoding/decoding of the message. Evidence from research using models of health behaviour change and of information seeking, shows that certain characteristics are associated with knowledge acquisition and attitude change. These are summarised in Figure 2.2 in a conceptual map addressing the whole process. For graphical simplicity this is shown as a linear process but it is acknowledged that the relationships are not necessarily linear, and certainly not unidirectional. This conceptual map and the two literature search topic areas described above in Sections 2.2 and 2.3 were used to inform the topic guide for the qualitative interviews and the content of the questionnaire survey. In the next chapter **[Chapter 3]** I describe the methods, results, conclusions and implications of the interviews. The survey is described in **Chapter 4**.

Figure 2.2 Conceptual map of health communication and behaviour change models



3. In-depth Interviews

3.1 Introduction

This chapter explains how unstructured open-ended interviews were used to explore topics in-depth with a range of mental health service users. First I explain the method and theoretical approach chosen (this section). Then I outline the methods used including recruitment of participants, conduct of interviews, transcription, and method of analysis (Section 3.2). I then describe the characteristics of the interviewees and the findings of the analysis (Section 3.3). In Section 3.4 I discuss the findings and consider their validity and the reasons for rejecting alternative research approaches such as focus groups or non-participant observation.

The aims of the interviews were:

- To explore the information behaviour and information needs of people with mental health problems.
- To understand the reasons for using different sources of mental health information, and in particular, to understand the role of the Internet.
- To generate hypotheses concerning mental health information needs.

3.1.1 Choice of method

In Chapter 2 I showed that little is known about mental health information needs and that (particularly in 2000 at the start of this project) there had been little research into consumer use of the Internet for health information beyond concerns with quality and access. I therefore decided that an exploratory qualitative approach was required in order to identify and explore the attitudes and behaviour of mental health users towards information sources, including the Internet. I wanted to identify the reasons that mental health users give for seeking out certain information and to generate hypotheses about this behaviour. Qualitative research is useful to explore the meanings of social phenomena as experienced by individuals.[467] In-depth interviews allow respondents to describe the world in their own words. Unlike structured questioning they do not assume that a fixed sequence of questions is suitable for all respondents. They also allow participants to raise previously unidentified issues. This approach has been used in previous studies of information needs.[457] The benefits of an interview approach to identifying information needs were summarised by Nicholas (Box 3.1).[73]

Box 3.1 The benefits of using an open-ended interview approach to identifying information needs (after Nicholas 2000)[73]

1. In-depth interviews are important for exploring unfamiliar territory.

2. Data comes in the words of the interviewee. This avoids the limitations of questionnaires and possible bias in how closed questions are asked.

3. Interviews provide an opportunity to question, explain and reflect. Information needs and information seeking are complex issues which benefit from exploration.

4. Full and complete responses can be obtained by the use of prompting.

5. Observation and non-verbal communication can benefit the eliciting of information.

3.1.2 Theoretical approach

I chose to use a modified grounded theory approach to the analysis of the interviews.[468] Grounded theory is an inductive technique using a systematic and comprehensive set of coding procedures to develop theory about social processes.[468,469] The theory is *grounded* in the data in that the findings are allowed to emerge from the content of the interviews rather than have researchers impose their preconceived ideas. The modified approach acknowledges that the coding of interview data would be informed by my prior experience as a health professional and the knowledge I had gained from the literature review. Modified grounded theory approaches have been used before to identify health consumers' views,[470] and specifically health information behaviour.[471]

I took the ontological position of Hammersley's 'subtle realism',[67] which acknowledges that the data obtained from interviews is subjective, but unlike anti-realism it allows for the existence of underlying phenomena that can be studied.[472]

3.2 Methods

3.2.1 Recruitment of participants

Adult mental health service users were purposively recruited as participants for interviews from settings in primary and secondary care as well as from user organisations and from Internet users. The inclusion criteria were to be aged 18 or over, and to be self-defined as having experience of mental health problems. I was unable to offer interviews to individuals who could not speak English.

The maximum variation sampling aimed to recruit both male and female mental health users of a wide age range, from varying social backgrounds, with experience of a range of mental health problems from across the patient pathway, including users with both acute and chronic conditions.[473] It was important to ensure that this exercise was not just convenience sampling, but a critical and explicit process of identifying cases of interest.[474] The purposive sampling was used to identify a number of users with experience of using health information on the Internet as this was one of the main interests of the study. Sampling continued until theoretical saturation occurred, when further sampling failed to yield new information.[469]

For primary care sampling, I met with Oxfordshire general practitioners at their monthly Continuing Professional Development meeting and explained the research study and enlisted their help in identifying prospective interviewees for interview. General practitioners were given copies of information sheets, which had further information and contact details, to hand to suitable patients (see Appendix 1). In addition, posters were distributed to be placed in general practice waiting rooms (see Appendix 2). For secondary care recruitment I wrote to the clinical director of Oxfordshire Mental Healthcare NHS Trust (which covers the whole of the county) and requested the assistance of senior clinicians to recruit patients from secondary care. Clinicians were given information sheets to distribute and posters advertising the research study were placed in psychiatry and psychology outpatient waiting rooms. I also visited inpatient wards and liaised with nursing staff in order to recruit psychiatric inpatients. I wrote to all mental health user organisations listed in the local MIND (mental health charity) directory of mental health organisations, and those with existing links with the Centre for Evidence-Based Mental Health. These letters explained the study and enclosed information sheets and contact details. I contacted Netdoctor.co.uk, which is Europe's largest independent consumer health information website, who agreed to place the study information and my contact details on their depression virtual community pages. I also established a study website (www.mhis.org.uk) explaining the study and giving the information sheets and my contact details. This website was submitted to popular Internet search engines (Yahoo, Altavista etc.) and the Mental Health Foundation placed a link to the site on their user information pages.

3.2.2 Conduct of interviews

Both face-to-face and telephone interviews were held, lasting between 30 minutes to one hour. These were in-depth, unstructured interviews. A topic guide was used to prompt the interviewer to cover certain areas of interest. The guide was based on the review of previous research, the theoretical literature, and the conceptual map (Figure 2.2). It is included as Appendix 3. The guide was not fully comprehensive, nor prescriptive, and additions were made during the interview process, guided by emerging findings. It served as a useful framework to prompt the interviewer to initiate discussions in relevant areas. As far as possible open-ended questioning was used,[475] and the order of questioning was determined by the flow of each individual interview.

I conducted all the interviews. Face-to-face interviews took place at the Warneford Hospital Outpatients Department in Oxford or in the interviewee's home. All volunteers were given at least 24 hours to consider their participation in the study, and were reassured that they could withdraw their consent at any time. The consent form is included as Appendix 4.

A Sony Professional Walkman tape-recorder was used to record interviews, using a tabletop microphone and standard audio-cassettes. A Sanyo T-30 telephone adaptor was used for telephone interviews. Audiotapes were labelled with the study participant identification number only. All participants gave signed consent to the audiotaping.

3.2.3 Transcription

Interview tapes were transcribed for analysis using one professional transcriber.

Additionally I fully transcribed two interviews to check for accuracy of the professional transcriber. I also checked the accuracy of a further five transcripts by playing the recorded interview while reading through the transcript. Transcripts were labelled with the study participant identification number only.

Transcripts included hesitations ("umm") and pauses, but these have not been included in the quotes given in the results section (Section 3.3) as I am not presenting a content analysis, and the quotations are easier to read without hesitations and pauses.

3.2.4 Ethical approval

Ethical approval for the in-depth interviews was sought from the Oxford Applied Qualitative Research Ethics Committee (AQREC) in September 2000. Following clarifications regarding the study protocol, and minor revisions to the consent form and information sheet, ethical approval was granted in January 2001.

3.2.5 Method of analysis

Two investigators (the author and one supervisor, AC) familiarised themselves with the transcript data through repeated reading and reflection and independently subjected the transcripts to a process of *open coding* by going through each transcript line by line. Open coding is the "analytic process through which concepts are identified and their properties and dimensions are discovered in data".[468] It is an 'open' process in that the data are explored without any prior assumptions about what might be revealed. This was carried out by hand using printed transcripts and by highlighting lines of text and adding annotations in the margin.

Open coding began once the first transcript was available. This process of interim analysis allowed subsequent interviews to be informed by the findings of earlier ones – to guide questioning in areas of interest or that had not been covered.[476] The *constant comparative method* was used to refine emerging conceptual categories through comparison and searching for deviant cases.[477] Constant comparison allows the sampling of deviant or negative cases where findings were contrary to the emerging themes. Once transcripts had been read and coded, the two investigators met to discuss the open codes and through extensive discussion determined a series of thematic codes to describe agreed groups of categories and subcategories - a process of *axial coding*.[468]

I then prepared the transcripts for QSR NUD*IST software and using this computer package to organise the data went back through each transcript applying the agreed thematic coding. QSR NUD*IST allows complex indexing and retrieval of data within interview transcripts.[478] It allows algorithms and Boolean search terms. I used the software to explore coded passages, for example by looking for intersections between identified codes, or identifying codes co-occurring in the same transcripts. These techniques supported the process of *selective coding* which is concerned with building theory by integrating identified categories around explanatory concepts.[468] I used selective coding to generate related themes which explained the information needs and behaviour of participants.

3.3. Results

3.3.1 Characteristics of participants

36 participants were purposively recruited and all consented to be interviewed. There were 25 females and 11 males from different points in the mental health system

representing a variety of occupational backgrounds and with an age range from 25 to 64 years. Their characteristics are shown in Table 3.1. Names have been changed to preserve anonymity. Self-reported mental health problems have been recorded. No formal assessment of psychiatric diagnosis was made. The list in the table indicates the primary problem described by each individual, but it should be noted that several individuals had a complex mix of mental health problems.

Table 3.1 Pseudonyms and characteristics of interviewees

Pseudonym		Gender	Age	Occupation	Setting	History
1	Ray	Male	58	Retired civil servant	Face-to-face	Bipolar affective disorder
2	Lisa	Female	30	Research biochemist	Telephone	Borderline personality disorder
3	Steph	Female	35	Unemployed	Face-to-face	Depression
4	Paul	Male	64	Retired council worker	Face-to-face	Depression
5	Justine	Female	37	Teacher	Telephone	Obsessive-compulsive disorder
6	Tanya	Female	40	Statistician	Face-to-face	Depression
7	Kate	Female	43	Unemployed	Face-to-face	Schizophrenia
8	Elizabeth	Female	49	Medical records clerk	Face-to-face	Depression
9	Helen	Female	30	Nurse	Telephone	Anxiety
10	Melanie	Female	30	Television researcher	Telephone	Depression
11	Alison	Female	43	Mature student	Telephone	Depression
12	Lynne	Female	48	Unwaged carer	Telephone	Schizophrenia
13	Anna	Female	27	Teacher	Telephone	Schizophrenia
14	Caroline	Female	43	Care worker	Telephone	Postnatal depression
15	Nicola	Female	30	Freelance journalist	Face-to-face	Alcohol problems & self-harm
16	Claire	Female	33	Homemaker	Telephone	Depression
17	Jon	Male	32	Unemployed	Telephone	Depression
18	Brian	Male	41	IT support worker	Face-to-face	Depression
19	Tracy	Female	46	Shop assistant	Face-to-face	Depression
20	Gail	Female	60	Homemaker	Face-to-face	Anxiety
21	Penny	Female	42	Homemaker	Face-to-face	History of abuse
22	Mary	Female	38	Social scientist	Face-to-face	Eating disorder
23	Polly	Female	56	Secretary	Face-to-face	Nervous breakdown
24	Dean	Male	36	Charity worker	Telephone	Depression
25	Zoë	Female	52	Artist	Telephone	Hearing voices
26	Scott	Male	38	On disability benefit	Face-to-face	Schizophrenia
27	Cameron	Male	52	Business executive	Face-to-face	Depression
28	Sue	Female	46	Office manager	Face-to-face	Depression
29	Gill	Female	38	Office worker	Telephone	Bipolar affective disorder
30	Tom	Male	52	Building contractor	Telephone	Bipolar affective disorder
31	Sally	Female	55	Occupational therapist	Face-to-face	Depression
32	Stuart	Male	48	Retail manager	Telephone	Depression
33	Rose	Female	50	Homemaker	Face-to-face	Bipolar affective disorder
34	Lee	Male	25	Unemployed	Telephone	Depression
35	Darren	Male	27	Accountant	Telephone	Stress
36	Julia	Female	34	Shop manager	Face-to-face	Depression

3.3.2 Major themes

Five main linked themes were identified from the analysis to explain information needs and behaviour. They are listed below, followed by in-depth illustrations of these themes taken from the content of the interviews, showing how they emerged from the analysis.

Theme 1: Lack of information and lack of respect.

Mental health users are often not put in touch with information that they would like, and this lack of information is often linked to the perception of a lack of respect by mental health workers for individuals with mental health problems. The need here is for a level of information sharing that enables mental health service users to feel respected.

Theme 2: Personal research and the challenge to professionals.

Partly as a result of the lack of information, people are carrying out their own research into their problems, often using technical sources. Information can be empowering, and users recognise the challenge to professions that this self-learning represents (particular in relation to the Internet). The need here is for an environment that supports personal research and acknowledges the difficulties that may arise in the practitioner-patient relationship as a result.

Theme 3: Information seeking can be inhibited by the stigma of having a mental illness.

The information seeking research that individuals are undertaking for themselves can be inhibited by stigma. Users' descriptions of the inhibitory nature of stigma indicate a widespread mind/body dualism in the perception of mental and physical illness. This is not a direct information need, but a need for reducing the stigma associated with mental health problems, supported by an understanding that mental health problems are not less worthy of help than physical problems.

Theme 4: The role of the Internet.

The Internet is a valued source of information on mental health issues and users describe its benefits, particularly concerning privacy. It is meeting the need for a private space to discuss mental health issues. There are concerns about the Internet, and these are related more to misuse than to inaccuracy.

Theme 5: Other people's experience.

One of the main types of information people are seeking is hearing about other people's experience of mental health problems – and individuals are often using the Internet to find this. The benefits of hearing the experience of others can be categorised into meeting the following needs: (1) **universality** - knowing you are not alone; (2) **instillation of hope** - knowing that others get better; and (3) finding **understanding and empathy** (because only others who have been through the same problems can really understand what it is like).

Each of these themes will now be described in turn with selected extracts from the interviews which illustrate each point. I will then describe two interview narratives in detail which demonstrate the links between these themes.

3.3.2.1 Lack of information and lack of respect

A strong theme throughout the interviews was of a general lack of information for people with mental health problems, and that people associated this with not being respected. This especially related to information about treatment. Clearly those volunteering to take part in NHS research to investigate the information needs of mental health users may have a particular experience to relate. The study information explicitly stated that the interviews would concern personal experiences of using health information.

A good illustration of this theme is when interviewee 22 (Mary, a 38 year old social scientist) talks about what she wanted to know when first diagnosed:

Mary: *"I think I wanted to know more, why I was being treated the way I was and I would have liked a better or any explanation of the diagnosis. I was treated heavily with antidepressants without actually being offered much counselling or talk. So basically I was put on, on quite a lot of medication without any much, much explanation. So going through the why, why have we reached this diagnosis and what that means and are there other types of treatment available I was given none of that, those choices."*

Mary interprets this lack of choice as patronizing and explains how this is not helpful and the effect it has:

Mary: *"There's been no choice, it's just been, 'this is what is wrong with you', and 'this is the cure for it' and I find that extremely patronizing and not very helpful, I mean, as I said to you, you become a uncooperative patient in a sense, you, you don't get well."*

Another participant, interviewee 5 (Justine, a 37 year old teacher) explains how she was not given information despite repeatedly requesting it. She was learning to find her information elsewhere:

Justine: *"There was no information available, or certainly wasn't presented to me to be available, despite protesting for something along those lines to be available .... Nobody has ever sat me down and given me some literature and said, you know read through this, this might help you understand or this might help you explain to other people."*

Interviewer: *"Would you have wanted that?"*

Justine: *"Oh desperately, desperately."*

Interviewer: *"But you ended up finding it yourself through the Internet?"*

Justine: *"Yeah, as always."*

In this third example interviewee 1 (Ray, a 58-year old retired civil servant) gives a vivid description of the lack of information following his admission to psychiatric hospital:

Ray: *"I think there is some good information available but I am not certain whether the patients and carers are put in touch with that information and when you are first in, you can't even ask the questions that you need to ... I mentioned I wasn't told what the medication did positively or negatively - you were just told to take it. I was just told, well take the medication and you get, talk about change of brain chemistry, well, you wonder what it means. It's a term that's just thrown out generally and the kind of rationale, it's more complicated than that...I think you end up with a situation, and I always end up with a situation where I couldn't ask the questions to get the answers I need to know. Its like going into a psychiatric hospital where* [there are] *people called psychiatric nurses, there are people called charge nurses, there is someone called the* *blood lady, what do these people do? ... What is occupational therapy? You, you just go along to it, I was put on, electro-convulsive therapy and all I was told, is don't eat or drink beforehand, I wasn't told it was an electrically induced seizure which I could have understood, I mean, its, its as bad as that."*

Interviewer: *"Tell me about the blood lady."*

Ray: *"She kept on taking my blood, but then didn't tell me the results of it, and someone gave me a physical check and didn't tell me the results of the check ... I mean, its just basic, basic courtesy, I think ... I was told my diagnosis at a ward round, in terms, 'it's a manic depressive disorder, keep taking the tablets and you will be alright'. What do those tablets do? I mean, you are not told what the tablets are for. You were just told to take it. ... I did in fact makes a suicide attempt, and part of it was my lack of understanding of mental illness, I thought what had happened to me was like a computer blank out, that my skills and my knowledge had gone. I needed someone to tell me that mental illness wasn't like that."*

These three examples illustrate a clear message from the interviews that people with mental health problems report a lack of information and that this is interpreted as not being afforded respect by the health service. The exchange of sufficient information was seen as a key element of respect. This particularly included information about diagnosis, investigations and treatment options. The final quote highlights the desperation people feel when denied the "basic courtesy" of reasonable communication.

3.3.2.2 Undertaking personal research and the challenge to professionals.

Many interviewees described how they had undertaken their own research into their condition. Many used technical sources to obtain information.

Interviewee 2 (Lisa, a 30 year old biochemist) who complained about lack of information and described wanting to be treated like an *"intelligent adult"* rather than a *"dependent child"*, carried out her own research at libraries and by contacting mental health charities:

Lisa: *"I wasn't really getting any information from anywhere, it was only after I came out of hospital for the first time and started digging around for myself, in libraries and books and, you know, ringing up people like MIND for example and SANE, the better known Mental Health Charities."*

Lisa goes on to describe the reaction of health professionals when she has taken information that she has found through her research to the consultation:

Lisa: *"They hate it, they absolutely hate it I have to say, they really do hate it. I mean, my psychiatrist now is great, he is, you know, he kind of like treats me like an equal now. But people I have had in the past, you know, they didn't really cope with the fact that I could turn round to them and say 'yes, but the side effects of Haloperidol are this, this and this and therefore I am not taking it', you know, they look at you as if to say, 'good grief, this woman knows what she is talking about you know'. Most of them don't like it very much."*

This challenge to professionals was echoed by many of the interviewees. Interviewee 33 (Rose, a 50 year old homemaker) describes how the medical knowledge of her father (a doctor) was like a "secret world" when she was growing up, but now welcomes the opening up of this world and sees it as empowering:

Rose: *"Well, my father was a doctor and he has all these medical books all over the place and we weren't meant to look at them. ... It was his sort of secret world almost, but, it wouldn't be accessible and now it is, you know, everybody, well its happening, yes, it must be quite challenging to the doctor. Because you have the power, you have the information."*

Many users turn to medical textbooks from libraries or use technical sources on the Internet such as online medical journals or online formularies. Much of this process of personal research relates to finding out about medication. Interviewee 11 (Alison, a 43 year old mature student) initially turned to medical textbooks after becoming frustrated at the lack of information from the health service, and she followed this with Internet searching:

Alison: *"Nobody told me anything, I have researched it myself. I knew a fair amount and I got that information from work, but, nobody offered me any information, nobody pointed me in the right direction I should say ... I came across something in a book, which, which pointed me in the direction of something, and is currently being researched. That's Borna disease virus. I didn't know whether this was anything relevant ... I came across a reference to it in a book, just one or two short paragraphs and thought it was interesting, so I then did some research through the Internet. I ran a search on the name of the disease. I also contacted the National Farmers Union and, one or two organisations concerned with psychology. And, oh and the Mental Health Foundation ... They were very useful."*

Interviewee 14 (Caroline, a 43 year old care worker) undertook her own research into her symptoms by searching the Internet and describes the reaction of the health professionals to this:

Caroline: *"I diagnosed myself with fibromyalgia, my doctors hadn't done it and I did take stuff from the Internet and leaflets and said, I think that's what I have got, you have not listened to me all these years, you have just said 'oh yes, we think you are depressed you know' ... and this doctor actually read it and my symptoms and said 'oh you are very clever ... you have diagnosed yourself' ... and this was just information ... We went to see the specialist and he said to me, the doctor has diagnosed.. and I said 'no I did it' and he said 'how' and I said 'I got information off the Internet, looked up symptoms that I was suffering and then went to a library and got some information and then a girl by pure chance had a leaflet' ... and apparently, I have just recently found out that depression is part of fibromyalgia."*

Interviewee 1 (Ray, a 58 year old retired civil servant) describes the empowering effect of finding information, how this can "arm" the patient:

Ray: *"Well, I don't think I am making an original idea that if patients can actually get information off the Internet, they've got something to argue with the doctor about, I think in terms of empowering people, being without information is disempowering and this evens up the power between the doctor and the patient and the doctors may think you are a nuisance simply because you arguing with me and there is an element of the doctor knowing best, but, I mean, that it, that is my view and certainly gathering* *information in the last few days felt quite armed to go in and sort out the psychiatrist simply because we got this information."*

These examples highlight the three categories that came together within this theme - people do their own research, and this is generally seen as empowering, but they also recognise explicitly the challenge this presents to health professionals in general, and doctors in particular.

3.3.2.3 Information seeking can be inhibited by the stigma of having a mental illness.

The stigma of mental illness was a prominent theme. As interviewee 28 (Sue, a 46 year old office manager) explains:

Sue: *"I would much rather have been told that it was something that was physically wrong with me. I felt threatened because anything like mental health is the sort of thing that frightens me. I felt that if it was something physically wrong with me that it would be cured. I was ashamed, I was embarrassed, because I felt that it was something that I had either caused myself or could have controlled myself, and something that I was wasting the GP's time with."*

This shame and embarrassment was described by many respondents who explained that it inhibited their information seeking. Interviewee 10 (Melanie, a 30 year old television researcher) talks about her use of Internet discussion boards which she reads but does not contribute to:

Melanie: *"I wouldn't want to post any messages just because I would be too scared that somebody might find out who I am and I would be very embarrassed."*

However for most interviewees the anonymity of the Internet actually afforded a way of side-stepping the inhibitory effect of stigma. As interviewee 15 (Nicola, a 30 year old freelance journalist) explains she finds it hard to access information where she might be observed, and prefers the Internet:

Nicola: *"I didn't go and ask about it but that's because I find it difficult to, to actually ask for mental health information. That's why I prefer the Internet. ... It is because partly I don't want to ask for mental health* [information] *because of the embarrassment. But at the same time, you know, in theory, I don't agree with the stigma of it all but when, when it comes to putting it into practice, yeah, I do get embarrassed and that is an issue, I mean, that's why, its quite hard. ... I have had information before, sometimes I get this from posters in libraries and things. But you know, even looking at those is, its alright if there is a crowd of people looking at a crowded notice board and you can't tell where you are looking but that sort of public face of it is quite difficult. Before now that stopped me picking up leaflets in a doctors surgery, so I might see a leaflet, and I think 'oh that would be very useful' but if there is loads of people waiting there, I don't go and pick it up."*

In terms of explaining the feelings of shame and embarrassment, this can be linked to the mind/body dualism that was clearly demonstrated by the participants. Interviewee 14 (Caroline, a 43 year old care worker) describes how having mental illness (being "doolally" in her terms) is not like being properly ill:

Caroline: *"'Am I really doolally or, is there something actually, wrong?' ... They* [health professionals] *will say, 'right, you know, you are ill with blah, blah' and I think, 'but I am not ill', because its not physical, to me I am not ill. I just, you know, I see it that, you know I don't know, I am just being, sad, or whatever I suppose. You know, there's people like, with physical, physically not well or people with cancer that, and its getting that through I think, because, we got people that think like that as well, 'big deal, you are depressed so pick yourself up and, get on with it, you know, we all get low', I mean, its that kind of thing."*

She goes on to describe a visit to the accident and emergency department of her local hospital when she was suicidal, where despite being very positive about the treatment she received, she felt she was undeserving of this help because she did not have something physically wrong, her problem was not a "real" emergency:

Caroline: *I had phoned there* [the accident and emergency department], *and they tell me to come up and I actually saw a psychiatrist, it was at night, and,* [it was] *absolutely brilliant you know, but I felt as if again I was wasting time because to me A & E* [is] *for people that, you know, with real emergencies, and I was bothered that I was taking, time I suppose off doctors who could be doing operations or you know, seeing people who have been in car crashes and things, but they were very, very good, very good.*

Having a mental problem was described by respondents as not being equivalent to having a physical one, and was also seen as incorporating an element of personal failure. In line with this, and in terms of information needs, several interviewees described that it was helpful for them to have an explanation of their condition in terms of a physical process. For interviewee 4 (Paul, a 64 year old retired council worker) this explanation was in terms of a chemical change in his brain:

Paul: *"I will never forget this, one lady worked at one of the hospitals and was quite high up there* [and she] *said, 'well, Paul, this isn't your fault, it's the chemical change in your brain has caused that' ... You see, you know that you can see a broken arm, a broken leg a damaged part of the body, you cannot see a damaged part of the mind and it's desperately easy for people to say 'pull yourself together', or 'you've got nothing to be depressed about'. That sort of throw away remark doesn't help. Like I said, you see a broken arm, you see a broken leg, you appreciate if somebody has got cancer or leukaemia but for mental* [illness], *there is nothing to show on the outside."*

In this extract Paul also explains the advantages of having a physical problem rather than a mental one in terms of having an obvious explanation for being ill - something that others can see. Physical problems were seen as having greater legitimacy than mental ones, and having a physical explanation ("the chemical change in your brain") gave legitimacy to the mental health problem.

3.3.2.4 The Internet is a valued source of information and has particular advantages and problems

Interviewees were asked about the Internet as an information source in open questioning. They reported valuing the "unobtrusive" nature of the Internet - both in terms of the anonymity it affords users and also the way that you can participate without interacting.

As interviewee 22 (Mary, a 38 year old social scientist) puts it:

Mary: *"It's such an unobtrusive, discrete way of doing it* [finding information]. *I mean you can do it very privately without even, having to talk to another person."*

Interviewee 30 (Tom, a 52 year old building contractor) also described the advantages of the Internet:

Tom: *"I think another advantage is that you can do it in the privacy of your own home because if you are conscious of the stigma or have difficulties with speaking about what you have with other people then, you know you can do it completely in your own privacy."*

Interviewee 36 (Julia, 34 year old shop manager) described the convenience (not having to go out), the possibility of interacting with other people in a similar situation (who may not be available in "real life"), but also the fact that one can "eavesdrop" and not conform to the normal social rules of "real life" - for example by just leaving:

Julia: "[Its] *easy to find information, so much easier than say... I don't use a library, or books. You don't have to go out. And other people, I think, the sort of support from other people, there is always someone who has had your problem, whatever it is you know. Which is amazing. Its nice to know that you are not alone, the silly little things you see coming on line and saying, thank God I found this great pal, I'm not alone anymore, you know, what they thought was some obscure condition that no one else had* *because maybe they are the only person in their city that has got it or something. There is always loads of other people on the Internet. And also you can just leave incidentally if you want to which you can't do in a real situation. ... You can just sit there and eavesdrop (laugh) ... but you couldn't really do that in a real situation, you can't just stand at a corner of the room and listen, people won't let you."*

Interviewee 15 (Nicola, a 30 year old freelance journalist) contrasts her experience of seeking help from her general practitioner and with that of Internet help-seeking.

Nicola: *"I tend not to be very assertive in things to do with myself and not, you know, not want to take up GP's time so I find it very difficult to ask for information that focuses on myself, whereas if I sit at the Internet, you know, I am anonymous, nobody would, uhh, I am not taking up anyone's time and its just a lot easier, a lot easier and I can do it when I am ready to do it and I don't have to wait and get stressed about it. Also I don't have to worry about, if I ask a question someone is going to say 'well, why are you asking' you know, whatever and I don't get the third degree. So that's why I prefer to do it* [on the] *Internet rather than in person."*

There also seem to be particular benefits of the anonymous nature of the Internet for people with mental health problems, as interviewee 32 (Stuart, a 48 year old retail manager) explains.

Stuart: *"From my point of view its* [using the Internet] *because I cannot interact in a social group. That's my worst problem, one of my worst problems is being able to interact with a group of people. I find it absolutely impossible anymore and I hide* *myself away, I am becoming a hermit I would say. But I do go, I do go out, I have to go out to the doctors, I have to take my wife to the shop, I don't go in the shop, but she goes, but, you know, so its anonymity, I haven't said that right but you know what I mean, because they can't see me, if they could see me, I would stay away."*

Regarding any particular problems with using the Internet as a source of healthcare information, the accuracy of online information was less of a concern for the interviewees than *misuse* of the Internet. People recognised that there are websites with poor or inaccurate information but this was not seen as a major issue. Individuals had developed their own strategies for dealing with inaccurate information, and had learned to trust certain websites - usually those with identities that they trust in the "real" world - such as sites run by the NHS, the BBC or mental health charities. Interviewee 14 (Caroline, a 43 year old care worker) commented on her fears of who might be using chatrooms for victims of abuse:

Caroline: *"I have come across* [websites] *where they have got like chat rooms for people who have been abused and things like that and mental health stuff and I wouldn't go in there because I am thinking 'ooh', you know, I don't know whether it would be full of genuine people or whether it would be full of, you know, if there is going to be people in there that want to hear about people who have been abused and get a kick out of it."*

Interviewee 16 (Claire, a 33 year old care worker) and interviewee 32 (Stuart, a 48 year old retail manager) describe the disruption of websites they were using:

Claire: *"Then, over a period of time, the site seemed to be taken over by some very young teenagers particularly, some at boarding schools and everything, and they were using the chat rooms and the messageboards making threats saying, 'I am going to kill myself now' and then they would sign off and things like that, and to me that wasn't helpful ... I know the Internet is all about free speech and free opinion and everything but for somebody, yeah, I mean, I won't deny, I, I have made three serious attempts on my life and a number of others and, I, I spent nearly three months in a coma and I have got liver damage and I live with that permanently and to then find sites on telling you how to commit suicide, I do find it somewhat distasteful (pause) and you, you had that on NetDoctor* [a health information website] *people were asking the best way to kill themselves and I can't deal with that, and a lot of people couldn't deal with that."*

Stuart: *"Unfortunately you do get people who come on there that are not ill. You can tell they are not 'cause they start arguing, not arguing but leaving nasty comments and like I have just said there was one person not long* [ago] *who come on and say, 'you are not depressed, you are just this, that and the other, get your self together'. ...When people come on and are being nasty like that, I don't like that."*

The major concern about using the Internet for health information for our interviewees therefore concerned disruptive online behaviour, rather than poor quality information.

3.3.2.5 Hearing about other people's experience

The importance of hearing about other people's experience of mental health problems was a very prominent theme emerging from the interviews and one of the main information needs identified. Individuals are particularly using the Internet in order to meet this need. This had not been anticipated in advance of the interviews.

Three sub-themes were identified relating to other people's experience:

- universality
- installation of hope
- understanding and empathy.

Universality refers to the benefit of finding out that one is not alone - that there are other people with similar problems. There was a remarkable similarity in the way many interviewees described this. To highlight three brief examples:

Interviewee 35 (Darren, a 27 year old accountant):

Darren: *"It's reassuring to know that you are not alone and that ... you know there are hundreds of people, thousands, I don't know the numbers, out there that are going through these experiences."*

Interviewee 18 (Brian, a 41 year old IT support worker):

Brian: *"It's nice to know that you are not alone. That other people have got the same problems as you. And they have been through the same sort of things, that's really nice."*

Interviewee 2 (Lisa, a 30-year old biochemist):

Lisa: *"I think it has helped in that, I understand that I am not the only person to act and behave in the way I do, Certainly since joining Borderline UK* [website] *its just so nice to read what people write, thank goodness I am not as mad as I thought I was."*

These quotes illustrate that knowing one is not alone is reassuring, and also that it helps the individual reject their notion of 'madness'. In these interviews madness was seen as something individual, idiosyncratic, an extreme deviance from normality. "Some kind of alien" as interviewee 15 put it. Whereas if you have something that other people also have, then you no longer see yourself as 'mad'. As these two interviewees illustrate:

Interviewee 21 (Penny, a 42 year old housewife):

Penny: *"I realised I wasn't going completely mad, I just thought I was the only one feeling these feelings and it* [finding out about other people's experience] *really helped me to sort of pin point it."*

Interviewee 31 (Sally, a 55 year old occupational therapist):

Sally: *"I think the most helpful thing was to know that some other people had similar feelings and I wasn't going mad."*

A further insight in to the benefit of universality - of knowing that you are not alone with your problem was given by interviewee 30 (Tom, a 50 year old building contractor):

Tom: *"There are things that you think, are they idiosyncratic? Are you the only person who has got them? You know, are they part of a condition, or is it some strange quirk of yourself? And when you hear somebody else say, 'hey, you know, this is happening to me' then it helps you to bring it out in the open and recognise it and accept it in yourself."*

So the knowledge of universality brings reassurance - that one is not *"going mad"*, because there are others like you - and also helps in the acceptance of having a problem - one can accept it because others have.

Installation of hope was the next sub-theme related to other people's experience that was identified. This refers to the benefit of not only knowing that one is not alone, but also that other people have had the same problem *and got better.* For example, interviewee 35 (Darren) who described the reassurance of knowing you are not alone above, goes on to say:

Darren: *"You can talk to people that have been through it, been through the medication cycle, been through the counselling cycle and come out of it. And that's very positive because then you, you personally feel, okay, I can go through this process and its going somewhere, I am not wasting my time doing this. I am not just treading water waiting for another big fall, you know, there is a light at the end of the tunnel as it were."*

Darren found this experiential information on the Internet as did interviewee 13 (Anna, a 27 year old teacher):

Anna: "As I got a bit braver and kind of went back to work and so on, I did the odd search on the Internet and I would read other people's experiences of schizophrenia and it was often by their families, or sometimes it was by the person themselves, and just hearing that somebody had recovered would mean so much to me because when I was still kind of in the recovering process, I was heavily depressed thinking that I was never going to be the same person that I had been before, I became ill, and reading experiences where people had recovered, it was such a boost, because you thought well, if they can do it, you know, I will be damned if I can't."

While it seems that the Internet is of particular value in locating experiential information from others, interviewees were also seeking this information from more traditional sources, such as support groups and books. For example, interviewee 14 (Caroline, a 43 year old care worker) used the Internet to carry out her own research but also found helpful information in books:

***Caroline:** "Its like, in the Overcoming Depression one* [a book], *there was like inserts of passages from people who had suffered from depression. So it was like, relating to that and like thinking, reading like the positive bits of it, like these people have actually got better."*

Understanding and empathy was the third sub-theme related to the experience of others. We found that individuals not only want to know that they are not alone and that others have got better, but they also want to interact with others or read material from others, because only other people who have been through the same experiences as them can truly understand and empathise with them - others know "what it's like".

Interviewee 34 (Lee, a 25 year old unemployed man) who has depression talked about his experience of using an Internet bulletin board, and the value of interacting with others who also have this diagnosis:

Lee: "They can understand and know what you are going through as well. ... If you have not been through the experience you don't understand what it is."

Interviewee 3 (Steph, a 35 year old unemployed woman) describes the value of interacting with others who 'know what it's like' in self-help groups and how a book she read by someone who had been through depression was one of the most useful books she had come across:

***Steph:** "I would say that from the books and from the self help group the most obvious thing that comes out is the first hand experience, I would say, because there are books that are written not as manuals, or textbooks whatever. They are written by people who have got depression and actually know exactly what it's like. And take Sue Atkinson for example, she's written some very good books where you know you can tell by the way its written she knows exactly what it is and she has been ill, you know, herself. And I think that's very very valuable, actually I think those are the most useful books I have come across. And then you have the first hand experience of people in the groups so I think that is the, fundamental thing, is the experience of it and people sort of saying what their situation is and then you relating to that. That's the best. ... And nobody sort of judges you which is very nice, 'cause people don't, I mean, people will just be supportive and they will listen and they won't sort of try and put words in your mouth,* *and they won't try and change your point of view and they wont say, 'oh you can snap out of it and you will feel better by doing X, Y and Z'. They don't do those things because they know what its like."*

Interviewee 16 (Claire, a 33 year old care worker) describes how personal information from other people with similar problems allows her to understand what "official" information "really" means:

Claire: *"You can reach the end of your doctor's knowledge and then you can go online, and you can talk to other people who have also been treated for years and years and years and they can help you to come up with new ideas ... For me, personal information is the most useful, you know, what it was like to take this particular drug, or what its like to have a particular condition because the person who has got it or who is taking that drug they can describe what it is really like and sometimes it then kind of makes sense. You may have seen that in the official description but you didn't really understand exactly what it meant."*

Claire identifies personal information as an information gap that her doctor was unable to fill.

3.3.3 Narrative examples

In order to demonstrate the linked nature of these five themes, two examples are presented below which illustrate these themes in single interview narratives.

3.3.3.1 Narrative 1: Mary

Mary (Subject 22) is a 38 year old social scientist. She has a history of eating disorder since the age of 18. As shown earlier (repeated here for convenience) she describes a lack of information from the health services:

Mary: *"I wanted to know more. Why I was being treated the way I was and I would have liked a better or any explanation of the diagnosis. ... Basically I was put on, on quite a lot of medication without any much, much explanation. ... There's been no choice, it's just been, this is what is wrong with you, and this is the cure for it and I find that extremely patronizing and not very helpful."*

As this excerpt shows, she describes the lack of information as a lack of choice and finds this patronizing. Elsewhere in the interview she contrasts her experience as a mental health patient with that of her son who has eczema. She describes how the dermatology nurse provides helpful information:

Mary: *She actually comes out and she talks with me and my son about what we can do and what different types of treatment, something similar to that. I think that would have been brilliant* [if she had had the same experience in mental healthcare] *and I would probably have been a much more co-operative patient as well. If I had been told what was going on. ... Because the doctor-patient relationship can be intimidating."*

Mary describes how she would feel if she had been given information about mental health in the way that her son was given information about eczema:

Mary: *"I would have felt that I was informed and that there was some respect for me* *that, that I actually was seen as being able to know what was going on."*

As a result of not receiving the information she desired, Mary has carried out her own research into her condition. She describes how she has learned to find things out for herself and how her research includes searching the Internet for information and the advantages of using it:

Mary: *"Well, well you do learn so you actually learn how to find out these things yourself. ...I would go on the Internet and try and find out what, because its such a, an unobtrusive, discrete way of doing it, I mean you can do it very privately without even, having to talk to another person."*

Finally Mary describes how helpful it was to find out that there were other people with the same problems as her.

Mary: *"I think its helpful as a support, just to know that there are other people out there who have the same, worries and, and problems as you have, and, and some of them will, will give you some kind of good advice or, or 'this is what I did'."*

Interviewer: *"And what is it that's helpful about other people being in the same situation?"*

Mary: *(pause) "Realising that you are not the only one."*

3.3.3.2 Narrative 2: Darren

Darren (Subject 35) is a 27 year old accountant. He became depressed after losing his job and consulted his general practitioner. He was prescribed antidepressant medication and given some advice about his lifestyle, but did not feel that he had received an adequate explanation of his illness or the treatment:

Darren: *"You walk away feeling, okay that's great but now here is this box of pills and get on with it."*

He therefore turned to the Internet to carry out his own research into the pills he had been given:

Darren: *"I did spend a lot of time doing some personal research."*
Interviewer: *"Right, and that was through the Internet?"*
Darren: *"Yeah.* [I] *searched for the drug name and that brings up dozens of sites."*

Darren reported that he could not turn to his friends for information due to his perception of the stigma that exists:

Darren: *"Its like, if I had said to a friend, you know, I am on antidepressant medication, they make that link to think, 'oh my God, he is totally off his nut'. So I can't tell my friends that I am on medication which sort of removes the level of support. Not even my closest friends because, because of the general perception of mental health."*

The anonymity of the Internet allowed him to avoid revealing his situation to anyone he knew:

Darren: *"I think the nice thing about the Internet is that its possible to remain* *completely anonymous, and yet have real time communication with people."*

As highlighted in the section on Theme 5 above, Darren reports the reassurance of knowing "that you are not alone" In particular he describes finding out about other people's experience of going through the process of finding the right anti-depressant medication for them:

Darren: *"There is a lot of people, obviously, on there that have gone through the same sort of process, and its quite open, and, 'cause its obviously anonymous and you are quite happy to chat about, what you are going through, and what your doctors have been saying, you can draw on other peoples experiences so that's quite reassuring."*

3.3.4 Deviant and negative cases

During the reading and coding of interviews we constantly compared the emerging findings across the interview transcripts, not only to identify common themes but also to look for contradictory or unsupportive evidence. In this section I will briefly describe and explain the areas of deviation from our identified themes.

The five linked themes emerged clearly from the data. The link between lack of information and lack of respect was made explicitly by some participants, and was implicit in the responses of others. There were one or two deviant or negative cases who were satisfied with the information they had received and/or who did not feel disrespected. However in these cases it was noteworthy that the individuals reported this as being exceptional, and explained "how lucky" they were to have had a good experience. It was clear that even those individuals who had experienced receiving adequate information considered this to be unusual, and had an expectation of information lack.

Not everyone had conducted their own research, but those that had all recognised that the potential problems this presented for their health professionals. When individuals had not conducted their own research this was linked primarily to stage of illness. Several reported that when they had first encountered mental health problems they had been too unwell (often reporting lack of concentration) to undertake research, although they would have liked to know more. We therefore did not consider that these cases threatened the identification of this theme, although perhaps it limits the period of personal research to a time after the acute phase of illness. This may be disease-specific as lack of concentration and poor motivation are elements of depressive illness.

The perception and effects of stigma were evident across the interviews, often implicit rather than stated explicitly. Individuals who volunteered an understanding of mental illness all displayed elements of mind/body dualism in their thinking. None of the interviewees felt that having mental health problems allowed them to be seen in a more positive light.

Having deliberately oversampled individuals who use the Internet, it is not surprising to find many individuals undertaking their personal research using this means. However the content of this theme is related to the advantages and disadvantages of the Internet as a source of health information, rather than Internet use *per se*. Convenience, anonymity and privacy were valued by most users, and the consequences of misuse by others was the most substantial reported problem. One Internet user deviated from this in believing that her identity could be traced if she used the Internet and therefore avoided posting online messages. This is understandable as many messageboards require an email address. Inaccuracy of online information was reported as a problem but inaccuracy was also reported in other sources such as the mass media and leaflets whereas misuse was much more Internet-specific, and a more prominent theme.

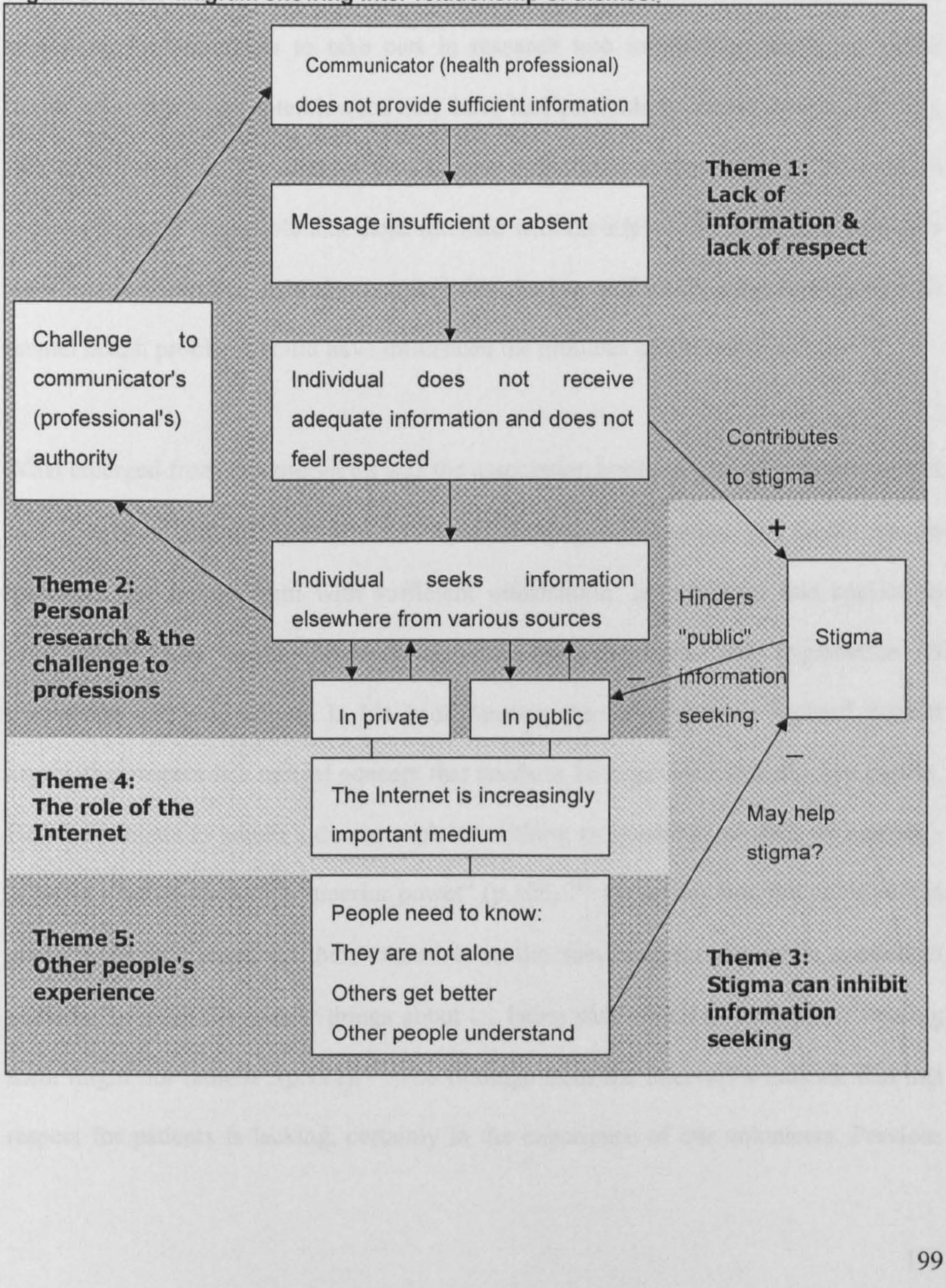
Regarding the final theme, there were very few examples of deviance from wanting to hear about other people's experience. Two interviewees were not interested in the experience of others, both preferring scientific facts from their doctor or a textbook. These individuals had academic or scientific backgrounds. It is important that this theme is not interpreted to mean that information from official sources was not generally valued, but that when individuals were interviewed about their information needs, the desire to have more experiential information from others in the same situation was very striking.

3.4 Discussion

3.4.1 Summary and discussion of themes

The interlinking themes identified are summarised in Figure 3.1. In the subsequent sections I will discuss these, in relation to the findings from previous research.

Figure 3.1 Flow diagram showing inter-relationship of themes.



3.4.1.1 Lack of information and lack of respect

Lack of information is a frequent finding in the health information literature. The limited previous research in the area of mental health shows this,[91,479] as does the more researched area of cancer information needs which has repeatedly demonstrated that there is less information available than health service users want.[316,480] Dissatisfaction with information giving has also been shown in primary care.[481] For this project we advertised for volunteers to take part in research into information needs in mental health, and clearly the interviewees may have had particularly stories to tell regarding lack of information. We attempted to sample individuals with a range of information experience but it is possible that those satisfied with their level of information provision were less forthcoming. It is also possible that the low self worth often associated with mental health problems could have influenced the attitudes of interviewees.

What emerged from the interviews was the association between lack of information and lack of respect, and that individuals feel patronised or disrespected by a health service that does not supply them with sufficient information. In particular this applied to information from health professionals regarding diagnosis and explanation of medication and side effects. In his book *Respect* the social theorist Richard Sennett argues that respect is a mutual concept that needs to be negotiated between two parties. He sees patients to whom a doctor explains nothing as spectators to their own needs - "objects worked upon by a superior power" (p.106).[482] He argues that just as respect is given to doctors based on their expertise, so the same respect should be granted to patients "because they know things about ... being sick which the person ... treating them might not fathom" (p.122).[482] The findings from the interviews indicate that this respect for patients is lacking, certainly in the experience of our volunteers. Previous work has also shown that even when information is provided this can often be patronising in style.[28]

In *The Autonomous Patient,* Angela Coulter argues that clinicians should facilitate the process of moving away from a paternalistic model of medical care to one where patients are equal partners in the management of their illness.[64] This facilitation includes giving appropriate information to encourage and support informed decision making. Coulter summarises the evidence which clearly demonstrates that patients want to be more informed about their care than they are at present. This includes research showing that failures in information giving are the commonest source of patient dissatisfaction.[483,484] Coulter presents findings from her own work with the Picker Institute in five European countries which show that respect for patients' preferences is often lacking.[64] Studies have shown variation in the extent to which patients wish to be informed about their care, but it is clear that describing the experience of a lack of information, and associating this with a lack of respect, is not a surprising finding from our study.

3.4.1.2 Personal research and the challenge to professionals

The second theme around personal research and the challenge to health professionals again supports the need for more of a partnership between the patient and the practitioner, or at least an interaction in which the patient feels comfortable about raising issues that are important to them. Other research has shown that patients, particularly when dissatisfied with the information they have received from healthcare professionals, will undertake their own research into their condition using a variety of sources including the Internet.[316,481,485] It is interesting that many of our interviewees recognised that their information research can represent a challenge to health professionals, something which has been discussed by many commentators,[1] [47] [343,344,486,487] and which is now being supported by empirical evidence from studies of both healthcare professionals,[346,354] and patients.[351,488]

For both the first two themes, lack of information is seen as disempowering. At one level, the information needs here are for a degree of information giving that makes health consumers feel respected, and for an environment that supports personal research into illness and values the contribution patients can make to the consultation. Underlying these needs is the need for a strong and more equal partnership between health consumers and health professionals.

3.4.1.3 Information seeking can be inhibited by stigma

The third theme, concerning stigma and information seeking, is grounded in the descriptions interviewees gave concerning how stigma can inhibit the seeking of information and other help. The stigma felt by those with mental health problems has been well documented.[489] In Goffman's terms, mental illness is a discreditable stigma, that is a stigma which is (usually) not immediately apparent.[490] However the act of seeking information or other forms of assistance reveals the stigma, thereby rendering the individual discredited. One could postulate that individuals therefore avoid information seeking in order to avoid becoming discredited, and other work shows that people with mental health problems often do not disclose these problems, and that the stigma can lead to isolation and the avoidance of help-seeking.[489] However, it is interesting that a frequent comment in our interviews was that the participants would find it easier if they were to have a visible (i.e. discredited) problem, such as a broken leg. Interviewees valued having explanations of their problems in physical terms, for example "a chemical change in the brain". It has been speculated that identifying a physical basis for mental disorder could reduce stigma.[491] It seems that there is something about the nature of mental illness, which makes people feel ashamed when this diagnosis is apparent. In terms of Parsons's sick role, these individuals with experience of mental health problems did not feel that they had the right to be absolved of responsibility for their condition.[492] Having a mental health problem was seen as a personal failing in a way that having a physical health problem was not. This finding is supported by a US survey of public attitudes to depression, conducted by the National Mental Health Association, which found that 43% of respondents believed depression to be a "sign of personal or emotional weakness".[493] An Irish survey also found that depression was widely viewed as a sign of being weak-willed or feeling sorry for oneself.[494] The predomination of negative cultural stereotypes of mental illness produces and maintains this stigma. The need here is not a direct information need, but a need to reduce the stigma associated with mental illness.

3.4.1.4 The role of the Internet

Regarding the fourth theme, as described in the literature review various other studies have identified the benefits of the Internet for health consumers of anonymity and convenience of access.[23,281,315,395] Our interview analysis supports these previous findings particularly around the advantages of "privacy". Privacy encompasses both anonymity and the private access that people have to the Internet in their own homes. Privacy and anonymity are important for the avoidance of stigma. The Internet is both a medium of mass communication and for individual interaction. It can provide both a public and a private space for information seeking from a variety of sources while allowing the concealment of individual identity.

Two recent studies support our finding that users do place trust in certain websites and that these are usually related to organisations they would trust in the real world.[495,496] A focus group study in eight European countries found that participants often reported a feeling of being overwhelmed by the volume of information on the Internet, and had concerns about information quality.[23] While we found that individuals did express reservations about the reliability of online information, they were actually more concerned with Internet misuse than with untrustworthy information. This is supported by a US population survey which showed that 81% of Internet users expect to find reliable information about health or medical conditions online.[497] Indeed 46% of Internet users in this survey said they would use the Internet as the first source next time they needed reliable medical information, compared with 47% who would contact a medical professional. This is interesting in the context of the overwhelming volume of articles published in the biomedical literature expressing concern at the quality of online information.

3.4.1.5 Other people's experience

Previous work has shown that one source used by people seeking health information is other people with the same experiences.[5,87,498] What this study adds is some understanding of the reasons for seeking experiential information on the Internet. Communication dynamics on the Internet have been likened to the interactions in psychotherapeutic groups.[499] There are similarities between a group of individuals with common mental health issues assembled together with therapeutic aims, and individuals with mental health problems choosing to seek out help from others online. Preliminary studies of online support groups show that the processes found in face-to-face support groups are present online.[500,501] It is striking that our findings regarding the value of hearing about other people's experience reflect several of the characteristics that the group psychotherapist Irving Yalom identified in his therapeutic factors in group therapy.[502] These characterise the ways in which Yalom felt group processes helped individuals. Yalom's factors are listed in Table 3.2.

The first two factors of instillation of hope and universality are clearly reflected in our own findings, and I explicitly used his terminology in this thesis when it was clear that we were describing the same thing. The concept that I have described as the understanding and empathy of others relates to Yalom's factors of 'imparting of information' (the benefit of which he described as conveying "mutual interest and caring" rather than specific information) and 'altruism' (of those providing the understanding and empathy). Yalom did not propose the eleven factors as separate concepts in isolation, but as being linked and interdependent. The concept of universality - of 'knowing you are not alone' has been demonstrated in studies of non-Internet communication, particularly in the area of cancer care. In the field of mental health, the charity Rethink (formerly the National Schizophrenia Fellowship) have recently published a research report on patient self-management, based on interviews, focus group discussions, and a questionnaire survey of individuals with schizophrenia.[503] This showed that a number of respondents reported relief at finding out that other people had the same unusual experiences, and talking with others with similar experiences was seen as the most helpful way of obtaining this information.

Table 3.2 Yalom's therapeutic factors in groups[502]

Therapeutic Factor	**Explanation of benefit**
1. Instillation of Hope	Interacting with others who have had similar problems and have coped with them effectively gives hope.
2. Universality	Knowing that you are not alone in your suffering gives relief and reassurance.
3. Imparting of Information	This includes both didactic information from a therapist but also information given by other group members. The benefit of the latter is not for the content of the advice, but that it conveyed "mutual interest and caring".
4. Altruism	Receiving through giving - the benefit felt by group members from giving support, reassurance, suggestions, and insight to others. The feeling of usefulness.
5. The corrective recapitulation of the primary family group	The group provides its members with the opportunity to relearn primary relationships in a more healthy way and to clarify distortions.
6. Development of socializing techniques	Groups are a place you can be with others, listen, and talk to others and develop social skills.
7. Imitative behaviour	Group members can learn new (healthy) behaviours by imitating others - also described in social learning theory.
8. Interpersonal learning	By receiving feedback from others (including the therapist) and experimenting with new ways of relating, group members can learn to know themselves in the ways in which they are known.
9. Group cohesiveness	The relationships that members of a cohesive group develop facilitate healthy intimacy and relationships.
10. Catharsis	The benefit of being able to vent and explore feelings and gain relief from having expressed them.
11. Existential factors	Group members benefit by learning of the universal nature of pain, death, isolation, and individual responsibility.

Clearly individuals want hope - it is not surprising that people want to know that they will get better. The value of hope to aid the recovery of mental health patients has been discussed.[504] The imparting of hope as an information need has been shown in studies of cancer patients.[87,505] What the present study demonstrates is that hope can be gained not only from factual information from the healthcare provider, but by talking to other people who have been through the same situation, and who have got better - experiential evidence that there is hope. The need for understanding and empathy from others who have been through the same experiences is also not surprising, but it is interesting that individuals are going online to find this.

While previous work had described the fact that patients do exchange information with each other online,[279,284] and there had been discussion regarding the benefit of contacting other patients online,[506] the value of hearing other people's experience on the Internet had not previously been the subject of empirical investigation when this research was started. However there are now some other emerging findings. An in-depth qualitative analysis of postings to three Internet discussion fora for people with systemic lupus erythematosus showed that users are sharing information about their own experiences with each other to give emotional support to others with this chronic condition.[507] A grounded theory study of an email list for parents of children with autism identified the 'narrative sharing of experiences' as one of four main themes, along with 'searching for meaning', 'adjusting to changes', and 'providing support and encouragement'.[508] In two thorough qualitative studies Ziebland and colleagues have shown that cancer patients use the Internet (amongst other reasons) to find experiential information from other patients.[315,495] The sociologist Michael Hardey has discussed how his studies of interviews with Internet users and analysis of Internet-based illness narratives show that individuals use the Internet both for finding out and displaying personal experiences as well as for professional information and advice, and how the sharing of experiences is part of a wider shift in the relationship between lay and medical expertise.[488]

3.4.2 Validity

The concept of validity in qualitative research is much debated,[509] and the assessment of validity is clearly a contentious matter.[510] Checklists of validity criteria have been criticised for their rigidity and for leading to homogenised, consensus methods and restricting innovation.[510] Yet to have credible results with implications that can reasonably be generalised, qualitative research requires rigorous, systematic methods which should be subject to critical analysis. The generalisability of qualitative findings is not related to the representativeness of the sample but to the validity of the emergent concepts which may have relevance in other settings.[511]

Based on a synthesis of recent work and her experience of reviewing publications and grant applications, Barbour identifies five techniques that strengthen validity, if used within a broad understanding of qualitative research.[512]

These are:

- Purposive sampling
- Grounded theory
- Multiple coding
- Triangulation
- Respondent validation.

I shall explain how we addressed the issues raised by each of these.

We employed **purposive sampling** in order to cover the diversity of experience and views of the population of mental health users, and to seek deviant (or negative) cases. Green emphasises the importance of researchers explicitly seeking to falsify emergent hypotheses through such theoretical sampling and accounting for deviant cases.[511] Purposive sampling is clearly preferable to convenience sampling (for example of a clinic population) as it offers researchers a degree of control and reduces the selection bias of convenient samples.[512] The nature of our recruitment methods, using primary and secondary care settings, user organisations, and Internet sites, provided a diverse population to sample. One issue is that in a study that relies on volunteers, it is likely that many participants may have been active help-seekers, a description which does not apply to all those with mental health problems.[513]

We used a **grounded theory** approach for the analysis. Grounded theory is a term "invoked with greater frequency than it is practised".[514] Various commentators have warned that such an approach can be used as a convenient label to achieve academic credibility for work that is no more than journalistic reportage.[511,512] In its pure form, the grounded theory approach demands that the researcher does not allow any prior knowledge to impinge on the emerging results. We therefore used a modified version of grounded theory. This acknowledges that while the theory is grounded in our qualitative results, it has also been informed by the prior knowledge of the researchers and the results of the literature review. It allowed us to use the topic guide when conducting the interviews and to use our prior knowledge when identifying codes. Much research labelled as 'grounded theory' uses the same compromises but less explicitly.

The modifications we made to grounded theory were therefore: (1) use of a topic guide as an interview prompt; (2) our prior knowledge as health professionals, and having completed the literature review, informed our discussion of axial coding; (3) the process of selective coding identified a group of explanatory concepts not just one single unifying theory.

The constant comparative method ensured that attention was paid to deviant or negative cases and that attempts were made to falsify emergent hypotheses as the interview data were analysed.[477,511]

We employed **multiple coding** of the interviews, with two researchers independently reading and coding all transcripts, then subsequently meeting to compare and discuss the results. The aim of multiple coding is not to achieve complete concordance but to be used as a cross-check for coding strategies and interpretation of data, and to enable insights to be gained from areas of disagreement and discussion between the researchers. The meetings that we held to discuss our coding were very useful in clarifying the five main themes and discussing how they fitted with each other, and with the graphical summary of the process of information seeking. The dialogue also helped to reduce the potential for bias in identifying themes.[515]

The fourth technique is **triangulation**. Triangulation as a test of validity has been criticised both from a relativist perspective (triangulation assumes a fixed point of reality that can be viewed from different angles) and because it can lead to the data losing the value it gains from being seen in the context in which it was collected.[510] Furthermore, triangulation only tells you whether differing viewpoints concur, not whether or not they provide an accurate interpretation.[516] Nevertheless finding similar results using different methods at the very least provides reassurance, and supports the credibility of conclusions. We did not use multiple qualitative methods (see discussion of alternative approaches, below) but multiple methods of literature review and a quantitative survey (see next chapter) were used to provide triangulation to the project as a whole.

Finally Barbour identifies **respondent validation** – the process whereby interim findings are cross-checked with the participants in the research. We did not undertake this. This was partly due to constraints on time and the practical difficulties entailed,[510] but also because of the concerns that have been expressed regarding respondent validation.[472] Murphy and colleagues have characterised these as: problems with isomorphism; with textual reference; and with three problems related to context - transactional, relational and organisational context.[510] Isomorphism is a concern as researchers and interviewees should not be expected to have identical perspectives on the data collected and respondent checking may wrongly influence a legitimate interpretation by the researcher. Textual reference (after Emerson and Pollner[517]) describes the problem whereby respondents do not necessarily read the material they are presented with or engage with it in the way the researcher wishes. Respondents may use the opportunity of validation to comment on other issues. The contextual problems are related to respondents believing that there are other purposes for the validation than simple checking - they may feel they are obliged to find errors, or conversely may feel a duty to confirm everything, regardless of whether it is accurate.

A final component of validity described by some authors is **transferability**.[518] This relates to the notion of representativeness in quantitative research, and requires description of the characteristics of the participants and the setting in which the research was undertaken in order that judgements can be made about the extent to which emergent themes may be applicable in other contexts. We have therefore provided a table describing the characteristics of participants and have outlined the setting for this study.

3.4.3 Reliability

Rigorous qualitative research must be reliable.[474] Reliability in qualitative interview research encompasses both the expertise of the investigators in all aspects of the research - from protocol development to coding and analysis - and the careful documentation of all procedures. Reliability is strengthened if the researchers have the required training and experience in the methods used, and these methods are well documented and open to critique.[474] I attended training courses in interview methods and in qualitative methods prior to undertaking this research. The methods have been documented above to allow scrutiny. A professional transcriber was used for all interviews and several transcripts were checked for accuracy. Coding was thorough and systematic. Computer software was used to facilitate the process of selective coding and the subsequent analysis.

Some authors include the concept of 'reflexivity' within reliability in qualitative research.[519] According to Malterud reflexivity is "an attitude of attending systematically to the context of knowledge construction, especially to the effect of the researcher, at every step of the research process".[467] My status as a medically and psychiatrically qualified practitioner was not shared explicitly with study participants. Professional roles can influence the interactions of qualitative interviews, and possibly the data obtained.[520] Preconceived views of psychiatrists may have influenced respondents. In the study adverts and information sheets I was described as a researcher working for the NHS and London University, and I gave the same description when introducing myself in person. However if an interviewee asked me directly about my qualifications I did disclose that I was medically qualified. This happened on two occasions. All participants were aware that the NHS funded this research and this was made explicit on the information sheets. The information sheets made it clear that the interviews were unrelated to any NHS care that participants might receive and I made it clear that I had no connection with the local NHS other than using their premises. Nevertheless the fact that I could be seen as a representative of the NHS had the potential to influence the content of interviews, although it is clear that many participants were still able to relate their negative experiences of the NHS.

One final aspect of reflexivity for this study was our prior knowledge and experience as NHS clinicians when analysing data. The modified grounded approach took account of this. Inevitably our own views had the potential to impinge on the emerging findings, but we attempted to minimise this bias through personal reflection on my role in interviews; thorough immersion in the data (reading and rereading) so that as far as possible the concepts were truly grounded in the interview results; and through joint discussion and challenging of our respective coding.

3.4.4 Ethical Considerations

Richards and Schwartz have identified four potential risks to participants in qualitative health services research.[521] These are: anxiety and distress of participants; exploitation of participants; misrepresentation of findings; and identification of participants in published results, either by self or others. In the same paper the authors identify five steps that qualitative researchers can take to minimise these risks.

The first step is **scientific soundness**, which is that the project should be necessary (to fill a gap in the research knowledge base), properly designed and carried out by qualified researchers with adequate supervision. We identified the need for this research through reviewing the existing literature, consulting with experts in the field and through the peer-review of the funding application. We designed and refined the protocol in discussion with the advisory group. I attended training in advanced qualitative methods and a specific qualitative interviewing training course.

The second step to minimise risk suggested by Richards and Schwartz is to **provide follow-up care**. Participants may present with a current health problem and it is ethically advisable to arrange for them to see a health practitioner for this. In this project a consultant psychiatrist (Professor Geddes who collaborated on this project as Director of the Centre for Evidence-Based Mental Health) agreed to see any participants who were in need of urgent assessment (for example if they expressed current suicidal ideas). For participants requiring less urgent follow-up care it was agreed that I would write to their general practitioner (having obtained the prior permission of the participant to do this). In practice neither of these two courses of action was required for any participant.

The third step is that of **consent**. In our study all participants were required to read an information sheet and then provide written consent to take part in the study. The consent form was detailed (see Appendix 4), requiring acknowledgement that the information sheet had been read and that an opportunity for further questions had been given; an understanding that participation was voluntary; agreement with the audiotaping of interviews; agreement with the use of anonymous quotes; and finally consent for overall participation in the study.

The fourth step is to **avoid misrepresentation and misinterpretation**. Richards and

Schwartz suggest two approaches. To minimise misinterpretation they recommend the use of a co-worker in the interpretation of data, and we used two researchers in the analysis of transcripts (my supervisor and I). They also suggest that respondent validation can be used to reduce the chance of misrepresentation. Tape-recorded, transcribed interviews should minimise misrepresentation. As explained in Section 3.4.3 we did not take the further step of respondent validation because this would have required an unnecessary amount of further voluntary commitment from our participants and given the length of time that it took us to recruit participants and subsequently analyse data it would be impractical. As discussed above, this technique has also been criticised as the comments from respondents can be an *interpretation* of the results rather than a validation of the data.[522]

Finally **confidentiality** is recommended as a method of reducing the risks to participants. All our tape recordings were kept securely in a locked cabinet when not being used. Tape recordings, electronic and paper transcripts were all labelled with a study participant number only. No personal identifying labels were used on any of the interview materials. The key to the study participant codes was kept separate and secure.

3.4.5 Problems encountered

The first problem encountered related to a delay resulting from the ethics committee approval. Provisional approval was granted quickly, subject to changes to the information for patients and the obtaining of an honorary NHS contract. There was then a delay while the information sheet changes were submitted and resubmitted, and the contract was obtained.

The second problem related to slow recruitment. Despite using all our planned methods of recruitment, there was an average of only one volunteer per week. I attended several psychiatric outpatient clinics and inpatient units to personally explain the study to boost the recruitment. I also reminded Oxfordshire general practitioners, consultant psychiatrists and clinical psychologists about the study in order that they could pass the information to potential participants. Recruiting women was easier than recruiting men. Women are more likely to experience mental health problems,[523] and it is possible that they were also more likely to volunteer for interviews about information sources. We were also not able to recruit many participants from black and minority ethnic groups - recruiting two out of 36. We considered the possibility of offering incentives to volunteers but as we had no budget for this, and it would have entailed submitting a revised proposal to the ethics committee, we did not pursue this. In any case, financial inducements to take part in research are generally disapproved of by research ethics committees.

Where possible, interviews were conducted face-to-face, either in the participant's home or using an outpatient clinic room. In general, clinical settings are not considered ideal locations for interviews, but the outpatient rooms used in this study were designed for in-depth psychiatric interviews, were situated in a building which is not part of the hospital, and the interviews took place when no other clinics were in progress. Individuals who were recruited after seeing the study website were inevitably spread across the UK. When it was not possible to arrange to see them in Oxford I conducted the interview by telephone. Telephone interviews are sometimes criticised for lacking the benefits of non-verbal communication that are picked up in a face-to-face situation.

There is some evidence that answers to open questions can be shorter and the interview proceed more briskly than with face-to-face interviews.[524] However research also suggests that telephone methods are as successful as face-to-face interviews in eliciting information related to health and health-related behaviour.[524] In practice the data from the telephone interviews in this project were as valuable in the analysis as the data from the face-to-face ones and no significant problems were encountered.

Regarding the tape recording of interviews, on one occasion the recording did not start until five minutes into the interview due to interviewer error, but as this was identified at the time the interview was restarted. On one occasion the recorded sound level on a telephone interview was very poor, but fortunately the transcriber was still able to accurately transcribe the text. Audiotaping and subsequent transcription is a more reliable method of recording interviews than note-taking, but transcription is time-consuming and costly.[475]

The only other problem encountered was that one volunteer was too unwell to give a clear account, although this was not apparent until the interview started. Her schizophrenic symptoms of thought disorder and paranoid ideas were too prominent in her narrative to allow meaningful use of her interview data.

3.4.6 Alternative approaches

A qualitative approach was necessary to explore concepts and behaviours of people within their social world.[510] Although we adopted an unstructured interview approach, we considered several alternatives. In particular we looked at other qualitative methods that have been used to identify information needs. These approaches have been summarised by Nicholas,[73] and by Case,[457] and are described in Table 3.3 with the advantages and disadvantages of each approach in relation to this research question.

Table 3.3 Alternative qualitative approaches to identifying the information needs of mental health users (after Nicholas (2000) and Case (2002)).[73,457]

Method	**Main advantages**	**Main disadvantages**
Structured interviews	Ensures some standardisation of questions asked. Easier to analyse than unstructured responses. Can test specific hypotheses.	No opportunity for in-depth exploration of a topic. Not very flexible and difficult to pursue new ideas arising during the research.
Focus groups	Useful for obtaining views from large number of participants in relatively short space of time. Can explore topics in-depth. High face validity. There are pre-existing groups of mental health users.	Practical difficulties in assembling groups and recording all contributions made. Less easy to control than an interview. Tend to give you a group view rather than a collection of individual views.
Diary sampling	By asking participants to keep a diary relating to their information needs, specific data can be recorded close to the point of action. Can identify intent as well as behaviour. Relatively quick method of collecting large amount of data.	Prone to bias in how participants choose what to record. Also problems with completeness and accuracy and high drop-out rates.
Participant or non-participant observation	Obtain an unfiltered view of what actually happens. Participants do not need to do anything other than provide consent. Would include people who had not volunteered to tell their story about their information experiences.	Observation can affect what is being observed. Can only observe actions, not beliefs and intents. Difficult to choose a setting to observe mental health users - a ward or a clinic or a library would only cover one small aspect of information behaviour. Following individuals in various settings would be very time-consuming.
Documentary or content analysis	For example, analysis of posts to an Internet discussion forum. Can make deductions about information needs and behaviour by analysing content of messages. Data collection can be quick and easy.	Ethical issues regarding analysis of private messages without consent. Analysis of multiple messages very time-consuming. Difficult to decide what and how to sample. No opportunity to explore the meaning or purpose of messages with the author.

This chapter has described and discussed the in-depth qualitative interview study investigating the information needs and behaviour of mental health users. In the next chapter I describe the second part of this project, a quantitative cross-sectional population-based survey.

4. Cross-sectional Survey

4.1 Introduction

In this chapter I describe the design and administration (Section 4.2) of a population-based cross-sectional survey to further investigate the research questions with respect to the health information needs of people with mild and moderate mental health problems. I undertook descriptive, univariate and multivariate analysis of the survey (Section 4.3) and I discuss the results as well as the strengths and weaknesses of this methodology (Section 4.4).

In order to obtain the views of a representative sample of the general population regarding mental health information needs, a cross-sectional survey was carried out. The content of this self-completion postal questionnaire was informed by the results of the literature review and interview analysis. Cross-sectional surveys are useful in quantifying the views of a large number of people in a relatively cheap and timely manner. They have been used successfully in previous information needs research.[73,457]

The aims of this survey were:

- To quantify the main mental health information needs and attitudes towards information sources identified in the qualitative work;
- To investigate the relationship between current mental health status and mental health information seeking, including the use of the Internet;
- To investigate respondent attitudes to stigma and mental health problems, and the relationship between stigma and Internet information seeking.

The survey was posted to a random sample of the Oxfordshire population. My supervisor at the Institute of Health Sciences and my collaborators at the Centre for Evidence Based Mental Health had established links with the Oxfordshire Health Authority Information Specialists who helped with the population sampling; the Oxford University Health Services Research Unit who gave advice based on their experience of previous surveys; and with local general practitioners.

4.2 Methods

4.2.1 Design of questionnaire

The design of the questionnaire was informed by my literature review findings and the interview analysis. I attended the course "Design and Administration of Postal and Self-Completion Surveys" run by the Centre for Applied Social Surveys, and the course and accompanying workbook informed the design of the questionnaire, alongside a recent review of the literature on questionnaire design.[525,526] Where possible, questions from previous relevant surveys were used. When no such question was available, relevant experts were consulted about question wording. When all questions had been designed, piloting and pretesting was undertaken to ensure that the survey instructions were understood, that the questionnaire had a clear layout, that the questions were readable and interpreted correctly, that they were placed in an appropriate order, and that they could be easily answered.

Table 4.1 shows the domains of interest and how these were operationalised into questions, which were refined in pre-testing. The final survey is shown in Appendix 5.

Table 4.1 Domains, items, questions and sources for the postal questionnaire survey.

Domain	Items	Question (with question number)	Source
Individual characteristics (including demographics)	Age	1. Please indicate your age group (choice 1 from 8).	Survey methods course.
	Sex	2. Please indicate whether you are male or female (choice of male or female).	Survey methods course.
	Educational level	3. Please indicate the highest level of educational qualifications that you have obtained (choice 1 from 8).	Office of National Statistics - personal contact.
Mental health status	Current mental health status	14. Finally please would you complete the 12 questions of the General Health Questionnaire on the page opposite (12 items, each requiring a response).	GHQ-12.[527]
	Past psychiatric history	13. Have you ever had a serious mental health problem that you consulted a doctor about? (choice of 1 from 4).	Developed in pre-testing.
Information needs	List of possible information needs	12. If you had a mental health problem what sources of information would you be most likely to use to find out more about this? (choice of 3 from 14 options).	Based on interview findings and literature review, e.g. Price 2002.[97]
Sources of information	List of sources of accurate information	4. Please read the list below and indicate which of these sources of information in your view provide the most accurate information on mental health issues. (choice of 3 from 13 options).	Based on interview findings and literature review, e.g. Pennbridge *et al* 1999;[27] Diaz *et al.* 2002.[305]
	List of sources you would use	11. If you had a mental health problem what sources of information would you be most likely to use to find out more about this? (choice of 3 from 14 options).	Based on interview findings and literature review, e.g. Pennbridge *et al* 1999;[27] Diaz *et al.* 2002.[305]
Internet use	Internet use	5. Have you ever used the Internet? (yes or no).	Based on surveys of Internet use, e.g. Pew Internet & American life project surveys.[52,53]
	Frequency of use	6. How often do you use the Internet? (choice of 1 from 5).	
	Internet use for health information	7. How many times have you ever used the Internet to find out about any aspect of health or healthcare? (not just mental health issues) (choice of 1 from 4).	
	Internet use for mental health information	8. How many times have you ever used the Internet to find information about a mental health issue? (choice of 1 from 4).	
	Internet use to chat about mental health	9. Have you ever used the Internet to chat to other people about mental health issues? (yes or no).	
Stigma	General perception of stigma	10. Do you agree or disagree with...In general most people have negative attitudes towards others who have mental health problems.	Derived from previous surveys and theoretical literature on stigma, e.g. Wahl 1999[528]; Lai *et al.* 2000.[529]
	Personal feeling of embarrassment	10. Do you agree or disagree with...It is embarrassing to have a mental health problem.	
	Not wanting others to know	10. Do you agree or disagree with...If I had a mental health problem I would not want other people to know.	
	Stigma inhibiting information seeking	10. Do you agree or disagree with...Other people's attitudes to mental health problems would prevent me from looking for information on mental health issues.	
Empathy or understanding of others	Other people with the same experiences understand these better	10. Do you agree or disagree with...People who have had a mental health problem understand this problem better than the mental health professionals.	Based on interview findings.

As can be seen from the table and the final survey, demographic questions on age, sex and educational status were included. It was important to include some measure of social status, in order to allow for the effect of this (and the demographic variables) when analysing the relationship between health status and information use. The ward-level score on the Index of Multiple Deprivation 2000 (IMD) was available,[530] but this is subject to ecological bias because an individual living in a deprived area is not necessarily personally deprived. The IMD score is based on routine data in six domains collected in the census and by local authorities (the domains are: income; employment; health and disability; education, skills and training; housing; and geographical access to services). The IMD score for each individual's postcode in the survey sample was calculated and used for comparisons between respondents and non-respondents, where no other data were available. However, for the analysis of respondent data alone, a more accurate individual measure of social status was preferred. This was discussed with Dr Roger Thomas, Deputy Director of the Centre for Applied Social Surveys, who recommended that rather than use the standard validated eight combined questions to determine social class (which would lengthen the questionnaire considerably),[531] it would be advisable to use one question to determine the highest level of individual educational attainment. I subsequently discussed the wording of the question with Dr Tony Manners of the Office of National Statistics (ONS) Social Survey Division who had recently reviewed the measurement of educational attainment,[532] and he gave advice on the wording of this question.[533]

In order to measure the mental health of respondents I used the short form of the General Health Questionnaire (GHQ-12), a validated self-completion instrument to assess current mental health status.[527] This was chosen for its established validity and its brevity. This was used under licence from Nfer-Nelson. As the GHQ-12 measures current mental health distress, one question regarding past psychiatric history was also included.

In order to investigate specific information needs, and the sources of information which were used and which were regarded as most accurate, item response questions were included which required respondents to choose up to three responses from a limited list. This provides an answer to a particular question: 'How many people list a particular source or need in their top three choices?' The content of this list was based on interview results and the information needs literature review, and was refined during pre-testing. The lists of information needs and sources specifically included items related to hearing the experience of others, as identified in the interviews. One of the attitudinal statements in question ten was used to investigate further the value of hearing information from someone else who had been through the same problems, enquiring whether it was felt that these people had a better understanding of mental health problems than health professionals.

The interviews demonstrated the importance of stigma, and how this can affect information seeking. Attitudinal questions were therefore designed to allow an estimate of the prevalence of perceived stigma (to what extent do people feel that others have negative views regarding mental health problems), as well as the prevalence of felt stigma (do people feel that mental health problems are embarrassing, and would they prefer others not to know about them). One attitudinal statement was also included to directly enquire about the possible effect of stigma on information seeking.

As one of the main outcomes of interest of this research, several questions were included to investigate Internet use, both in general and with respect to health and mental heath information. Again, these questions were based on the literature review findings, derived from surveys investigating the use of online health information.

The above questions were all subjected to pre-testing.[534] Cognitive pre-testing was undertaken to check how respondents coped with the draft questions and instructions; whether questions were understood as intended; whether there were any difficulties in answering questions; and to review questions for inclusion, exclusion or revision.[525,535]

Cognitive interviewing has been shown to be a useful method for exploring how respondents understand, interpret and respond to questions.[526] Draft questions were given to a convenience sample of 12 adults (both male and female, age range 24 to 73, including several current users of mental health services). Each was asked to 'think aloud' as they described their understanding of the instructions and the questions, while I took notes of their reactions and thought processes. Direct questions were used to prompt responses, for example "what did you think you needed to do to answer that question?"[525] Members of this sample were also encouraged to make written comments on the draft questions, and to suggest alternative questions. The wording and sequence of questions, and the format for responses were revised in response to this pre-testing.

Piloting of the questionnaire followed pre-testing, when the revised questions were put together in a draft final layout, together with the instructions and accompanying documentation. The appearance of the questionnaire was informed by best practice in questionnaire design, based on research findings,[526] and supported by expert opinion from the Centre for Applied Social Surveys. A double-sided A4 booklet format was used. The layout avoided crowding questions, and questions were not split across pages. A large 14 point font size was used. The front cover contained the title of the survey, the NHS logo and brief instructions, including assurances about confidentiality. The back cover contained a 'thank you' message and contact details. The questionnaire was kept as brief as possible as having a shorter rather than a longer questionnaire is associated with a higher response rate.[536]

Copies of the draft questionnaire, instructions and covering letters were sealed in dummy addressed envelopes and given to a convenience sample of five adults for piloting. Members of this sample were asked to comment on how they would respond if the envelope was delivered to them in their home post - including whether they would open it, whether they would choose to read the contents, and whether they would respond to the survey. They were also asked to comment on the final draft survey content, and in particular the layout and instructions for completion. Final modifications to survey design were made during this process. This included alterations to the wording of the front page, using shorter sentences and increasing readability, as well as adding information to reduce ambiguity. Changes were also made to the layout of other pages, with the aim of increasing the clarity and ease of completion. The final questionnaire is shown in Appendix 5.

4.2.2 Study population

The sampling frame was the population of all patients registered with general practices in Oxfordshire. The setting was convenient for a general population survey where I and collaborators already had established links with local health services and academic units. The 2001 Census found that Oxfordshire has a population of over 605,000, of whom 90% describe their ethnicity as being White British, compared with a national average of 87%.[537] The population lives in a mixture of rural and urban settings, with 630 people per square mile, compared with a national average of 900.[538] It is a relatively affluent county (1.8% of the economically active aged 16-74 are unemployed, compared with a national average of 3.3%)[537] with pockets of deprivation, particularly in urban centres. There are also areas of rural deprivation which suffer poor access to key services.[539] The Mental Illness Needs Index for 2000 (MINI2000) gives an estimate, based on deprivation figures, of admission rates to mental health services in Oxfordshire as being at 60% of the national average.[540]

The study sample was randomly selected from the Exeter database of general practice registers using computer-generated random numbers. The sample was restricted to those aged 18 or over on the day of sampling. No other restrictions were made, and the sample was not stratified.

4.2.3 Sample size

To estimate required sample size, two calculations were carried out. The views of both those who do and do not use the Internet were of interest, but for this calculation the primary outcome was taken as the accuracy of identifying *the prevalence of "ever using the Internet for mental health information" among people with current experience of mental health problems.* I assumed that approximately 45% of the population use the Internet, and 60% of those (range from literature review 50-75%) use the Internet for health information, and 50% of those (13.5% of the overall sample) have done so for a mental health reason. I also assumed that 25% of the population have current experience of mental health problems. The sample required with 95% confidence and allowing a 5% deviation of the estimate was approximately 700 people. Allowing for a 50% response rate, a survey sample of 1400 people was required.

The second sample size calculation was undertaken to determine the sample required to test the hypothesis that *people with current experience of mental health problems are more likely to use the Internet for mental health information seeking, compared with those without current mental health problems.* Using the same assumptions of prevalence of current experience of mental health problems (25%) and use of the Internet for health information (60% of Internet users), the required sample size to detect a 25% increase in use of health information by those with current experience of mental health problems with 80% power and alpha value of 5% is approximately 400 Internet users. Allowing for a rate of Internet use of 45% and a response rate of 50%, the required sample was 1800.

Based on the above calculations, a survey sample of 1800 individuals was chosen. A random sample of 1800 adults (aged over 18) was therefore selected from the primary care register described above using computer-generated random numbers.

4.2.4 Survey administration

Address labels for the study population were produced using Microsoft Word and attached to 1800 envelopes. Each member of the study population was sent the questionnaire and copy of the GHQ-12 (not reproduced due to copyright restrictions), with a covering letter (Appendix 6), information sheet (Appendix 7), entry form for a prize draw (Appendix 8), and postage-paid return envelope. I undertook the process of 'envelope stuffing'. Survey envelopes were franked automatically and sent out from the Institute of Health Sciences, Oxford. The return address was included on the outside of the envelope to allow undelivered surveys to be returned unopened.

In order to maximise the response rate three postal reminders were sent to each potential respondent, and respondents could opt to be entered in a prize draw to win £100 of shopping vouchers. The first reminder took the form of a postcard (see Appendix 9), the latter two were complete resendings of the initial mailing, including a revised covering letter (see Appendix 10). I undertook the administration of all these repeat sendings. Individuals who had already responded were excluded from the reminder mailings, as were respondents identified as being dead or not known at address.

4.2.5 Ethical approval

Ethical approval was sought from the Oxford Psychiatric Research Ethics Committee (OPREC) and the London School of Hygiene & Tropical Medicine (LSHTM) Ethics Committee. Final ethical approval was granted in July 2002, following clarifications regarding survey administration and assurances that reminder letters would not be sent to anyone who had died.

4.2.6 Data entry, data cleaning and methods of analysis

The data from returned questionnaires were double entered (for accuracy) into a comma separated value (CSV) data file consisting of respondent ID numbers and entries for each of the survey variables. All responses were confidential and all data for analysis were anonymised. Data cleaning was carried out in Microsoft Excel. Some new variables were then created through recoding using SPSS statistical software, for example to create a total GHQ-12 score. SPSS and StatsDirect statistical software packages were then used to analyse this data file.[541,542]

Descriptive analyses of frequencies and proportions were used for the characteristics and health status of respondents and non-respondents. Further descriptive analyses and univariate cross-tabulation were used for responses to questions on information needs and sources, Internet use, and agreement with attitudinal statements. Significance testing was carried out using chi-square (χ^2) difference in proportions. Multivariate analysis was undertaken to explore the relationship between mental health status and past history, and the outcome measures of information use and Internet use. In order to avoid *post hoc* data dredging of multiple comparisons, univariate and multivariate analysis was restricted to the investigation of prior hypotheses, unless otherwise stated.

4.3 Results

4.3.1 Response rate

Of 1800 surveys sent out, a total of 917 replies were received (50.9%). After exclusion of deceased individuals (n=13) and surveys returned unopened as "not known at this address" (n=212) a total of 917 out of 1575 valid respondents were identified (58.2%). This method of excluding unknown addressees and deceased individuals from the denominator was used for the previous surveys of the Oxfordshire population carried out for the Oxford Healthy Lifestyle Surveys, using the same primary care database [personal correspondence].

4.3.2 Comparison of respondents and non-respondents

The survey was confidential and all results anonymised, however a participant ID number was included on each return envelope in order to identify where to send reminder letters. This process also allowed us to use data in the original dataset to compare the characteristics of respondents and non-respondents. Ten respondents removed the ID number from their return envelope (there was no attempt to make this number hidden) and therefore for this analysis their details are necessarily contained within the non-respondents, as there was no other way of identifying them.

Table 4.2 shows the characteristics of respondents and non-respondents which were available to be compared. Age and sex data were available, and the Index of Multiple Deprivation scores were identified using postcodes. Deceased individuals and those 'not known at address' have been excluded from the analysis shown in this table. Statistical testing showed that respondents were significantly more likely to be older, female and come from less deprived areas than non-respondents.

Table 4.2 Characteristics of respondents and non-respondents.

	respondents (n=907*)	**non-respondents (n=668*)**	**test result P-value**
mean age in years (s.d.)	49.3 (18.4)	43.8 (18.3)	$P<0.001$ (unpaired t test)
sex: % men	46.0**	55.7	$P<0.001$ (χ^2 test difference in proportions)
median deprivation score	8.94	10.5	$P<0.001$ (Mann-Whitney U test)

*NB ten respondents removed the identification number from the survey and are therefore included with the non-respondents for this analysis as they cannot be identified.

**This figure based on the 917 returned questionnaires as this data is more accurate for the respondents.

Separate analysis of the 'not known at this address' sample showed that this group were significantly ($P<0.001$ for all analyses) more likely to be male (69.3% men, 147/212) and younger (mean age 37.4 years) than either of the other groups of respondents and non-respondents. The median deprivation score for this group was 9.61.

4.3.3 Age, sex, educational level, past history and mental health status

The survey results are based on the analysis of the 917 completed questionnaires returned. The denominators vary from question to question depending on the total number of responses received for the question concerned. Overall there were few missing data items (the maximum amount of missing data for a question requiring a response was 3.2% for question 3, educational level).

Respondents were asked to tick a box indicating their age range. The median age group was 46-55 for both men and women. There were 46% men and 54% women in our respondent sample. The age distribution by sex is shown in Figure 4.1. This shows that the predominance of female respondents is more marked in younger age groups. The distribution of education level among respondents (by sex) is shown in Figure 4.2.

Figure 4.1 Age distribution of respondents, by sex.

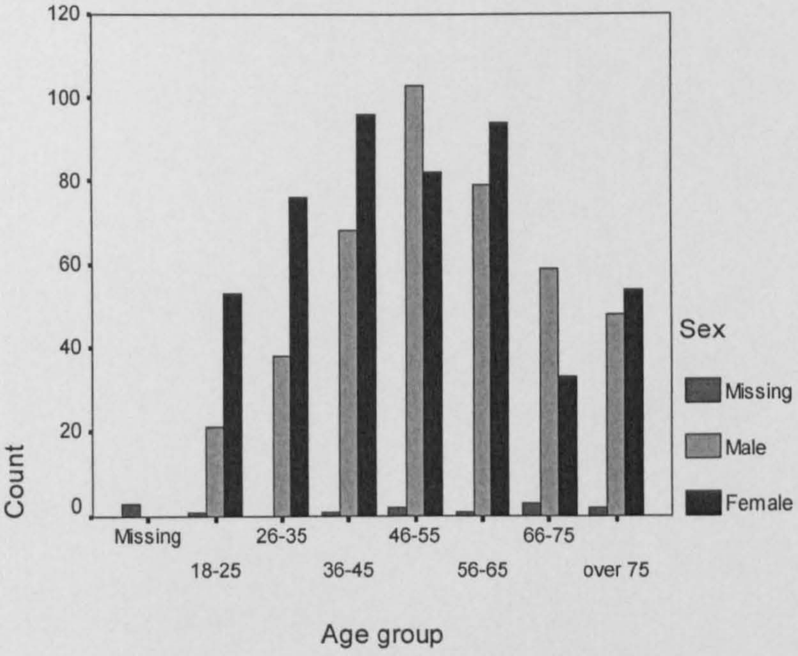
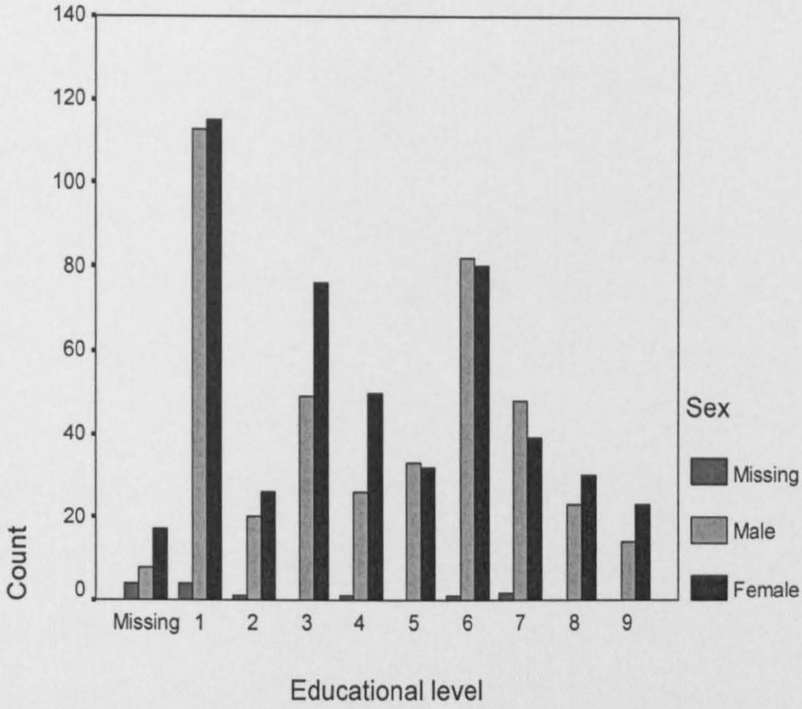


Figure 4.2 Distribution of educational level among respondents, by sex.



Key to educational level	
1	No formal qualifications
2	O-levels or GCSEs below grade C or equivalent
3	O-levels or GCSEs grade A - C or equivalent
4	A-levels or AS-levels or equivalent
5	Higher education below degree level
6	Undergraduate degree or degree-level qualification
7	Postgraduate degree
8	other
9	more than one option ticked

To determine health status the GHQ-12 scores of respondents were calculated using the standard GHQ scoring method.[543] The results are shown in Table 4.3.

Table 4.3 GHQ-12 score of respondents.

GHQ-12 score	Number of respondents (%)
0 or 1 (low or no disturbance)	605 (66%)
2 or 3 (mild to moderate disturbance)	128 (14%)
4 or above (high to severe disturbance)	184 (20%)

This table shows that 34% of our respondents had some evidence of current mental health disturbance (scores of two or more indicate psychological distress)[527], and that 20% of respondents had mental health disturbance rated as high or severe. In the subsequent analyses a GHQ-12 score of 2 or above has been taken as indicating psychological disturbance. All these analyses were repeated using the higher GHQ-12 cut-off of 4 or above (indicating high to severe psychological disturbance), but these are not presented here as they did not alter the results.

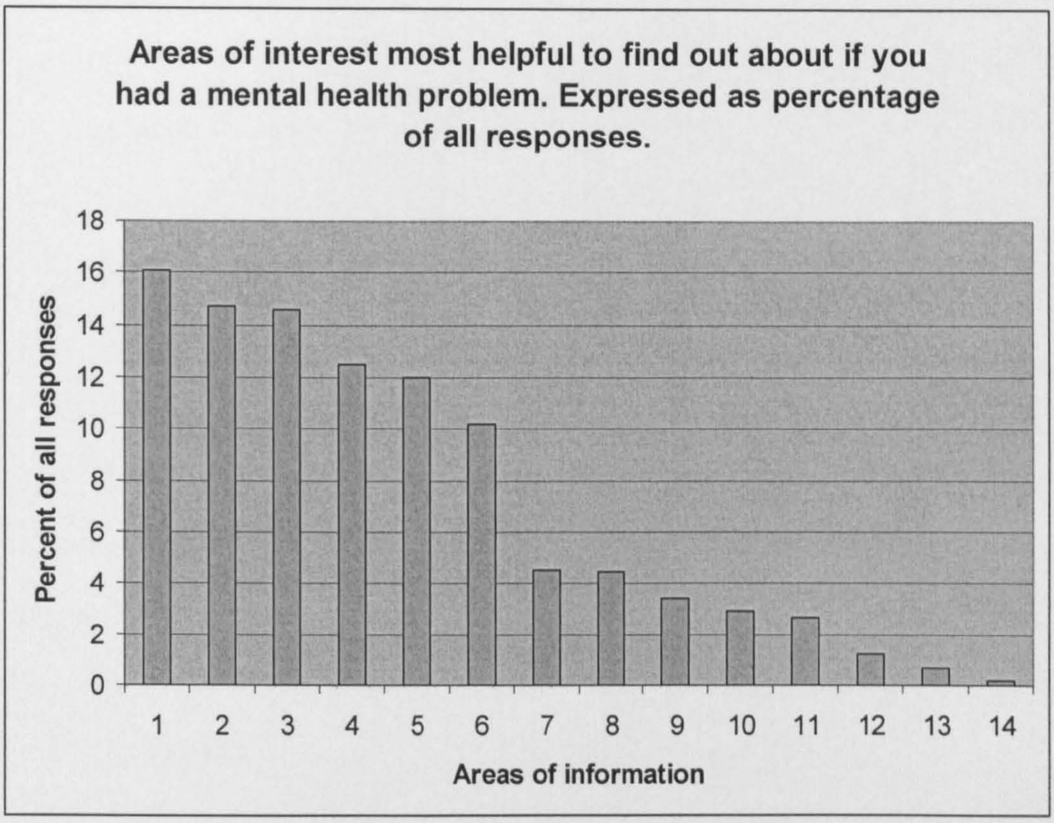
Of the sample, 18.2% had a self-reported history of serious mental health problems (166 of 910 who answered this question), serious being defined as something that had led to a consultation with a doctor or other health professional. There was a sex difference with 15.7% of men (65/415) and 20.9% of women (101/484) reporting this (difference 5.2%, 95% confidence interval 0.1% to 10.2%, P=0.039, χ^2 proportion comparison).

4.3.4 Information sources

4.3.4.1 Areas of information most helpful to find out about

Respondents were asked to indicate what areas of information would be most helpful to find out about if they had a mental health problem. They were given a limited choice of 13 areas derived from the previous literature on information needs and the interview results. Each respondent was asked to indicate up to three choices. Only four respondents wrote anything in the 'other' category and the details were not analysed. Seventeen respondents indicated that they would not be interested in finding out information; five of these were suffering current mental health distress. The results are shown in Figure 4.3, with responses to each area expressed as a percentage of all responses received.

Figure 4.3 Areas of interest most helpful to find out about if you had a mental health problem.



Key to areas of interest		Total responses (respondents ticked up to three choices)	Percent of all responses
1	What the problem is	396	16.08
2	What treatments are available	363	14.74
3	How to help myself	359	14.58
4	Where to get help from	307	12.47
5	What has caused the problem	295	11.98
6	The future course of the problem	251	10.19
7	Hearing other people's experience of this problem	111	4.51
8	What can cause the problem to get worse	109	4.43
9	How to prevent mental health problems	83	3.37
10	Side effects of treatments	72	2.92
11	Finding out I am not the only person with this problem	65	2.64
12	Finding out the results from research	30	1.22
13	I would not be interested in finding out information	17	0.69
14	Other	4	0.16

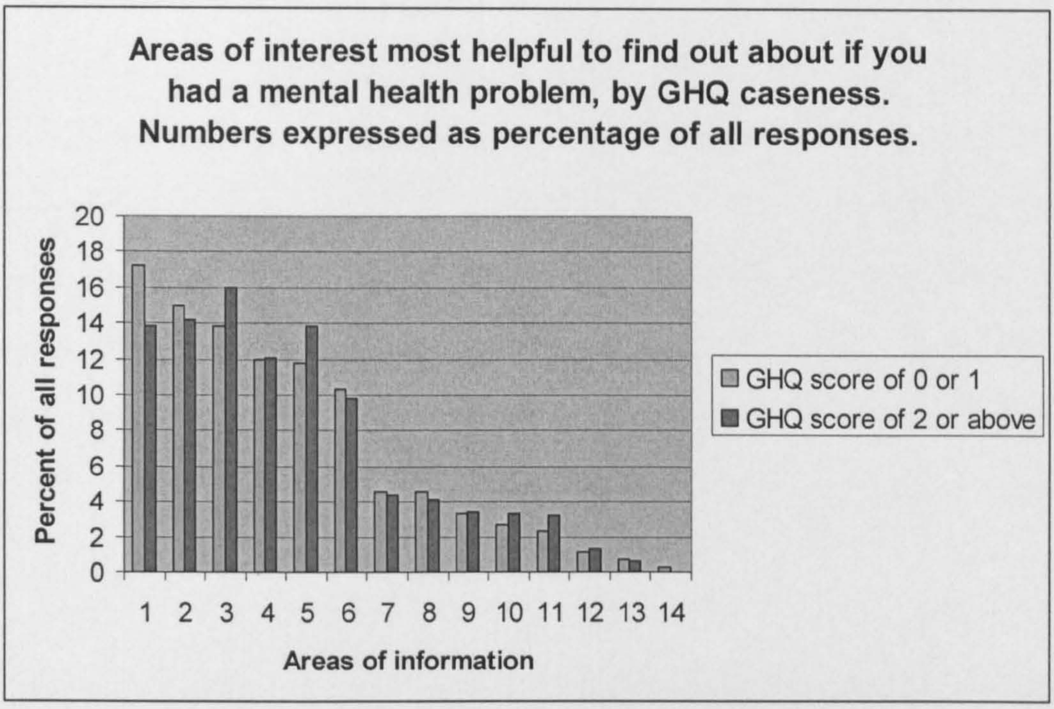
Figure 4.3 shows that there were six areas chosen much more frequently than the other areas. The six, in order, were:

1. What the problem is
2. What treatments are available
3. How to help myself
4. Where to get help from
5. What has caused the problem
6. The future course of the problem

Figure 4.4 shows the areas of interest by presence or absence of current experience of mental health distress. This shows that the needs of those who were current GHQ-12 cases were similar to those of non-GHQ-12 cases and the population as a whole. In order to assess the association between classification by GHQ-12 and areas of interest a two by k χ^2 test was carried out, this showed no significant association ($\chi^2=12.92$, df=13, P=0.45).

In part, this question was used to investigate the value of hearing other people's experience, and of universality which had both been highlighted in the interview analysis. These needs were ranked 7th and 11th, both for the whole population and for those with current mental health distress.

Figure 4.4 Areas of interest most helpful to find out about if you had a mental health problem, by GHQ-12 caseness.



Key to areas of interest		Responses (%) for GHQ-12 score ≤1	Responses (%) for GHQ-12 score >1
1	What the problem is	279 (17.26)	117 (13.83)
2	What treatments are available	243 (15.04)	120 (14.18)
3	How to help myself	224 (13.86)	135 (15.96)
4	Where to get help from	193 (11.94)	102 (12.06)
5	What has caused the problem	190 (11.76)	117 (13.83)
6	The future course of the problem	168 (10.40)	83 (9.81)
7	Hearing other people's experience of this problem	74 (4.58)	37 (4.37)
8	What can cause the problem to get worse	74 (4.58)	35 (4.14)
9	How to prevent mental health problems	54 (3.34)	29 (3.43)
10	Side effects of treatments	44 (2.72)	28 (3.31)
11	Finding out I am not the only person with this problem	38 (2.35)	27 (3.19)
12	Finding out the results from research	19 (1.18)	11 (1.30)
13	I would not be interested in finding out information	12 (0.74)	5 (0.59)
14	Other	4 (0.25)	0 (0)

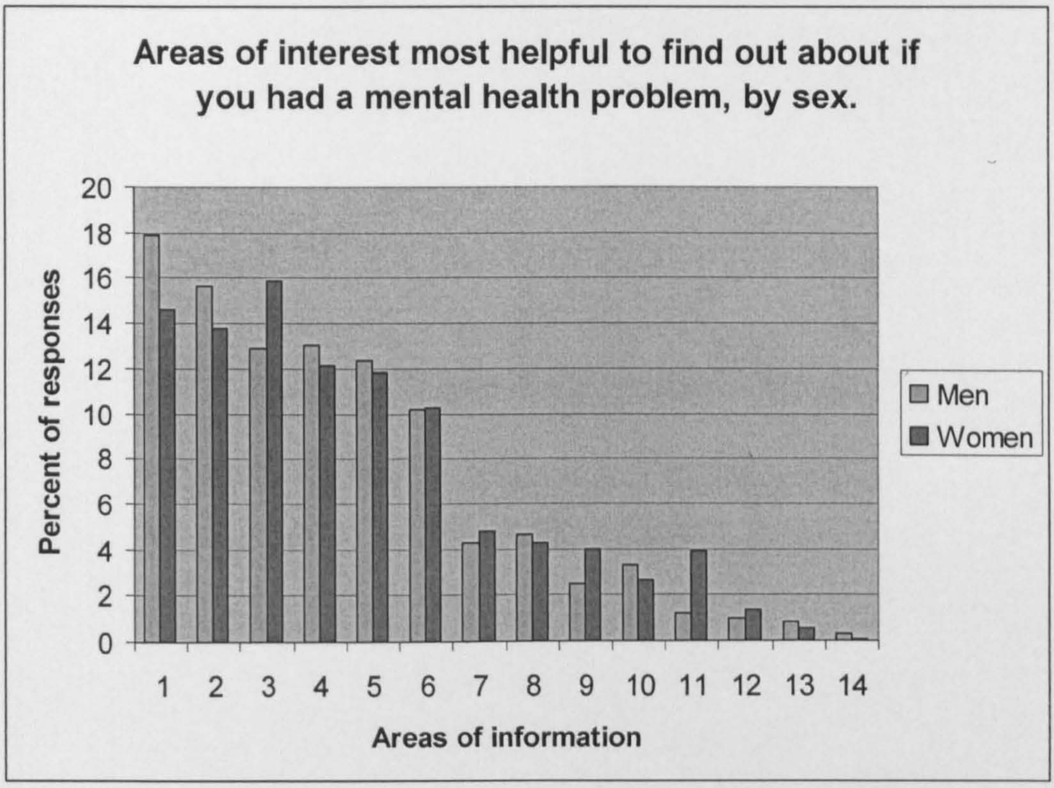
Each respondent was allowed to select up to three areas of information need. The denominator used in the analysis was the total number of responses received. This method accurately reflects the most popular choices, but it is also necessary to consider the absolute number of selections in relation to the total number of respondents, in order to understand how many individuals identified each need. Thus information on "what the problem is" was chosen by 396/917 respondents (43.2%). The total number of respondents has been used for the denominator as the 8.4% who chose not to respond to this question may have decided that none of the needs listed were satisfactory, and therefore their non-response should not be treated as missing data. The figures for all the needs analysed in the same way are shown in Table 4.4.

Table 4.4 Areas of interest most helpful to find out about if you had a mental health problem, as a percentage of all respondents.

	Area of information need	**Number of responses as a % of all respondents**
1	What the problem is	43.2
2	What treatments are available	39.6
3	How to help myself	39.1
4	Where to get help from	33.5
5	What has caused the problem	32.2
6	The future course of the problem	27.4
7	Hearing other people's experience of this problem	12.1
8	What can cause the problem to get worse	11.9
9	How to prevent mental health problems	9.1
10	Side effects of treatments	7.9
11	Finding out I am not the only person with this problem	7.1
12	Finding out the results from research	3.3
13	I would not be interested in finding out information	1.9
14	Other	0.4

The literature review suggested that there may be differences in information needs by gender, and analysis of the responses from men and women did demonstrate a significant difference (χ^2=34.78, df=13, P<0.001), but both men and women identified the same top six needs, and the difference was only in the rank order of these. The results are shown in Figure 4.5. For men the top three needs (in order) were "what the problem is", "what treatments are available" and "where to get help from". For women they were "how to help myself", "what the problem is", and "what treatments are available". Figure 4.5 also shows that women were more likely than men to identify "finding out I am not the only person with this problem" (item 11) as a need.

Figure 4.5 Areas of interest most helpful to find out about if you had a mental health problem, by sex.

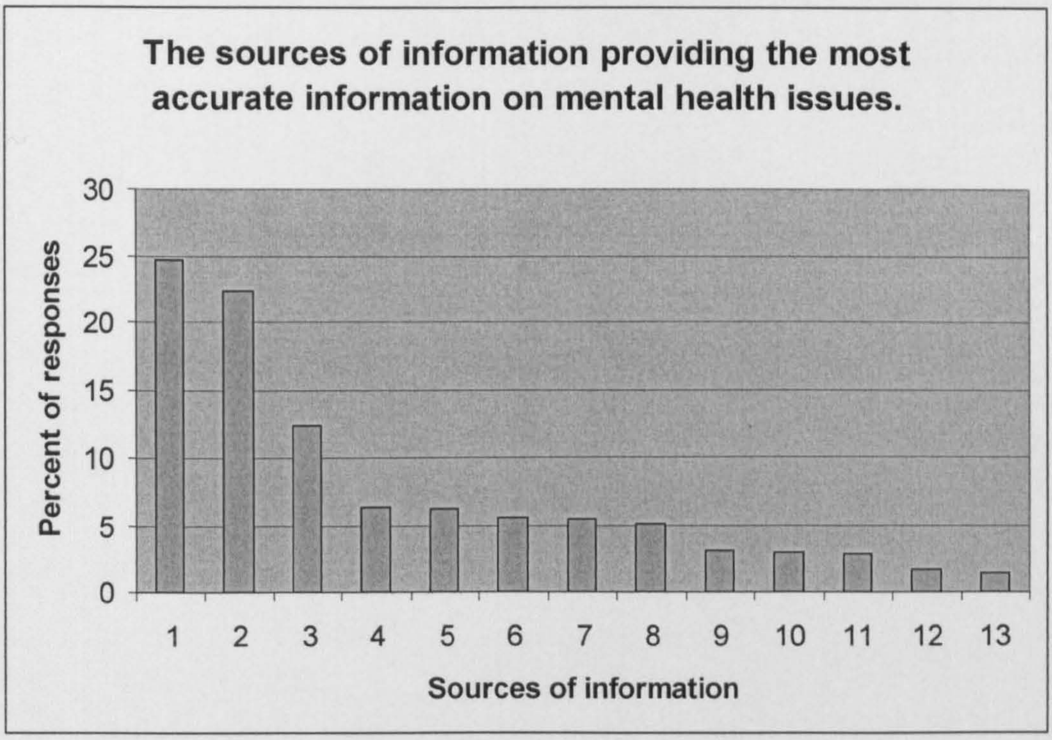


Key to areas of interest		Responses (%) for men	Responses (%) for women
1	What the problem is	197 (17.93)	195 (14.61)
2	What treatments are available	172 (15.65)	184 (13.78)
3	How to help myself	142 (12.92)	212 (15.88)
4	Where to get help from	143 (13.01)	162 (12.13)
5	What has caused the problem	136 (12.37)	158 (11.84)
6	The future course of the problem	112 (10.19)	137 (10.26)
7	Hearing other people's experience of this problem	47 (4.28)	64 (4.79)
8	What can cause the problem to get worse	51 (4.64)	57 (4.27)
9	How to prevent mental health problems	27 (2.46)	53 (3.97)
10	Side effects of treatments	36 (3.28)	35 (2.62)
11	Finding out I am not the only person with this problem	13 (1.18)	52 (3.90)
12	Finding out the results from research	11 (1.00)	18 (1.35)
13	I would not be interested in finding out information	9 (0.82)	7 (0.52)
14	Other	3 (0.27)	1 (0.07)

4.3.4.2 Most accurate sources of information on mental health issues

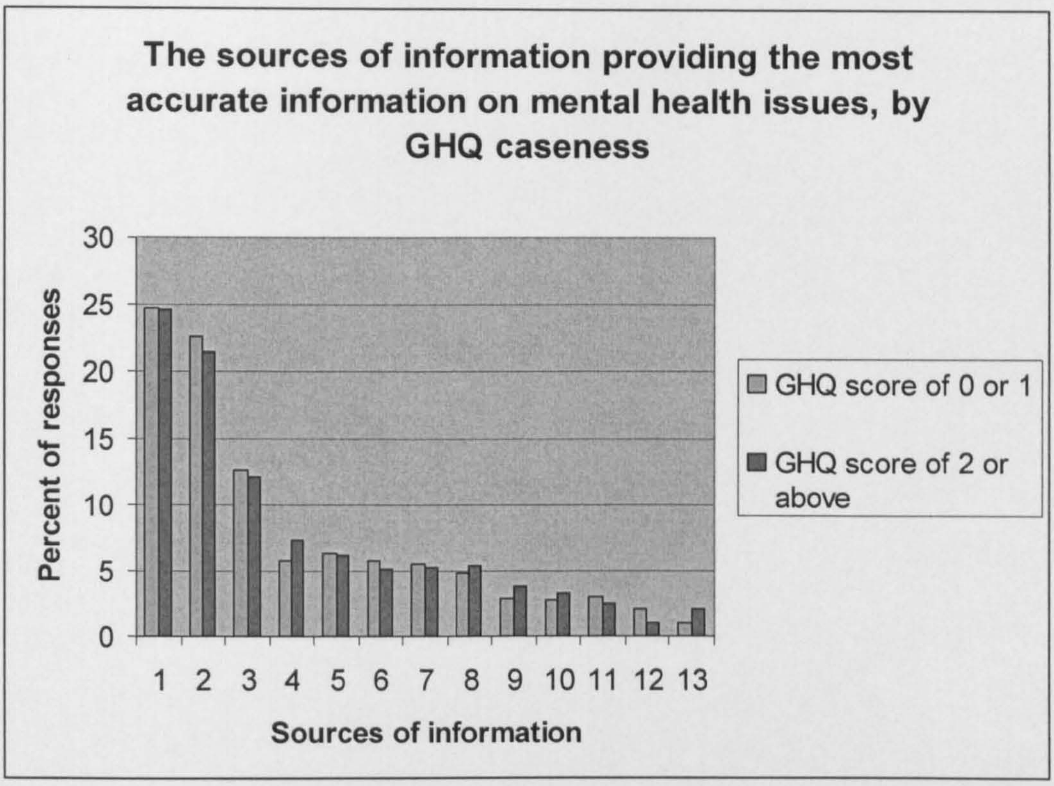
Respondents were asked to indicate which sources of information they believed provided the most accurate information on mental health issues. The results for all respondents are shown in Figure 4.6. Figure 4.7 shows the results by presence or absence of mental health distress (GHQ-12 caseness).

Figure 4.6 Sources of information providing the most accurate information on mental health issues.



Key to sources of information considered accurate		Total responses (respondents ticked up to three choices)	Percent of all responses
1	Mental health professional	547	24.73
2	General Practitioner (GP)	493	22.29
3	Leaflets produced by the NHS or voluntary organisations or charities	273	12.34
4	Someone else with the same mental health problem	140	6.33
5	Television or radio programmes	138	6.24
6	Friend or family member	123	5.56
7	Newspaper or magazine articles	120	5.42
8	The Internet	111	5.02
9	Other telephone helpline	70	3.16
10	Home medical encyclopaedia or similar books	65	2.94
11	NHS Direct telephone helpline	62	2.80
12	Other	38	1.72
13	Alternative or complementary therapist	32	1.45

Figure 4.7 Sources of information providing the most accurate information on mental health issues, by GHQ-12 caseness.

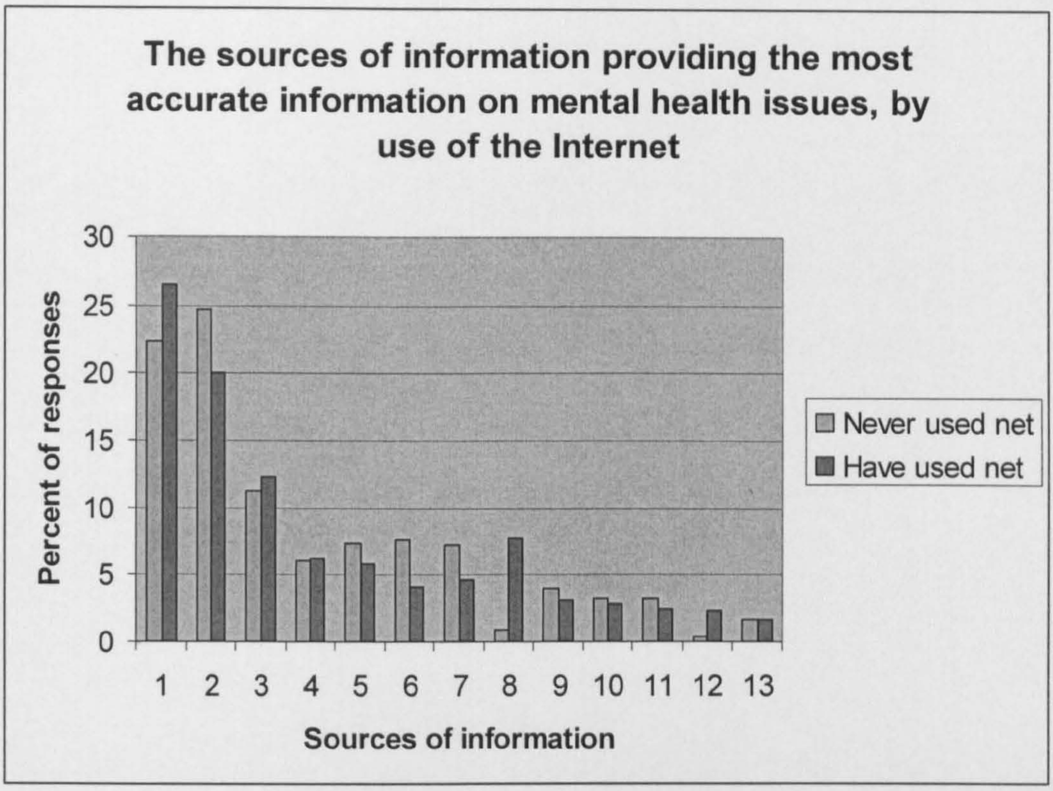


Key to sources of information considered accurate		Responses (%) for GHQ-12 score ≤1	Responses (%) for GHQ-12 score >1
1	Mental health professional	358 (24.76)	189 (24.67)
2	General Practitioner (GP)	328 (22.68)	165 (21.54)
3	Leaflets produced by the NHS or voluntary organisations or charities	181 (12.52)	92 (12.01)
4	Someone else with the same mental health problem	84 (5.81)	56 (7.31)
5	Television or radio programmes	91 (6.29)	47 (6.14)
6	Friend or family member	84 (5.81)	39 (5.09)
7	Newspaper or magazine articles	80 (5.53)	40 (5.22)
8	The Internet	70 (4.84)	41 (5.35)
9	Other telephone helpline	41 (2.84)	29 (3.79)
10	Home medical encyclopaedia or similar books	40 (2.77)	25 (3.26)
11	NHS Direct telephone helpline	43 (2.97)	19 (2.48)
12	Other	30 (2.07)	8 (1.04)
13	Alternative or complementary therapist	16 (1.11)	16 (2.09)

For the whole population and those with and without mental health problems, the results clearly demonstrate the trust put in health professionals, with mental health workers and general practitioners being rated the most accurate sources. It is clear from the plots that there are no major differences by GHQ-12 caseness, and this was confirmed in a χ^2 test (χ^2=11.74, df=12, P=0.47). Third place was taken by leaflets produced by the NHS or voluntary organisations or charities. Fourth ranking was "someone else with the same mental health problem", and received relatively more votes from people with mental health problems. The Internet was ranked 8th overall, and 6th by people with mental health problems, although the scoring between the 4th and 8th ranked sources was very close. There was a sex difference (χ^2=31.76, df=12, P<0.01), explained by mental health professionals being ranked ahead of general practitioners by women, whereas men ranked general practitioners slightly ahead of mental health professionals.

Figure 4.8 shows that Internet users have a higher opinion of the accuracy of Internet based information than non-users (giving the Internet a ranking of 4th place). This finding is not surprising and to some extent this is, of course, a self-fulfilling prophecy as those more likely to distrust the Internet are also less likely to use it.

Figure 4.8 Sources of information providing the most accurate information on mental health issues, by use of the Internet.



Key to sources of information considered accurate		Responses (%) for non-Internet users	Responses (%) for Internet users
1	Mental health professional	106 (22.41)	356 (26.47)
2	General Practitioner (GP)	117 (24.74)	270 (20.07)
3	Leaflets produced by the NHS or voluntary organisations or charities	53 (11.21)	166 (12.34)
4	Someone else with the same mental health problem	29 (6.13)	84 (6.25)
5	Television or radio programmes	35 (7.40)	79 (5.87)
6	Friend or family member	36 (7.61)	56 (4.16)
7	Newspaper or magazine articles	34 (7.19)	62 (4.61)
8	The Internet	4 (0.85)	105 (7.81)
9	Other telephone helpline	19 (4.02)	42 (3.12)
10	Home medical encyclopaedia or similar books	15 (3.17)	38 (2.83)
11	NHS Direct telephone helpline	15 (3.17)	33 (2.45)
12	Other	2 (0.42)	32 (2.38)
13	Alternative or complementary therapist	8 (1.69)	22 (1.64)

As with the areas of information need, each respondent was allowed to select up to three options. The absolute number of selections in relation to the total number of respondents are shown in Table 4.5.

Table 4.5 Sources of information providing the most accurate information on mental health issues, as a percentage of all respondents.

	Source of information	**Number of responses as a % of all respondents**
1	Mental health professional	59.7
2	General Practitioner (GP)	53.8
3	Leaflets produced by the NHS or voluntary organisations or charities	29.8
4	Someone else with the same mental health problem	15.3
5	Television or radio programmes	15.0
6	Friend or family member	13.4
7	Newspaper or magazine articles	13.1
8	The Internet	12.1
9	Other telephone helpline	7.6
10	Home medical encyclopaedia or similar books	7.1
11	NHS Direct telephone helpline	6.8
12	Other	4.1
13	Alternative or complementary therapist	3.5

4.3.4.3 Sources of information on mental health issues most likely to be used

In order to compare the sources considered most accurate with the sources of information actually used, respondents were asked to identify the sources of information on mental health issues which they would be most likely to use if they had a mental health problem. The results for all respondents are shown in Figure 4.9, with the absolute number of selections in relation to the total number of respondents shown in Table 4.6.

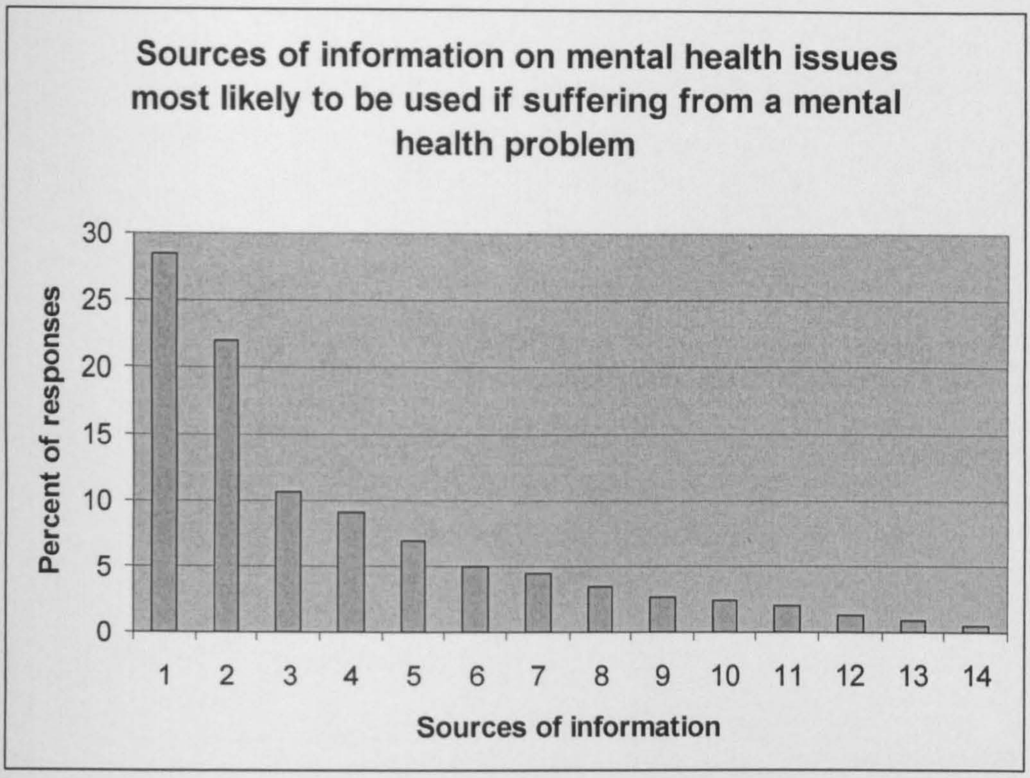
Figure 4.10 shows the results by presence or absence of mental health distress (GHQ-12 caseness). Again, there is no significant difference in the distribution by GHQ-12 caseness (χ^2=9.72, df=13, P=0.72). For the whole population and those with and without mental health problems, the results show that general practitioners and mental health workers are not only considered the most accurate sources, but are also most likely to be used. Official leaflets were again ranked in third place. The Internet was rated fourth overall and third equal by those with mental health problems, suggesting that the Internet is used more than it is trusted as an accurate medium. A bar-chart plot and χ^2 analysis by sex showed little evidence of differences (χ^2=22.59, df=13, P=0.05).

Table 4.6 Sources of information on mental health issues most likely to be used, as a percentage of all respondents.

	Source of information	Number of responses as a % of all respondents
1	General Practitioner	74.2
2	Mental health professional	57.1
3	Leaflets produced by the NHS or voluntary organisations or charities	27.7
4	The Internet	23.6
5	Friend or family member	18.0
6	Someone else with the same mental health problem	13.0
7	Home medical encyclopaedia or similar books	11.7
8	Other telephone helpline	8.8
9	NHS Direct telephone helpline	7.0
10	Newspaper or magazine articles	6.3
11	Alternative or complementary therapist	5.5
12	Television or radio programmes	3.5
13	I wouldn't look for information	2.4
14	Other	1.3

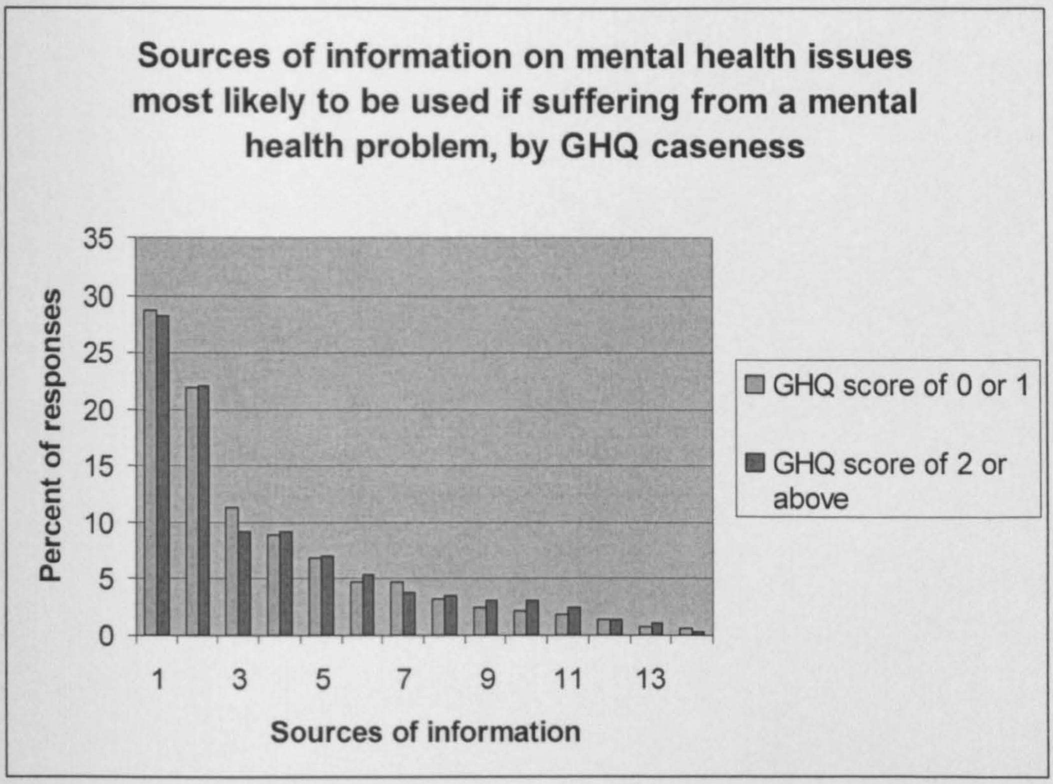
Figure 4.11 shows the sources that would be used, by whether the respondent is an Internet user or not. Clearly Internet users will be more likely to report the Internet as a source they would use, but the aim of this analysis was to examine whether there were sources that Internet users would report using less, in preference for using the Internet. Meaningful statistical testing is not possible as the responses are not independent and a test of the overall distribution would be too influenced by the differential responses to use of the Internet. Examination of the bar chart shows that there is not one obvious source that the Internet is substituting for. General practitioners, leaflets, friends or family members, and the NHS Direct telephone line, all received fewer nominations as sources likely to be used by Internet users. Conclusions regarding this must be treated with caution given the multiple *post-hoc* comparisons and the lack of independence in the data.

Figure 4.9 Sources of information on mental health issues most likely to be used.



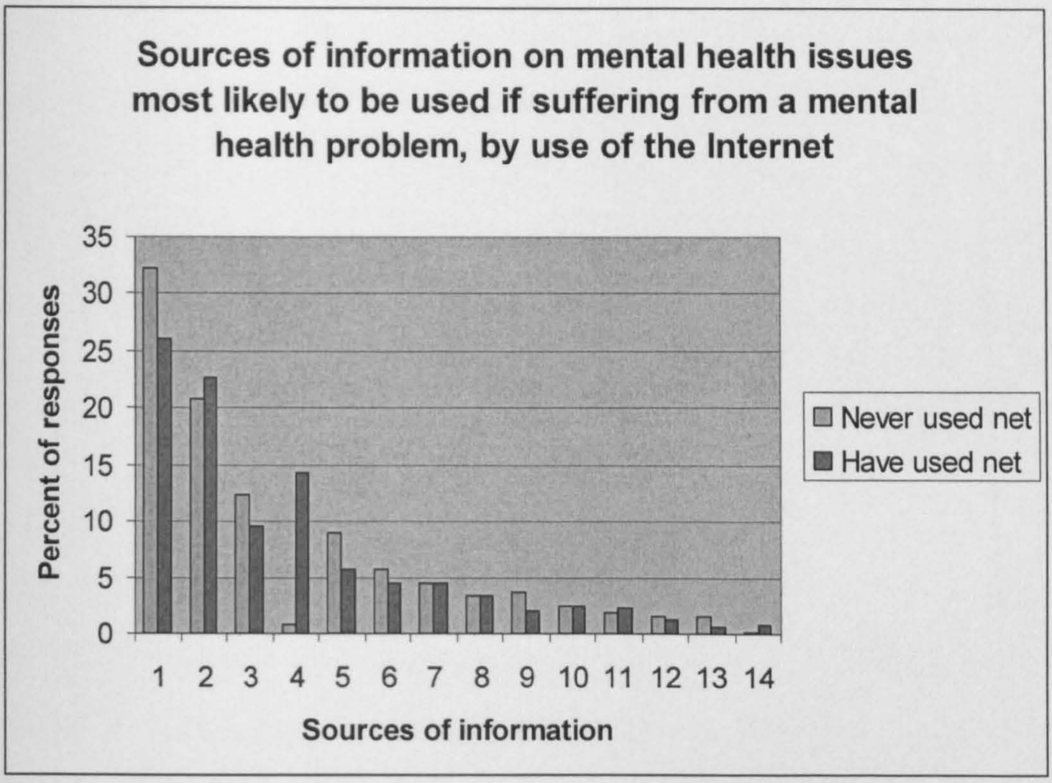
Key to sources of information likely to be used		Total responses (respondents ticked up to three choices)	Percent of all responses
1	General Practitioner	680	28.52
2	Mental health professional	524	21.98
3	Leaflets produced by the NHS or voluntary organisations or charities	254	10.65
4	The Internet	216	9.06
5	Friend or family member	165	6.92
6	Someone else with the same mental health problem	119	4.99
7	Home medical encyclopaedia or similar books	107	4.49
8	Other telephone helpline	81	3.40
9	NHS Direct telephone helpline	64	2.68
10	Newspaper or magazine articles	58	2.43
11	Alternative or complementary therapist	50	2.10
12	Television or radio programmes	32	1.34
13	I wouldn't look for information	22	0.92
14	Other	12	0.50

Figure 4.10 Sources of information on mental health issues most likely to be used, by GHQ-12 caseness.



Key to sources of information likely to be used		Responses (%) for GHQ-12 score ≤1	Responses (%) for GHQ-12 score >1
1	General Practitioner	452 (28.68)	228 (28.22)
2	Mental health professional	346 (21.95)	178 (22.03)
3	Leaflets produced by the NHS or voluntary organisations or charities	179 (11.36)	75 (9.28)
4	The Internet	141 (8.95)	75 (9.28)
5	Friend or family member	108 (6.85)	57 (7.05)
6	Someone else with the same mental health problem	76 (4.82)	43 (5.32)
7	Home medical encyclopaedia or similar books	76 (4.82)	31 (3.84)
8	Other telephone helpline	52 (3.30)	29 (3.59)
9	NHS Direct telephone helpline	39 (2.47)	25 (3.09)
10	Newspaper or magazine articles	33 (2.09)	25 (3.09)
11	Alternative or complementary therapist	30 (1.90)	20 (2.48)
12	Television or radio programmes	21 (1.33)	11 (1.36)
13	I wouldn't look for information	13 (0.82)	9 (1.11)
14	Other	10 (0.63)	2 (0.25)

Figure 4.11 Sources of information on mental health issues most likely to be used, by use of the Internet.



Key to sources of information likely to be used		Responses (%) for non-Internet users	Responses (%) for Internet users
1	General Practitioner	300 (32.29)	380 (26.12)
2	Mental health professional	194 (20.88)	330 (22.68)
3	Leaflets produced by the NHS or voluntary organisations or charities	115 (12.38)	139 (9.55)
4	The Internet	7 (0.75)	209 (14.36)
5	Friend or family member	83 (8.93)	82 (5.64)
6	Someone else with the same mental health problem	53 (5.71)	66 (4.54)
7	Home medical encyclopaedia or similar books	41 (4.41)	66 (4.54)
8	Other telephone helpline	31 (3.34)	50 (3.44)
9	NHS Direct telephone helpline	35 (3.77)	29 (1.99)
10	Newspaper or magazine articles	23 (2.48)	35 (2.41)
11	Alternative or complementary therapist	17 (1.83)	33 (2.27)
12	Television or radio programmes	15 (1.61)	17 (1.17)
13	I wouldn't look for information	14 (1.51)	8 (0.55)
14	Other	1 (0.11)	11 (0.76)

4.3.5 Internet use

Table 4.7 shows the results for Internet use, use of the Internet for health information, and use of the Internet for mental health information. All significant tests are χ^2 comparisons of two proportions, and the P values and confidence intervals for the absolute difference between proportions are given. For the purposes of clarity, the confidence intervals for the individual proportions have not been given in the text, but are included as Appendix 12.

4.3.5.1 Use of the Internet

Table 4.7 shows that 58.8% of the sample reported ever having used the Internet (539/917). There was no difference by sex with 59.9% men (249/416) and 58.2% women (284/488) having used the Internet (difference 1.7%, 95% CI -4.8% to 8.1%, P=0.59). As might be expected, there was a large and significant difference by age with 84.5% of respondents aged 45 and under (n=299/354) reporting ever having used the Internet, versus 42.9% (n=240/560) of those aged 46 and over (difference 41.6%, 95% CI 35.8% to 47.0%, P<0.001).

For education level, the group who had the equivalent of A-level qualifications or above was compared with those who did not ("other" responses and those who had ticked more than one option were excluded). Again, there was a large and significant difference between these two groups, showing that 37.9% (153/404) of those who did not have qualifications at A-level standard or above had used the Internet, compared with 85.0% (335/394) of those who had this qualification or above (difference 47.2%, 95% CI 41.1% to 52.9%, P<0.001). In the group who reported no qualifications, only 21.1% (49/232) had ever used the Internet. The significant relationships between

Internet use and both age and educational attainment remained after controlling for each of these variables and for the effects of sex, current psychological distress or past history of mental health problems using logistic regression (see Appendix 13).

Of those reporting at least one previous episode of mental illness, 65.1% (108/166) had used the Internet compared with 57.8% (430/744) of those not reporting a previous episode (difference 7.3%, 95% CI -1.0% to 15.0%, P=0.082). There was a significant difference in Internet use by mental health status: of those scoring two or above on the GHQ-12, 66.0% (206/312) had used the Internet, compared with 55.0% (333/605) of those scoring 0 or 1 (difference 11.0%, 95% CI 4.3% to 17.4%, P=0.001). However this relationship between mental health status and use of the Internet did not remain after controlling for the effects of age, sex, and level of educational attainment (see Appendix 13).

Table 4.7 Univariate analyses of respondents' use of the Internet by age, sex, educational level, health status and psychiatric history. Significance testing using χ^2 tests for comparison of proportions, P values <0.05 shown in bold. Confidence intervals for significance tests are shown in the text. Confidence intervals for individual proportions are shown in Appendix 12.

	All	**Sex**			**Age**			**Educational level**			**Health status**			**Past psychiatric history**		
	% of all respondents (n=917)	% of men	% of women	P value	% of younger	% of older	P value	% of more educated	% of less educated	P value	% of GHQ-12>1	% of GHQ-12≤1	P value	% of those with past psychiatric illness	% of those without past psychiatric illness	P value
Have you ever used the Internet?	58.8	59.9	58.2	0.59	84.5	42.9	**<0.001**	85.0	37.9	**<0.001**	66.0	55.0	**0.001**	65.1	57.8	0.082
Have you ever used the Internet to find out about health or healthcare?	37.4	35.8	39.3	0.27	55.4	26.3	**<0.001**	56.6	21.3	**<0.001**	34.5	42.9	**0.012**	45.8	35.8	**0.014**
Have you ever used the Internet to find information about a mental health issue?	10.6	9.1	12.1	0.13	15.8	7.3	**<0.001**	16.5	6.7	**<0.001**	15.1	8.3	**0.001**	20.5	8.5	**<0.001**

4.3.5.2 Use of the Internet to find out about health or healthcare

Of the whole sample, 37.4% had used the Internet for health information (343/917). As Table 4.8 shows this represented 63.6% (343/539) of those who had have ever used the Internet. The percentages by sex were 35.8% (149/416) of men and 39.3% (192/488) of women using the Internet for health information. This difference was not significant on χ^2 test for difference in proportions (difference 3.5%, 95% CI -2.8% to 9.8%, P=0.27).

There were far fewer users of the Internet for health information among the less educated group 21.3% (86/404) than among the more educated group 56.6% (223/394) (difference 35.3%, 95% CI 28.9% to 41.5%, P<0.001). This is partly explained by the differential use of the Internet in these two groups, but not entirely: 56.2% (86/153) of those who had ever used the Internet in the lower educated group had used it for health information, compared with 66.6% in the higher educated group (223/335), (difference 10.4%, 95% CI 1.1% to 19.7%, P=0.027). In other words, even after allowing for access to the Internet, the more educated group in our survey were more likely to use the Internet for health information. This association with higher level of educational attainment remained after controlling for age, sex and current psychological distress or past history of mental health problems using logistic regression (see Appendix 13).

Older respondents were much less likely than younger respondents to use the Internet for this reason, with figures of 26.3% (147/560) for older respondents, and 55.4% (196/354) for younger (difference 29.1%, 95% CI 22.7% to 35.3%, P<0.001), but as Table 4.8 shows this difference disappears after allowing for Internet access.

There were also significant differences by past psychiatric history and by GHQ-12 status. The analysis showed that 45.8% (76/166) of those with a previous episode of mental illness had used the Internet for health information, compared with 35.8% (266/744) of those without a previous episode (difference 10.0%, 95% CI 1.8% to 18.4%, P=0.014). However this difference is not statistically significant after allowing for access to the Internet (70.4% (76/108) versus 61.9% (266/430), difference 8.5%, 95% CI -1.7% to 17.1%, P=0.095). For respondents scoring two or more on the GHQ-12, 42.9% (134/312) had used the Internet to find out about health or healthcare compared with 34.5% (209/605) of those scoring 0 or 1 (difference 8.4%, 95% CI 1.8% to 15.1%, P=0.012), but again this difference disappears once access to the Internet is allowed for, with 65.0% (134/206) of those GHQ-12 cases who have used the Internet reporting having used it for health information, versus 62.8% (209/333) of non-cases (difference 2.2%, 95% CI -6.1% to 10.5%, P=0.58).

4.3.5.2 Use of the Internet to find out about a mental health issue

Of the whole population sample, 10.6% (97/917) had used the Internet to find out about mental health, representing 18.0% (97/539) of all people who had used the Internet. The figures were 9.1% (38/416) for men and 12.1% (59/488) for women (difference 3.0%, 95% CI -1.1% to 7.0%, P=0.13). As Table 4.8 shows, the statistically significant differences by age (younger age group 56/354=15.8%, older age group 41/560=7.3%, difference 8.5%, 95% CI 4.3% to 13.1%, P<0.001) and educational level (less educated group 27/404=6.7%, more educated group 65/394=16.5%, difference 9.8%, 95% CI 5.5% to 14.4%, P<0.001) did not remain once access to the Internet was allowed for (i.e. when analysing the responses from those who had ever used the Internet). Differences by past psychiatric history and GHQ-12 status remained statistically significant, suggesting that previous Internet users with current experience of mental health distress are 50% more likely to use the Internet to find information about a mental health issue than those without current mental health distress (22.8% (47/206) versus 15.0% (50/333), difference 7.8%, 95% CI 1.1% to 14.9%, P=0.022); and those with a past history of a serious mental health problem are more than twice as likely to have used the Internet for this purpose than those with no such history (31.5% (34/108) versus 14.7% (63/430), difference 16.8%, 95% CI 8.0% to 26.6%, P<0.001).

Table 4.8 Univariate analyses of use of the Internet to find information about health or mental health, among those who have ever used the Internet (n=539). Significance testing using χ^2 tests for comparison of proportions, P values <0.05 shown in bold. Confidence intervals for significance tests are shown in the text. Confidence intervals for individual proportions are shown in Appendix 12.

	All	Sex			Age			Educational level			Health status			Past psychiatric history		
	% of those respondents who have used the Internet (n=539)	% of men	% of women	P value	% of younger	% of older	P value	% of more educated	% of less educated	P value	% of GHQ-12>1	% of GHQ-12≤1	P value	% of those with past psychiatric illness	% of those without past psychiatric illness	P value
Have you ever used the Internet to find out about health or healthcare?	63.6	59.8	67.6	0.059	65.6	61.3	0.28	66.6	56.2	**0.027**	65.0	62.8	0.58	70.4	61.9	0.095
Have you ever used the Internet to find information about a mental health issue?	18.0	15.3	20.8	0.094	18.7	17.1	0.58	19.4	17.6	0.62	22.8	15.0	**0.021**	31.5	14.7	**<0.001**

Two multivariate analyses of Internet use for mental health information were undertaken. The first investigated the effect of current GHQ-12 status (case or not) as the main predictor, the second investigated the presence or absence of a past history of self-reported serious mental health problem as the main predictor. In both analyses the use of Internet to find information about a mental health issue was the outcome variable. Sex (male or female), age group (aged 45 and under, or over 45), and highest level of educational attainment (A levels and above, or qualifications below A level, 'other' excluded), were included as co-variables. Effects of the main predictors independent of these potentially confounding factors were therefore investigated. Even though the potential confounders were not significant predictors of the outcome in univariate analyses, it was important to include them in the multivariate assessment as they could exert significant effects through interaction. On statistical advice the dichotomised age and education variables were used, rather than the original categories, due to the absence of linear relationships between these variables and the log odds ratio.

The results of multiple logistic regression are shown in Table 4.9. This shows that the presence of mental health distress remained significantly associated (P=0.012) with increased use of the Internet for mental health information, after controlling for the effects of age, sex and educational level. The same was true for the association between a self-reported history of serious mental health problem and use of the Internet for mental health information (P<0.001 after adjustment). There were no other significant associations in the multivariate analysis.

Table 4.9 Logistic regression to analyse the relationships between the predictor variable of either (1) the presence of mental health distress (present or absent); or (2) the presence of a past history of a serious mental health problem (present or absent); and the outcome (dependent) variable of use of the Internet for mental health information (yes or no), adjusting for the effects of age group, sex and educational level. Calculated using SPSS statistical software.[542]

(1) Outcome: use of the Internet for mental health information

Variables in the Equation

Factor	B	S.E.	P	Odds Ratio (95% CI)
AGE_GROUP	.061	.249	0.808	1.063 (0.652 to 1.732)
EDUC_LEVEL	.108	.259	0.676	1.114 (0.671 to 1.850)
SEX	.266	.244	0.277	1.304 (0.808 to 2.105)
GHQ_CASE	.597	.237	**0.012**	1.817 (1.142 to 2.891)
Constant	-2.212	.506	<0.001	0.162 (0.041 to 0.295)

(2) Outcome: use of the Internet for mental health information

Variables in the Equation

Factor	B	S.E.	P	Odds Ratio (95% CI)
AGE_GROUP	-.046	.251	0.856	0.956 (0.585 to 1.562)
EDUC_LEVEL	.153	.261	0.558	1.165 (0.699 to 1.943)
SEX	.184	.249	0.461	1.202 (0.737 to 1.958)
PAST_HISTORY	1.041	.257	**<0.001**	2.833 (1.713 to 4.684)
Constant	-2.086	.496	<0.001	0.124 (0.047 to 0.328)

Nine of the respondents had used the Internet to chat to someone else about mental health issues (1.0% of the whole sample, 1.7% of Internet users). These were four men and five women with a wide spread of age group (18 to 75) and educational attainment (O-levels to degree). All nine had current mental health distress (GHQ-12 score of two or above), five had experienced a past history of a serious mental health problem.

4.3.6 Attitudes

The survey included five attitudinal statements and asked respondents to agree or disagree with each (or to reply "not sure"). The results are shown in Table 4.10 which also includes univariate analyses of these responses by age, sex, educational level, mental health status, and self-reported past psychiatric history. In the text I have highlighted the comparisons which were found to be significant on univariate analysis. However, as previously, care must be taken with the interpretation of significance test results on these multiple comparisons. The confidence intervals for the individual proportions have not been given in the text, but are included in Appendix 14.

The first statement in the table relates to the perception of whether stigma is widespread. Three-quarters of respondents agreed that "in general most people have negative attitudes towards others who have mental health problems". Respondents with current psychological distress (GHQ-12 score of two or above) were more likely to agree with this statement than those with GHQ-12 score of 0 or 1, although both groups had a high percentage of agreement (82.5% versus 74%, difference 8.5%, 95% CI 2.8% to 13.8%, P=0.004).

Two attitudinal statements attempted to measure whether individuals themselves believe mental health problems to be stigmatising. These related to mental health problems being embarrassing, and not wanting other people to know about them. A third (33.5%) of respondents agreed that mental health problems are embarrassing to have. It is noteworthy that both those with current experience of mental health distress, and those with a past history of mental health problems were more likely to believe that having mental health problems are embarrassing and it is possible that this reflects their actual experiences. Older people were more likely than younger to believe mental health problems are embarrassing (36.7% versus 30.0%, difference 6.7%, 95% CI 0.3% to 12.9%, P=0.037).

Table 4.10 Percent agreement with attitudinal statements and univariate analysis by age, sex, educational level, health status and psychiatric history. Significance testing using χ^2 tests for comparison of proportions, P values <0.05 shown in bold. Confidence intervals for individual proportions are shown in Appendix 14.

	All	**Sex**			**Age**			**Educational level**			**Health status**			**Past psychiatric history**		
	% of all respondents (n=917)	% of men	% of women	P value	% of younger	% of older	P value	% of more educated	% of less educated	P value	% of GHQ-12>1	% of GHQ-12≤1	P value	% of those with past psychiatric illness	% of those without past psychiatric illness	P value
In general most people have negative attitudes towards others who have mental health problems	75.8	74.7	78.6	0.15	79.9	74.9	0.076	79.2	74.0	0.079	82.5	74.0	**0.004**	80.6	75.9	0.19
It is embarrassing to have a mental health problem	33.5	36.4	32.4	0.20	30.0	36.7	**0.037**	35.7	30.6	0.11	38.8	31.6	**0.032**	51.8	30.0	**<0.001**
If I had a mental health problem I would not want other people to know	25.2	26.3	25.0	0.65	25.3	25.7	0.88	22.2	28.1	0.05	28.9	23.7	0.092	33.5	23.6	**0.008**
Other people's attitudes to mental health problems would prevent me from looking for information on mental health issues	5.3	4.9	5.4	0.66	5.4	5.5	0.99	2.8	7.6	**0.002**	6.8	4.7	0.17	6.1	5.2	0.46
People who have experienced mental health problems understand these problems better than the mental health professionals	27.0	26.0	28.7	0.37	23.2	30.1	**0.022**	20.6	34.2	**<0.001**	27.5	27.3	0.88	34.5	25.8	**0.021**

Of the sample, 25.2% would not want other people to know if they had a mental health problem. As Table 4.10 shows, those with a past history were more likely to agree with this statement (33.5% versus 23.6%, difference 9.9%, 95% CI 2.4% to 18.0%, P=0.008). There was no difference between younger and older age groups on this question.

The attitudinal questions were used to test one of the hypotheses arising from the interviews, namely that information seeking can be inhibited by stigma. Only 5.3% of respondents agreed that other people's attitudes would stop them looking for information. There was a significant difference by educational level, with less educated individuals being more likely to agree with this statement (7.6% versus 2.8%, (difference 4.8%, 95% CI 1.8% to 8.1%, P=0.002).

The survey asked whether respondents agreed with the statement that people with mental health problems understand these problems better than mental health professionals. Over a quarter of respondents agreed with this (27%). There were differences by age, educational level and past history of mental health problems, with those who are older, less educated, and with a past psychiatric history more likely to agree with this statement.

One final analysis was undertaken to explore the relationship between stigma and Internet use. A stigma variable was created to identify those respondents who felt some aspect of personal stigma regarding mental health problems - that is those who agreed that mental health problems were embarrassing to have, or who would not want other people to know about these problems. The relationship between this stigma variable and use of the Internet for mental health information was then explored. There was no difference in the proportions between those Internet users who describe stigma and those who do not, as regards their use of the Internet for mental health information (18.2% versus 17.7%, difference 0.5%, 95% CI -6.2% to 7.0%, P=0.82). A stratified analysis was then carried out to investigate whether the presence of mental health problems might confound the relationship between stigma and use of the Internet for mental health information seeking. Again there was no difference in the proportions between those Internet users who describe stigma and those who do not, as regards their use of the Internet for mental health information, when looking at the group of GHQ-12 cases (24.8% versus 20.8%, difference 4.0%, 95% CI -7.6% to 15.4%, P=0.42) or the group of non-GHQ-12 cases (14.7% versus 15.4%, difference 0.7%, 95% CI -6.9% to 9.0%, P=0.76).

4.4 Discussion

4.4.1 Summary of principal findings

In this random sample of the Oxfordshire population, with a 58.2% response rate, six mental health information needs were clearly ranked higher than the other six options, by those both with and without current experience of mental health problems. These were: what the problem is; what treatments are available; how to help myself; where to get help from; what has caused the problem; and the future course of the problem. The most accurate sources of information were identified as mental health workers and general practitioners, followed by leaflets produced by the NHS or voluntary organisations or charities. The Internet was ranked in eighth place. General practitioners and mental health workers were also the sources of information on mental health issues most likely to be used, again followed by leaflets, while the Internet was rated in fourth place. "Someone else with the same mental health problem" was ranked as the fourth most accurate source of information, and the sixth most likely to be used.

Of the whole sample, 58.8% had used the Internet, with younger and more educated individuals being more likely users. Of all Internet users, 63.6% had used it for health information, and 18% had used it for information related to mental health. Logistic regression showed that those with a past history of mental health problems, and those with current psychological distress, were more likely to have used the Internet as a source of information on mental health, having adjusted for age, sex and educational level, confirming that the Internet is playing a role in mental health information seeking.

Stigma towards mental health problems is clearly widespread, with three-quarters of respondents agreeing that most people have negative attitudes towards others with such problems, and a third agreeing that these problems are embarrassing to have. However, only one in twenty respondents agreed that other people's attitudes would inhibit their information seeking.

The results are now discussed in relation to previous work in this area.

4.4.2 Discussion of principal findings

4.4.2.1 Information needs

Approximately 40% of respondents selected the need to have information on the areas of 'what the problem is', 'what treatments are available', and 'how to help myself'. The only comparable study of mental health information needs which was conducted to inform the design of a website, identified the top information needs as being: 'helping yourself if/when you are depressed'; 'causes of depression'; and 'recent research on depression'.[97] Our results showed these needs as having overall rankings of third, fifth and twelfth respectively. For those in our sample who had current mental health distress, a group that is probably more comparable to visitors to a depression website, 'how to help myself' and 'what has caused the problem' were ranked first and third. The low response to 'finding out the results from research' is therefore the major difference in our results. One can speculate that the active information seekers visiting a depression website may be more likely to want to know research results than a population sample.

Women were more likely than men to identify "finding out I am not the only person with this problem" as a need, and further work to investigate possible gender differences in the benefits of hearing other people's experiences would be useful. Overall, though, the needs related to hearing other people's experiences were not ranked highly by either men or women. One explanation may be that the top six information needs encompass some of the benefit that can be gained from hearing other people's experiences. For example, hearing that other people have recovered could be categorised as information on the future course of the problem. Other possible reasons for this discrepancy between the interview and survey results are discussed in Chapter 5, Section 5.2.

The survey is limited because respondents only had a finite list of information needs options to choose from, and they were asked the conditional question: "if you had a mental health problem..." which identifies what people *think* they would want to know, rather than what they would *actually* want to know. The analysis of the information needs of current GHQ-12 cases showed that there were few differences between what people with current problems actually want to know, and what others say they would want. One alternative would have been to request a free text answer rather than a response to a finite list, to allow all possible needs to be captured. However there would have been the potential problems of how to analyse the free text answers, and of non-response to this question.

4.4.2.2 Sources of information

Other studies support the findings of this survey in showing the primacy of health professionals as the most used and the most trusted sources of information for health problems.[23,27,318,544] Other work has also found that the Internet is ranked slightly higher as a source to use, than as a source to trust.[27] This was shown in the survey results, and had been suggested in the interview findings. Use of the Internet for mental health information was significantly higher in those with current mental health problems. It is not surprising that people with mental health problems are more likely to seek information on these issues. This finding suggests that the Internet is playing a significant role in mental health information seeking (used by 20% of all those with a history of mental health problems). However a weakness of this study is that equivalently worded questions regarding alternative sources of information (such as books), or use of the Internet for a physical health issue, were not included to allow direct comparisons. The relative importance of the Internet as a source of information is deduced instead from the question ranking the order of sources that would be used "if you had a mental health problem", where the Internet was ranked 4th overall (3rd equal for those with current mental health distress).

4.4.2.3 Use of the Internet

Other surveys of Internet use by UK residents support our finding of 58.8% of respondents having used the Internet. It is encouraging that this and other findings in the present study concur with the assumptions made in the sample size calculations. The Oxford Internet Survey (OxIS) which carried out face-to-face interviews with a nationally representative random sample of 2,030 persons found a prevalence of Internet use of 59%.[39] The finding of 37.4% of all respondents ever having used the Internet for health information, compares with a figure of 41.9% found in a survey of patients at one Oxfordshire general practice.[308] Our finding is also similar to the 39.7% found in a national US survey undertaken in December 2001 and January 2002, although this figure specifically relates to use in the previous year.[545] US surveys that have investigated lifetime use have shown higher figures, for example 53% in a recent Harris Interactive poll.[546] This same poll found rates of lifetime use of the Internet for health purposes in France, Germany and Japan of 24%, 38% and 38% respectively. The latter two results are very similar to that found in the present study.

Our findings demonstrated clear evidence of a 'digital divide' in access to the Internet, by educational level and by age. This divide remained for educational level when investigating use of the Internet for health information, but there were no other significant differences by age or educational level (or by sex) in use of the Internet for health or mental health information. It is possible that there are hidden effects here due to confounding by other variables. For example, the prevalence of other health problems might be independently associated with age, and with Internet use. A recent US survey from the Pew Internet and American Life Project supports the finding that educational level is a determinant of use of the Internet for health information.[61] The US study also found that being female and being aged under 65 were associated with greater use of the Internet of health information. My survey showed a non-significant difference by sex, and used a younger age cut-off.

4.4.2.4 Stigma

One objective of the survey was to explore whether the Internet, with its benefits of privacy and relative anonymity identified in the interviews and literature review, offered a preferred outlet for those experiencing stigma. The analysis comparing those who did and did not report feeling stigma showed no difference when comparing use of the Internet for mental health information seeking, whether or not this was restricted to those with current mental health problems. This analysis is dependent on the measurement of stigma, and in the absence of a validated instrument I used a pragmatic combination of attitudinal questions, which may well have been flawed (and possibly subject to self-presentation bias, see Section 4.4.4).

There has been little previous research quantifying stigma to mental illness in the general population. A postal survey of an Australian population sample used a vignette which described a patient with depression, and asked whether it was likely that such a patient would face discrimination, and 46% of the respondents felt it was likely.[547] The same authors showed that people consider that discrimination would be more likely if the diagnosis was schizophrenia.[548] This question could be seen to be similar to our statement "in general most people have negative attitudes towards people with mental health problems", which 75.8% of our respondents agreed with.

The responses to attitudinal questions were subject to multiple comparisons across variables of age, sex, educational level and mental health status, and care should therefore be taken in the interpretation of significant results. A general problem with attitudinal questions is that attitudes do not necessarily reflect behaviour; and responses to (for example) a theoretical question about whether "other people's attitudes to mental health problems would prevent me looking for information on mental health issues" may not correspond with what would happen in practice. This may account for the surprisingly low (5.3%) agreement with this question, given that this was one of the findings from the interview study.

4.4.3 Validity

Validity in this context refers to the degree to which a question or questionnaire measures what it purports to measure. Four main categories of survey validity are usually distinguished: (definitions adapted from 'A Dictionary of Epidemiology', 4th Edition).[66]

- Face validity - the extent to which a measurement appears reasonable on superficial inspection;
- Content validity - the extent to which the measurement incorporates the characteristics

of the topic under study;

- Construct validity - the extent to which the measurement corresponds to theoretical concepts concerning the phenomenon being studied;
- Criterion validity - the extent to which the measurement correlates with an external criterion of the phenomenon under study, either concurrently or in a predictive manner.

Face and content validity were established both through review of the survey instrument in various stages of development by members of the study steering group, and by the pretesting process. Content validity was supported by using the findings of the literature review and qualitative analysis to inform the design of the survey questions. I chose to use the GHQ-12 to measure mental health status. While this is a well validated measure of current psychological distress, it is not a measure of psychiatric diagnosis. A question relating to past psychiatric history was included, but not one relating to current use of psychiatric services, and perhaps such a question would have provided a useful additional variable. It was encouraging for content validity that the 'other' category, used in the three questions giving a limited range of options to identify information sources and information needs, was selected only rarely. This indicates that the lists of response items provided good coverage of the options that people wanted to choose.

To assess construct validity, one can examine the observed differences (or similarities) between groups within the survey who would have been expected *a priori* to differ (or be similar) in terms of certain characteristics, based on theoretical understandings of the concept under study. This is also called 'known-group validity'.[525] However as identified in the literature review there is little conceptual or empirical literature concerning mental health information needs with which to make such *a priori* predictions, and therefore it is difficult to formally assess the construct validity of several aspects of the questionnaire. Regarding health information needs in general, previous studies suggested that health professionals would have been rated as the most used and most accurate sources of information by all groups, and this was the case. Previous work indicated that Internet use would be higher among younger rather than older people, and more rather than less educated people, and again both of these expectations were confirmed.

It was not possible to assess criterion validity because of the lack of 'gold standard' measures of information needs, Internet use, or stigma attitudes. One possible method would have been to follow up respondents after a period of time to see whether their actual behaviour when faced with a mental health problem was predicted by their responses to the questionnaire. However I did not have the resources or time to do this. It was a particular disappointment that no well validated measure of attitudes in relation to mental health stigma was available.

4.4.4 Reliability

Reliability refers to the degree to which the results obtained by a procedure can be replicated.[66] The test-retest reliability of this survey was formally assessed. This checks whether the same answer is obtained from the same individual at two points in time.[525] The test-retest characteristics were determined by resending the survey to a convenience sample of 180 respondents, representing 10% of the overall survey sample. A 10% sample was chosen following discussion with survey methodology specialists (Dr Donna Lamping and Dr Sarah Smith) at the LSHTM. There is no accepted statistical determination of the sample size for a test-retest sample, but 10% is generally taken as the 'rule of thumb'. Given time constraints it was not feasible to construct a 10% random sample of all respondents after all responses had been received therefore the first 180 respondents were chosen as the test-retest sample. This convenience sample of 180 respondents was sent a second copy of the survey, together with a covering letter explaining the need for the second response (see Appendix 11). This was sent out four weeks after the first survey. The interval between test and retest sendings needs to be long enough that individuals are not recalling and repeating their previous answer, but short enough that there have not been real changes in the characteristics being measured.[525] The GHQ-12 was not included partly because its test-retest characteristics have been explored elsewhere, and partly because this instrument is designed to measure current mental health status which may well change between measurements.[543,549] It was also hoped that a shorter repeat survey would encourage a higher response rate.

The item responses within questions 4, 11 and 12 were treated as independent responses. There were therefore 55 questions to test. The test-retest reliability was calculated using StatsDirect software.[541] Cohen's Kappa statistic was used to test for agreement and Maxwell's χ^2 test for marginal homogeneity was used to test for disagreement.

Of 180 repeat surveys sent out, 129 completed retest surveys were returned, a response rate of 72%. Significant agreement ($P<0.05$) was found for all questions except two: Question

11 item 1 (P=0.54), and Question 12 item 10 (P=0.09). The latter question showed non-significant agreement. Significant disagreement in some category (P<0.05) was found for four questions: Question 4 item 1 (P=0.05), Question 4 item 11 (P=0.03), Question 11 item 4 (P=0.05) and Question 12 item 2 (P=0.002). But all four showed overall agreement.

Therefore the survey was robust to test-retest challenge with good test-retest reliability.

4.4.5 Potential sources of bias

Bias refers to any systematic deviation from true values.[66] This may arise due to errors in survey design, data collection, analysis or interpretation of results. The main categories of bias in self-completion questionnaire surveys are:

- Sampling bias - occurs if the survey sample differs from the population of interest in a systematic way;
- Response bias - occurs if non-responders to the survey differ systematically from responders;
- Measurement bias - occurs if there is a systematic error in the way that the survey measures outcomes.

4.4.5.1 Sampling bias

The population of interest was the general population. This was chosen as mental health problems are sufficiently common in the general population for specific identification of primary care mental health patients to be not only problematic, but also unnecessary, and would miss much of the mental health information needs that may exist. It is estimated that the most common mental illness, depression, will affect nearly half of all women and a quarter of all men by the age of 70.[550] The 1995 OPCS survey of psychiatric morbidity found a point prevalence of neurotic disorder (mental disorder *excluding* addiction, psychosis and dementia) of 16% in the preceding week.[551]

There is no existing sampling frame of people with mild to moderate mental health problems in the general population, and it would not be sufficient, for example, to identify those receiving psychiatric medication from their general practitioner. A population-based cross-sectional survey was felt to be the best method of sampling the majority of people with current or previous experience of mental health problems, and would also include those who have experience as friends or carers. I chose to use the primary care register as it offered a low cost method of obtaining a fairly up-to-date sample. The Oxfordshire Exeter database had been used successfully in the past to obtain a representative cross-section of the local population for the Oxford Healthy Lifestyle Surveys, which achieved response rates (adjusted) of 80%, 72% and 64%. This type of database has also been recommended based on experience with similar research.[552] However such registers are known to have the problem of 'list inflation' whereby people who have been registered with a general practice can remain on the register for a period after dying or moving away.[553] Nationally, this inflation is estimated at 6%,[553] but is known to be higher in University towns.[554] This may explain why 212 surveys (11.8%) were returned unopened as "not known at this address".

To examine possible sampling bias a comparison of the age and sex profile of respondents with that of the whole population was carried out. The mean age of the Oxfordshire population aged 18 or over is 46.2 years (source: Office of National Statistics, Census 2001). This is similar to the mean age of our sample of 46.0 years. Based on mid-year population estimates for 2002, the Oxfordshire population aged 18 or over has 49.0% men and 51.0% women (source: Office of National Statistics, Population Estimates Unit). However the sample used had 53.4% men and 46.6% women. The sex breakdown of the whole Exeter database was not available, so it is not possible to determine whether the difference in our sample represents a random variation from the population figures, or the proportions registered on the Exeter database. Given our relatively large sample size, it is unlikely that this difference was due to random error. Therefore our sample differed from the Oxfordshire population in having more men. The large proportion of men in the "not known at address" category suggests that their over-representation in this sample may be due to men being more likely to contribute to list inflation. Young men are known to be a more mobile population.[555] Indeed, if the sex distribution of the sample is re-analysed after the "not known at address" category are excluded the proportions are 51.3% men and 48.7% women, which is closer to the population distribution.

The use of a database of individuals who have registered with a general practitioner may also underrepresent certain marginalised groups such as the homeless and asylum seekers. However the same is also true of, for example, the electoral roll. With the resources available it would have been difficult to identify a general population sample without this underrepresentation. Cross-sectional sampling also identifies relatively more cases of individuals with chronic health problems, sometimes referred to as prevalence bias.

4.4.5.2 Response bias

The first stage in minimizing response bias is to maximise the response rate. In order to achieve this, the survey administration factors related to improved response rates identified in two recent reviews of this area were considered.[536] [526] One of the factors with the clearest positive effect on response rates is the provision of a financial incentive.[526,536] It was not possible to provide an incentive to all respondents. Instead all were offered entry into a prize draw to win £100 of shopping vouchers. This was drawn after all responses were received, with independent witnesses, and posted to the winner.

Questionnaires considered 'more interesting' are more likely to be returned.[526,536] A covering letter was therefore included which explained the salience of the questionnaire, and the importance of the findings to the NHS. The inclusion of sensitive questions is associated with a small negative effect on questionnaire response rates,[536] the covering letter therefore was used to emphasise that the recipient had not been 'singled out' to receive a questionnaire about mental health issues, and that all answers were anonymous and confidential. Nevertheless, personal mental health is regarded as a private and stigmatised issue, the questionnaire contained the words 'mental health' in its title, and sensitive questions such as those relating to past psychiatric history and current mental health symptoms did, of course, remain in the document. These are likely to be among the main reasons for the relatively disappointing response rate.

The covering letter was sent on joint University/NHS headed paper and postmarked from the University. Questionnaires originating from universities are more likely to be returned than those from other sources.[536] A freepost return envelope was included with the questionnaire mailing. Research shows that having a stamped return envelope is preferable to having a freepost one, but resources did not allow for stamped envelopes. Likewise it was not possible to send each survey by recorded delivery (also associated with higher response rate).[526,536] Having any sort of pre-paid return envelope is of course preferable to asking the respondent to pay the postage, both in ethical and response rate terms. Finally, in order to maximise response rate, three postal reminders were sent to each potential respondent.[526,536]

Despite these efforts, the final adjusted response rate was still only 58.2% (50.9% unadjusted) and the analysis comparing characteristics of responders and non-responders did show significant differences between these two groups. On average non-responders were 5.5 years younger, from areas with slightly higher deprivation scores, and were more likely to be male. This is in line with known associations with non-response in population surveys.[556] The survey was written in English and due to resource constraints it was not provided in other languages, or other formats (for example, audio-format), so it is likely (as with postal questionnaire surveys in general) that there was a response bias towards literate English speakers. It is difficult to know what effects non-response bias may have had on the findings. For example, Internet use is more prevalent in younger age groups (overrepresented among non-respondents) but also in less deprived groups (underrepresented among non-respondents).

People who were more interested in mental health topics, and perhaps who had had more experience of mental health problems, may have been more likely to complete the survey. However it is also possible that the presence of mental health problems may in themselves inhibit survey completion. The fact that our findings with regard to both the point prevalence of GHQ-12 caseness (34%) and a personal history of serious mental health problems (18.2%), were similar to the findings of previous UK general population surveys, suggests that any bias was not large. A recent survey in Somerset found that 35.1% of respondents scored two or above on the GHQ-12.[557] The 1-year prevalence of mental disorder of any severity is 21%.[68] A review of studies investigating the lifetime prevalence of major depression, the most common serious mental disorder, identified a mean figure of 16.1%.[558] Of course these previous surveys may have been susceptible to similar biases.

4.4.5.3 Measurement bias

Measurement bias in this context refers to both whether a factor related to the wording or ordering of the questionnaire led to a systematic error in the responses; and whether the question topic itself systematically affected the responses it generated (in terms of recall or presentation biases).

Regarding question wording and ordering, the main concern in this survey was that questions with multiple responses can be at risk of item order bias.[559] For written questions the risk is of a primacy effect, whereby items nearer the top of the list are more likely to be selected. This has been shown to be present in lists of seven items or more.[560] In this survey there were three questions with lists of 14 or 15 responses (questions 4, 11 and 12). Ideally order bias detection requires a cross-over test-retest study, but it was not feasible to undertake this. Also, it would be difficult to separate the influence of the test-retest reliability of these questions from any item order bias effect.

In order to make some judgement about item order bias the item order for responses in questions 4, 11 and 12 was reversed in 50% of the surveys sent out. The surveys were identical in every respect except that half (900) were on cream paper and the other half with the item responses reversed were on pale yellow paper. The allocation of cream or yellow survey was undertaken using a quasi-random method by study ID number (odd study ID numbers received cream surveys, even numbers received yellow surveys). Item order response bias in these questions was then investigated by a simple univariate analysis for each item response comparing the total responses (outcome as ticked or not ticked) for the item on the yellow surveys with the total responses for the item when its position in the item order was reversed on the cream surveys. The results of this analysis are presented in Appendix 15.

The results showed that there were some minor order effects for question 4, and for one item in question 11, but for the most part these questions did not demonstrate a major effect of item order. However question 12 is potentially problematic, with items towards both ends of the list showing significant effects. It is encouraging, however, that the analysis showed that despite the order effects, the clear separation of the top six items of information need from the other items remained. In addition, the fact that items were reversed in half the surveys does, to some extent, control for the order effect.

Questions related to personal beliefs and stigma could have been susceptible to presentation bias. This occurs when the response to the question is influenced by the individual's desire to present himself or herself in a particular way. It is possible that respondents would not want to be perceived as believing that mental health problems are embarrassing, or that they would not want other people to know about them. It is more 'politically correct' to state that such problems are not embarrassing (also described as 'social desirability bias'). Such bias is reputedly less prominent in postal surveys than in face-to-face questionnaires, but may still be present.[561] It is interesting that 75.8% of respondents believed that in general most people have negative attitudes towards others who have mental health problems, while less than half this number (33.5%) agreed that mental health problems are embarrassing to have. A similar issue may have arisen with the questions regarding information sources and needs. Respondents may have felt that the (NHS) investigators wanted certain responses regarding the value of (for example) mental health professionals or NHS Direct.

4.4.6 Ethical considerations

I was mindful of three major ethical considerations: the use of general practice registers as the sampling frame; the confidentiality and security of collected data; and the use of a financial incentive to encourage response. Permission to use the primary care database was obtained from Thames Valley Primary Care Agency and Oxfordshire Primary Care Trusts. This database had been used for similar NHS and academic surveys in the past, and permission was granted subject to the receipt of ethical approval, and assurances that guidelines on the confidentiality of data would be followed. I also wrote to all general practitioners in advance of the survey to inform them of it and to give them the opportunity to contact the research team if there were any concerns.

To ensure the confidentiality and security of collected data, no personally identifiable information was held after its use to mail out the survey and reminders. The only identifiers used were the respondent ID numbers. Returned surveys were kept in a locked cupboard, and all electronic data files were password protected. OPREC also requested the establishment of a process to ensure that reminders were not sent to anyone who had died, and this was put in place.

As financial incentives have been shown to increase response to postal surveys, entry in a prize draw was included for all respondents. OPREC was satisfied that this did not cause any ethical problems, but the LSHTM ethics committee, while giving permission for the survey to go ahead with the prize draw, expressed a general disapproval of the use of financial incentives.

4.4.7 Problems encountered

The main problems encountered have been discussed above. Foremost of these was the disappointing response rate, despite efforts to maximise this in the design and administration of the study. The complete survey was sent out on three separate occasions, rather than the two mailings initially planned, in addition to there being one postcard reminder. The extra survey mailing therefore delayed the analysis of results and added to the costs of the study. The multiple mailings contributed to a further problem, that of individual complaints from a few non-respondent recipients who were unhappy to continue to receive unsolicited surveys. There were less than ten complaints received by post or telephone, apologies were given and care was taken to ensure that further mailings were not sent to the complainants.

The other main problem which was also discussed above, concerned the difficulty of identifying previously validated questions for the survey. This was particularly for the questions related to information needs, and to stigma. The survey was pre-tested and piloted, but nevertheless these questions had not been validated in a population sample.

4.4.8 Alternative approaches

The aim of the postal survey was to quantify the issues raised in the qualitative research, particularly around health information sources and needs, and the use of the Internet, among a representative population sample. Alternative approaches could have included using face-to-face or telephone questioning, or using a non-population based sampling frame. Face-to-face and telephone questioning can lead to higher response rates, but are resource intensive, and have some disadvantages for the investigation of sensitive personal topics.[526] An alternative sampling strategy could have targeted individuals who had direct experience of mental health problems and/or mental health services. However, as noted above, any such sampling frame (for example of those on psychiatric medication, or those seen in secondary care) would have excluded the majority of individuals with experience of mental health problems. Such a focussed survey may be a useful follow-up piece of research to this work.

Having described and discussed the results from the interview study and the cross-sectional survey, the next chapter will provide conclusions regarding the answers to the research questions, and the lessons learned from this research project.

5. Discussion

In this final chapter I will summarise the main findings from each section of the thesis in relation to the original research questions (Section 5.1). The relationship between the findings and the results of previous research was discussed in Chapters 3 and 4. I will summarise the limitations of the methods used and make methodological recommendations to inform future work in this area (Section 5.2). I will then describe how the findings fit with the theoretical approaches described in Section 2.4 (Section 5.3), discuss the implications for policy (Section 5.4) and practice (Section 5.5), and make recommendations for future research (Section 5.6). Finally I will draw out some broad conclusions (Section 5.7).

5.1 Principal findings

I set out to answer three main research questions that had not been addressed by previous research. These were:

With regard to the users of mental healthcare:

- What are their health information needs?
- What are their attitudes towards different sources of health information?
- What is the role of the Internet in mental healthcare information provision, from the patient perspective?

The findings in relation to these questions are summarised in the next three sections.

5.1.1 The information needs of mental health users

In the literature review, I found that the information needs literature is dominated by cancer information needs, and has often been of poor methodological quality. Very little was known concerning mental health information needs, and no statements could be made regarding the needs of the vast majority of service users with mild to moderate mental health problems. No studies were found which undertook in-depth interviews with a range of mental health service users. The literature review findings were used to inform the in-depth interviews and questionnaire survey.

The exploratory nature of the interviews led to broad findings which suggested both direct and indirect information needs of mental health users. These were:

Direct needs:

- More information than exists at present. Specific areas included diagnosis, treatment and side-effects.
- A level of information giving that makes health consumers feel respected.
- Information about other people's experience of mental health problems.

Indirect needs:

- An environment that supports personal research into illness and values the contribution patients can make to the consultation.
- A stronger and more equal partnership between health consumers and health professionals.

- A reduction in the stigma of mental illness.

These findings fit with previous research on the motivations for consumers seeking information about their healthcare (see Chapter 2, including Box 2.3 and Box 2.4). The population survey was used to quantify specific information needs in a representative sample. The top six needs are listed below. These are listed in order as identified by those with current mental health distress. The same six needs (in slightly different order, see Section 4.3.4.1) were identified by the whole population sample.

- How to help myself
- What treatments are available
- What the problem is
- What has caused the problem
- Where to get help from
- The future course of the problem

Finding out about diagnosis ('what the problem is') and treatment ('what treatments are available') were identified both in the interview study and the survey. 'Side-effects of treatments' was a concern of interviewees, and has been shown in work on medicine information needs,[562] but did not rank highly in the survey. Notably, the interviews showed that people with mental health problems valued hearing other people's experiences, and finding out that they were not the only ones with their problems, but these needs were not ranked highly in the survey. Other people's experience may of course provide information that meets one of these six needs.

5.1.2 Attitudes towards different sources of mental health information

The interviews showed that a variety of sources are used to obtain information about mental health problems. The responses were used to help generate the item response list in the questionnaire survey. Health professionals were seen as having expert factual knowledge, but not always sharing this knowledge in a satisfactory way. When interviewees had had a good experience with a health professional giving them advice, they often commented that they were lucky to have (for example) a good general practitioner. The expectation was of an unsatisfactory level of information giving.

Clearly one important aspect of this research was to put the role of the Internet as an information source in context. The Internet was described as an important source, particularly for obtaining experiential information. Professionals' concerns with the quality of factual information on the Internet were not prominent in the attitudes of interviewees. Misuse of the Internet was seen as a more significant problem, with interviewees giving examples of people using (for example) bulletin boards in a disruptive way. For the most part interviewees felt that they could distinguish poor quality information, often relying on websites provided by organisations with known credibility. Interviewees also reported using leaflets and books, and again books containing experiential information were particularly valued.

The survey findings confirmed other research identified in the literature review which shows that health professionals are the most used and most trusted source of health information, and also showed that the Internet is an important source, although it is ranked lower as a source to be trusted than a source to be used. Leaflets provided by the NHS or voluntary organisations or charities were also ranked highly in the survey.

5.1.3 The role of the Internet in mental health information provision

As stated in the introduction, I used the colloquial meaning of the term Internet to refer to world-wide-web pages viewed in a browser window. The literature review showed that previous research on the role of the Internet in providing consumer health information has been preoccupied with measuring the quality of the information. There have also been survey studies measuring how frequently consumers access information, and speculation of the effects on the practitioner-patient relationship, but there has been little work on what people are actually looking for or how they use the information they find. There is undoubtedly much poor quality information available online. However, the issue is not that it exists, but how it is used. Additionally, in the area of mental health, the Internet has been shown to provide social support, and to be a feasible mechanism for delivering potentially therapeutic interventions.

The interview study contributes to the scarce literature on how consumers use the Internet for health information. The Internet has particular benefits which include anonymity, privacy and convenience of access. These benefits are of particular value to people with mental health problems which are often stigmatising and socially isolating. Another benefit is the ability to learn from others in the same situation, either through online interaction or through reading messages left by others. The need for experiential information was a general information need, but one which the Internet was particularly meeting.

The survey confirmed that Internet use for health information is common in the general population and amongst those with current or past mental health problems. Over ten percent of the population sample (which includes non-Internet users) had used the Internet to find out about a mental health issue.

5.2 Limitations of research methods

The strengths and weaknesses of the interview and survey methods chosen were discussed in detail in Chapters 3 and 4. Alternative approaches were also discussed. In this section I will simply highlight the broader limitations of this project. These can inform the methodology of future projects investigating health information needs and behaviour.

This project used a mixed methods approach of both in-depth qualitative methods and quantitative survey work to explore and identify information needs. However a general weakness of the whole project is that underpinning the research questions is an assumption that a generalisable set of information needs can be defined for people with mental health problems. The evidence from the cancer information literature suggests that individuals' information preferences vary widely, and that these preferences should be taken into account in information giving.[85,563] The interviews showed that common themes exist, but they also demonstrated that there is much individual variability in what people want to know and at what stage of illness. The survey was able to identify the top six needs (from a list of twelve) but the nature of the method limited individual expression of need. I chose not to use the alternative approach of allowing a free text answer, due to the problems this would have caused in coding and analysing replies, and because one aim of the literature review and interviews was to narrow down the information needs to a manageable list. However the problem remains that by using a survey to identify generalisable findings, the impact of individual variability may have been lost. The literature on medical consulting styles shows that people have their own individual preferences,[2] with obvious implications for clinical practice, and this may well apply to information giving more generally.

The main discrepancy between the interview findings and the survey results was in relation to finding out about other people's experiences. There are several possible explanations for this. Firstly, the interviewees were a different group, differing both from the general population, but also from those with current mental health distress. The interviewees were people with experience of mental health services, which would make them more likely to have a history of serious mental health problems, for these problems to be chronic, and to be in the minority of people with mental health problems who have sought health service help.[513] Secondly, the difference may be related to the nature of the methods used. The interviews were designed to explore needs in-depth with respondents, whereas the survey question requires a quick choice from a limited range of options. Thirdly, some of the information gained from hearing other people's experience might well be included in one of the other needs. Finally, it may be that the survey question "if you had a mental health problem which areas of information would it be most helpful to find out about?" identified information needs in general, whereas the interviews identified *unmet* needs; thus interviewees were reporting the information that they had wanted to know but had been unable to access.

The main weakness of the interview method was the sampling of interviewees. Despite using purposive sampling and continuing recruitment until saturation was reached in the emerging findings, we were still reliant on volunteers who wished to take part in a study of mental health information. It is likely that these individuals may have had a particular story to tell about their experience of finding information in the NHS. Clearly we were aware of this and attempted to sample volunteers with a range of experience, but there is a risk that we missed the views of the more satisfied patients. There may be value in this, in that the dissatisfied individuals have more to tell us about unmet needs, but this should be taken into account when considering the findings. Another related factor is that, in general, volunteers were describing their past experience, and their accounts may be subject to recall bias. An alternative approach could have confined questioning to recent events but this would have lost potentially important data, and as this was exploratory work this was considered inappropriate.

We also attempted to include individuals from a wide age range and with a variety of socio-economic backgrounds, but it proved difficult to recruit individuals under the age of 25, or from black and minority ethnic groups. The lack of representation from those under 25 probably explains the low use of online synchronous communication (live chatrooms and instant messaging) among the sample. Finally, we intentionally oversampled individuals with some experience of using the Internet (32 of 36 interviewees). We were not generating a representative sample, and this was an exploratory study, but the qualitative findings could be criticised as representing the mental health information needs of people who have Internet access. They are still of value, in informing the design of the survey, in generating hypotheses concerning mental health information, and in particular for identifying the role of the Internet in mental health information provision.

The main weakness of the survey is the response rate. In anticipation of the difficulties encountered in generating a high response rate to an unsolicited postal questionnaire, I reviewed the factors known to be associated with increased response rates and attempted to incorporate these wherever possible into the design and administration of the survey. Nevertheless it was not possible to incorporate all of these (such as sending questionnaires by recorded delivery), or to continue to send repeat mailings. The final adjusted response rate of 58.2% is acceptable for this type of survey, but not outstanding. The adjustment made to exclude surveys returned unopened from unknown recipients has been carried out in similar previous work. Without this adjustment the response rate was 50.9%.

There are two ways of addressing the low response in the analysis. I chose to be explicit about who the responders and non-responders were and to interpret the results accordingly, and allow the reader to take into account the differences in the two groups. The alternative approach is to apply non-response weights to the findings. This method makes the assumption that the younger, male, more deprived, non-respondents were on average likely to have responded in the same way as the younger, male, more deprived, individuals who did choose to respond. In effect the answers from the non-respondents are calculated and added to the 'real' responses (achieved by giving more weight to the responses from the underrepresented groups). I am not in favour of this approach. It is not, in my view, justifiable to predict what non-respondents would have said based on their demographic characteristics, as they are likely to differ from respondents in other ways. I preferred to attempt to minimise non-response in the first place, and then be explicit about the differences between respondents and non-respondents and allow the results to be interpreted accordingly.

Neither the interviews nor the survey included non-English speakers. I did not use an interpreter for the interviews and the survey was not available in other languages or formats. These decisions were made for pragmatic reasons related to the available resources. However, the research can be criticised for having a bias towards those who are literate in English.

5.3 Comparison with conceptual framework

The theoretical approach taken for the interviews was inductive and grounded, no *a priori* theory was being tested. However the literature on information seeking, health behaviour change, and models of mass communication was used to construct a conceptual framework in Chapter 2 (Section 2.4.5, Figure 2.2). This was a useful tool to inform the content, analysis and interpretation of the interview findings, and subsequently helped in the design of the survey. For example, this framework was helpful in delineating the roles and key characteristics of the communicator, the message, the medium and the receiver and in highlighting the importance of certain intrinsic and extrinsic influences on information behaviour. It was also useful to have a framework that combined models of both mass and individual communication, as the Internet is a medium for both. However, as others have noted, a single conceptual model is insufficient to explain the "multifaceted phenomenon" of information behaviour.[564]

The study of information behaviour and information needs does not have a unifying theory.[457] Researchers in this area have been criticised for always developing new models rather than building on old ones, or postulating different theories with each new project.[565] Case summarises nineteen theoretical approaches that have been invoked in information behaviour research,[457] and advance publicity for a forthcoming book promises an overview of over 70 theories for studying information behaviour.[566] I believe that the search for a satisfactory theory of information behaviour is probably unachievable and would be unhelpful, as information needs actually reflect more fundamental affective, cognitive or physiological needs. This may also explain the difficulties that arise when attempting to define information needs.

Information behaviour cannot be separated from other aspects of human behaviour. One can apply existing psychological theories to help understand attitudes and behaviour in relation to health information. For example, as outlined in Chapter 2, Wilson has demonstrated the usefulness of insights from psychological theories of Stress and Coping, Risk and Reward, and Social Learning.[459] Others have explained information behaviour in terms of Monitoring and Blunting,[567] or Social Network Theory.[568] Most of these theories are mutually compatible and can usefully explain different types of information behaviour in different contexts. However, in isolation none of them is able to provide a definitive explanation or understanding of all aspects of information behaviour. For example, although categorising people as Monitors or Blunters can be used to describe how some people intrinsically want to be fully informed shared decision-makers, while others do not, it does not explain why in different contexts the same individuals may switch roles. It is also too simplistic in that it reduces behaviour to one of two categories, and several psychological theories of human behaviour can be criticised for a similarly reductionist approach.

Interactionism offers an alternative approach to reductionism, and my grounded approach can be considered as part of the wider tradition of symbolic interactionism. I believe that information behaviour, as with all behaviour related to health and illness, cannot be considered outside its social and cultural context.[569,570] Information needs cannot be viewed as separate from the meaning that an individual attaches to that information, to the information source, or to the specific health concern.[571] By constructing the conceptual framework as an essentially linear flow-diagram, the importance of interaction and context at all stages may not have been adequately emphasised. The role of other health needs, and illness and help-seeking behaviour in influencing information needs was not considered here, but would be a valuable topic for further research. I did not explore with participants what it means to have mental health problems, nor how information behaviour relates to how people make sense of their mental health. Work in this area needs to explore the underlying motivations for information seeking. For example, in this research I was able to ascertain that the value of hearing other people's experience was related to the reassurance of not being alone and knowing that others get better.

The framework also used the assumption, implicit in most models of information seeking,[457] that the starting point for such activity is a feeling of uncertainty, ambiguity or uneasiness. The framework does not explicitly provide for the fact that information behaviour can sometimes be unintentional and needs are not always 'felt'. Again, this bias may have led to the research project concentrating on expressed need, while making some deductions from explanations of past behaviour about unexpressed needs. The research showed that information behaviour is an iterative process, and that information needs change with time and stage of illness, and in response to finding new information. People are not necessarily aware of what they do not know, nor what it might be helpful for them to find out. Observational work would have helped to investigate these latter needs further. Such work would have also directly ascertained behaviour rather than requiring this to be deduced from reported beliefs and attitudes, and might have provided useful triangulation for the findings.

5.4 Implications for policy

The results of this project provide support for initiatives such as the 'Expert Patient',[572] and for more of a partnership between patients and the health service.[573,574] Mental health service users want to be better informed and to feel less patronised. There is dissatisfaction at poor levels of current information provision and patients do not feel respected as a result. They are undertaking their own research into their health and recognise the challenge to professionals that this presents. Policymakers need to create an environment that supports a more equal relationship between practitioner and patient. The Internet is increasingly being used for health information and can support this partnership,[349] and policymakers should consider how best to use it.

This study has clearly identified the value of experiential information, and in the UK the Department of Health is already supporting the DIPEx project to provide this online.[575] In economic terms the Internet has many features of a perfect market and other suppliers are responding to the demand for experiential information, providing support for this research finding. The BMJ Besttreatments.org website includes a patient experience section.[576] Websites such as Thirdaid.org are providing fora for individuals to interact with others in the same situation, and sites such as Friendshealthconnection.org match people with similar health problems for the purpose of mutual support. Currently NHS Direct Online does not provide information on patient experience or messageboards or chatrooms, but given the value to patients of hearing others' experience, policymakers may wish to consider this option. Online 'patient helpers' (expert patients running their own websites) have been suggested as a way that the Internet could be used to harness patient experience and support practitioner-patient partnership,[506] and my findings support this.

Mental health information seeking is inhibited by stigma, widely recognised by the interviewees, contributing to the reasons why policymakers should act to reduce the stigma associated with mental health problems. Any strategy to improve mental health needs to tackle this associated stigma.

5.5 Implications for practice

Practitioners need to be aware that mental health service users may be dissatisfied with the level of information provision. The main needs identified in this research will help to inform practitioners regarding what information to provide, but they should also be aware that individual information needs and preferences vary. The relationship between practitioners and their patients needs to foster respect, and information giving is part of this. Practitioners also need to allow their patients to undertake their own research into their condition and not feel threatened by this. Health service users are increasingly using the Internet to find health information and practitioners need to be aware of the role this is playing, as a tool for personal research and as a source of information and support from others. Inaccurate information exists, but patients are aware that this is a problem and their need is for explanation and advice, rather than criticism. The role of information therapy on prescription needs further evaluation,[577] but the research findings support the practice of guiding consumers to useful information.

This research has identified the need to hear other people's experience, and practitioners need to understand the value of this. Supporting or enabling people with mental health problems to learn about others with similar experiences could be of benefit. This can be achieved through formal support groups, but also through informal social networks, the Internet, and traditional sources such as books detailing personal accounts of illness. Learning from such experiential information may also benefit practitioners.[578]

5.6 Recommendations for further research

Further research to investigate mental health information needs would be useful, as would more work on the role of the Internet in health information provision.

5.6.1 Information needs of mental health users

There is a need for further work exploring mental health information needs for individuals by subgroup. This could include looking at differences in needs by gender, social or cultural background, personality type, psychiatric diagnosis or at particular points on the patient pathway, for example when key treatment decisions are being made. Such work should also investigate further the value of hearing other people's experiences, again examining variations by personal characteristics such as gender. Future studies should also explore the relationship between information seeking and the wider context of illness behaviour. Studies should also investigate the influence of personal characteristics and available resources on information behaviour, including material, psychological and social resources.

Research to infer information need from information use in mental health would be useful to triangulate the findings of the present study. An example would be to analyse requests on mental health topics received by NHS Direct or NHS Direct Online, or to examine health-related website usage statistics.

There is a need for intervention studies of information-giving in mental health, examining the outcome on measures of health status, wellbeing and satisfaction. Such trials should look at information giving generally, for example investigating information therapy, or the value of giving personalised information,[280] or could focus on specific areas of decision-making, for example studies of decision aids to facilitate informed treatment choice.[83]

5.6.2 Internet use for health information

Much of the work conducted in the area of ehealth has been quantitative, perhaps explained by the skills and backgrounds of those who choose to research the impact of computers and information systems. Qualitative research has much to offer this area.[579] There is, for example, a need for more ethnographic work investigating how people are using the Internet in relation to their health, and the barriers and facilitators to this. Methods could include observation or analysis of narratives or diaries. There is a need to investigate the use of live chatrooms and instant messaging for communicating with other people about health issues. Additionally, there is a need for trials of online social support for people with mental health problems, and to measure the effects on health and social outcomes.[92,416]

The factors associated with mental health-related Internet use should also be studied further as is now happening for some other conditions.[300,580,581] The relationship between Internet use and specific health decisions and encounters with health services should also be investigated. Previous work has tended to provide basic survey data on the self-reported effects of Internet use on healthcare decisions,[545] or on the use of the Internet in relation to a consultation.[292,320] More sophisticated approaches are required to explore the role the Internet is playing at these times, and to understand the benefits or otherwise.

There is a need for well conducted trials of information-based mental health-related Internet interventions. These may be computerised decision aids, or interventions such as online therapies for prevention or treatment of mental disorders. Preliminary work in this area has demonstrated the potential benefit of online cognitive-behavioural approaches.[433,582,583] Psychotherapy via computer has been shown to be acceptable to patients, and may be of particular value to people unwilling to access such services via their general practitioner.[584] The Internet can also be used to screen for disorders such as depression or anxiety,[585,586] and trials are needed to test the value of this.

5.7 Conclusions

The motivation for this research came from a desire to investigate the impact of the Internet on consumer health information provision. I chose mental health as this is my specialism, but also because the chronicity and stigmatising nature of mental health problems led me to believe that the Internet may offer particular benefits, as well as its potential to deliver information-based interventions. Preliminary work showed that very little was known about mental health information needs in general, and I therefore determined that the research should identify these needs, and also consider the role of the Internet in meeting them.

Information needs research is an area that has been tackled by investigators from various disciplines. Library and information scientists have tended to look at consumer demand for information in settings such as libraries or clinic waiting rooms. By its nature this research is going to identify needs for factual information such as that found in books or other documentary material. Other researchers investigating information needs, coming from the computing disciplines, have tended to quantify needs by looking at, for example, usage statistics and inferring need from use. This, however, does not give a measure of unmet need. I did not consider either of these two approaches to be satisfactory for this project and instead decided to use a mixed methods health services research approach, firstly to use a qualitative method to explore the beliefs and motivations of people with mental health problems regarding their information needs, and secondly using a survey to quantify the needs identified, and to put the interviews in context.

In Section 5.2 I identified several limitations of this project, particularly the issue of whether a generalisable set of information needs can be defined. There is a danger of over-simplification and disregard for variation in individual preferences. Nevertheless I believe the research has identified important common themes which will inform policymakers and practitioners, as well as other researchers in this area. The approach used in the interviews was of particular value in identifying these themes, while the survey provided useful context as well as establishing a priority order for a list of needs.

Underlying much of the previous work in the area of information needs has been either an implicit or explicit deficit model of patient information. This can be likened to Thomas Gradgrind's approach to education in Dickens's *Hard Times*.[587] Gradgrind sees his pupils as empty vessels that are there to be filled up with facts, and once sufficient facts have been poured into them their curiosity will be satisfied, and they will be conformist, undemanding members of society. My findings show that people do not just want to be passive recipients of a (limited) downward flow of factual information. There is a need for more information and for more of a partnership between practitioners and patients. The participants in the interviews described wanting to be treated with dignity and respect. Not everyone wants to have patient-led or fully shared decision-making,[588,589] but they want to be respected and have their preferences taken into account. This is not about information giving for the sake of it, nor to quieten patient demand, but equally it is not about information giving to improve health outcomes. It is about information giving to improve patient experience, and a 'postmodern' health service must address concerns about values as well as evidence.[590,591]

However there are both individual and organisational barriers to overcome if this active partnership is to be achieved.[64,592] My research supports the findings of others that many consumers have difficulties obtaining information, or find themselves patronised.[592] Many participants in this research recognised that their becoming more informed presented a challenge to their practitioners. The traditional paternalistic health service model can be accentuated in mental healthcare due to the stigma of mental illness and the perception by some that mental health problems are not as legitimate as physical ones. Consumers are demonstrating their choice to be become better informed by carrying out their own research. They are also choosing to use experiential information from other consumers in addition to the information given by their healthcare provider. Consumers can be producers of health knowledge, interweaving their personal experience with health advice.[488] Providers must understand the motivations for this, otherwise, perceiving it as a challenge to professional authority, they may resist it.

The context for this research was a UK health service which is becoming increasingly consumer focused, in a society which is adapting to rapid technological innovation in the way information is stored and managed. Healthcare consumers are being encouraged to take a greater role in their healthcare and are encountering increasing sources of information to allow them to do so. The Internet is playing a key role in this. The very nature of the world-wide-web encourages consumer involvement and empowerment as it removes many of the traditional access barriers and it provides knowledge at all levels of expertise. Yet despite these fundamental changes, very little research had been carried out into how consumers actually use the Internet. We know how many use it, and we know something about which sites they visit, but we know little about what they are looking for and less about what they do when they find it. This study has contributed to this area by showing, for example, that people use the Internet to find universality, hope, and the empathy of others. However, there is a dearth of research linking information use with healthcare outcomes and this is particularly true with respect to online information. There is also a tendency to categorise the Internet as either beneficial or harmful, socially connecting or socially isolating, informing or misleading, when these are all functions of how it is used.[593]

This is the first qualitative study to have investigated the information needs of people with a range of mental health problems. The survey is the first attempt to quantify mental health information needs in the general population. When this research began there had been very little work exploring how consumers use the Internet for health information. The results make a significant and, I believe, original contribution to the information needs literature and the emerging and intriguing area of health-related use of the Internet.

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Appendices

Appendix 1: Interview participant information sheet

NHS

Mental Health Information Study

Information Sheet

(Study Number: AQREC A00.070)

October 2001

Full title of project: An assessment of the health information needs of the users of mental healthcare – will developments in electronic information help?

This sheet gives information on the above research study for prospective participants.

If you would like to volunteer to take part in this research please use the attached sheet or contact the lead researcher Dr John Powell on 01844 239363 or email mhis@mhis.org.uk. You can also visit the study website at www.mhis.org.uk

Please also contact us if you have any questions about this research study.

What is health information? Health information includes any information that people use to help with their health care. This includes talking to friends, reading leaflets, using reference books, and browsing internet sites. The researchers are particularly interested in how people use information on mental health – information that concerns psychological and emotional issues.

Why is this research being carried out? New developments in health information are taking place all the time, particularly concerning the internet. However there has been very little research into what the users of health information actually want, and how they use information to help with health care. This research project aims to identify the aspects of health information that people value, and how they use this information.

What would the research involve? The research asks for volunteers to talk about their experiences of using health information. Volunteers would be asked to take part in face to face interviews with one researcher. Interviews would last up to 50 minutes.

Would interviews be recorded? Yes. They will be audio-taped and transcribed. All information would be anonymous and no participant would be identifiable. The recording and transcribing is necessary in order to analyse the views expressed in the interviews and groups. All recordings would be destroyed after use.

Would what I say affect the care I get from the NHS? No. Although this is an NHS funded research project, there is no connection between this study and any aspect of NHS care. All comments made in interviews or groups are entirely confidential, and all recordings are anonymous. We would not ask for your name or address, but we would ask for your age and the sort of work you do.

Would I get paid to take part? Unfortunately we cannot pay volunteers for this study.

Who is funding this research? The research is funded by the National Health Service through the NHS research and Development Programme.

Can I change my mind if I volunteer now but have second thoughts later? Yes. You can change your mind at any time. This would not affect your medical care or legal rights in any way.

Where do the interviews take place? The interviews are scheduled to take place at the outpatients department of the Warneford Hospital, Oxford on Wednesdays and Fridays. But if this is inconvenient we will try to make alternative arrangements.

How do I volunteer? If you are interested in volunteering you can telephone the study line on 01844 239363, or you can email mhis@mhis.org.uk, or you send the tear-off slip below.
At this stage you are making no commitment to take part in research.

……

Yes I am interested in volunteering for the Mental Health Information Study:
"An assessment of the health information needs of the users of mental healthcare – will developments in electronic information help?" (AQREC A00.70)

Please contact me with further details.

Name: ______________________________

Address: ______________________________

____

Telephone: ____________________ Email: ____________________

Send this slip to: Dr John Powell, Honorary Clinical Research Fellow, University Department of Psychiatry, Warneford Hospital, Headington, Oxford OX3 7JX.

Appendix 2: Flyer for interview study

i	Mental Health Information Study	NHS

i is for information. Information about health and healthcare takes many forms – books, leaflets, television and radio programmes, internet pages, as well as information from speaking with healthcare professionals and with family and friends.

i is for individuals. Individuals need information about their health and their local health services.

i is for investigation. The NHS funded Mental Health Information Study is investigating how individuals use various sources of information about health and healthcare. The results of this study will be used to improve the information that is provided to patients.

The Mental Health Information Study is being carried out by researchers from London University in conjunction with the Oxfordshire Mental Healthcare NHS Trust. The study is currently looking for volunteers to take part in interviews. Volunteers should have some experience of mental health problems. Mental health problems include anxiety, phobias, depression, manic-depression, schizophrenia, and also other psychological difficulties. These interviews would take between 30 minutes and one hour.

The interviews will include discussion about various sources of information, and how useful these are. The interviewer will also be keen to know what information is most useful to users.

If you would like to find out more about the Mental Health Information Study please ask for our information sheet or look at our website at www.mhis.org.uk.

You can contact the NHS Mental Health Information Study on **01844 239363** or by email **mhis@mhis.org.uk**.

Appendix 3: Interview topic guide

Topic	Areas to cover and possible questions and prompts
Introduction	"Thank you for taking part". Reminder that participation is voluntary, has no connection with health service provision, and that consent may be withdrawn at any time. The research is funded by the NHS and the researcher is based at London University. Reminder that interview will be audiotaped, and that all tapes and all other records will be held securely and only anonymous data used in analysis. Set the scene for the interview, how the NHS and other organistaions provide health information, and we know that people also use other sources to find out about health and healthcare. However we know very little about what information people actually use, how they use it, what they think of the information, and what is helpful to find out.
First experience of mental health problem/illness	"Can you tell me about your experience of mental health problems?" "Tell me about the first time you had problems." Ask about initial help and information needs and action taken to seek information.
First contact with mental health services	"Can you tell me about the first time you came into contact with mental health services?" Discuss first contact with services, how this occurred, who with etc. Ask about initial information needs: "what did you want to know?" and whether these were met.
The course of the problem/illness	Discuss illness narrative. Take interviewee through course of illness step by step. Explore whether stage of illness affects information needs.
Other episodes	Explore other episodes of mental health problems, both when these led to formal and also informal help-seeking.
Communicator	Ask about views on specific information sources, and experience of using them. For what information? In what situation? With what result? How about the effect this had on the way the communicator was perceived, and any relationship with the communicator? Discuss practitioner-patient relationship if appropriate. Discuss whether information is trusted as being accurate from different sources. Cover both formal and informal sources, and explore any comparisons between the two. Can list specific sources as examples as a prompt - e.g. GPs, mental health workers, friends & family, books, leaflets, TV, radio, Internet etc.
Message	Ask about what people wanted to know at different times or at different stages of illness. Ask for examples of pieces of information obtained. Ask for examples of helpful and unhelpful information. Explore how people judge the quality of information they receive. Prompt using broad headings for areas of information, including information on diagnosis, symptoms, prognosis, treatment, side effects etc.
Medium	Ask about the different formats in which information is conveyed. Prompt using examples of media - e.g. verbal, leaflets, telephone helplines, books, magazines, newspapers, television, radio, Internet etc. Ask for examples of receiving information in these formats. Explore whether information giving in the medium was helpful or unhelpful. Enquire about advantages and disadvantages and overall views of different formats. Enquire about preferred medium.
Exposure to message and Information seeking behaviour	Explore how information was encountered. Was information being deliberately sought or was it found by chance? Link with stage of illness and contact with health services. How did people go about seeking information? Where did they go? How did they access it? How successful was this? Is there a difference in the information delibertely sought and that found by chance? What action is taken if desired information is not found? Prompt using examples of places to seek information - e.g. at home, in a healthcare setting, in a library, in other public settings etc.
Receiver	Explore personal characteristics and how these affect information needs and information seeking. Including age, gender, social background.
External factors	Discuss the role of external factors in information needs and information seeking. Prompt with the idea of stigma and/or embarassment if not volunteered, and discuss the importance of other people's views in influencing information behaviour. Discuss the role of the environment in which information needs occur - including the physical environemt (e.g. healthcare setting, at home, etc.), and also the social environment (e.g. who else was present, what was the social context). Explore what resources were available at different times and in different places.
Internal factors	Explore attitudes and beliefs to mental health issues and health services, as well as attitudes and beliefs towards information and information sources.
Specific needs	It may be necessary to ask about specific needs, after opportunities have been given to volunteer needs through open questioning. Specific needs include those around diagnosis, treatment, side effects, prevention, prognosis, self management, living with symptoms, relating to others, research findings etc.

Appendix 4: Interview consent form

NHS

Mental Health Information Study

Consent Form Study Number: AQREC A00.070

Full title: An assessment of the health information needs of the users of mental healthcare - will developments in electronic information help?
Lead Researcher: Dr John Powell, Honorary Clinical Research Fellow, University Department of Psychiatry, Warneford Hospital, Headington, Oxford OX3 7JX.

Please initial box:

1. I confirm that I have read and understand the information sheet dated October 2001 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that the interview will be audio-taped. ☐
4. I understand that anonymous quotes from interviews may be used by the researchers in publications. These quotes will always be anonymous and will not be attributable to any participant in the study. ☐
5. I agree to take part in the above study. ☐

Name of Participant Date Signature

Name of Person taking consent (if different from researcher) Date Signature

Researcher Date Signature

Appendix 5: Questionnaire survey

NHS

A SURVEY OF THE NEED FOR INFORMATION ABOUT MENTAL HEALTH ISSUES

What information is needed by the general public?

Thank you very much for taking the time to complete this survey. We hope that the results will help the health service in providing information on mental health issues. We realise that not everyone has experience of mental health problems, but we are keen to hear everyone's views. Your help is much appreciated. All your answers are treated as strictly confidential and anonymous, and are only used for this research project. We do not ask for your name on this questionnaire.

When you have completed this survey it should be returned in the envelope supplied (no stamp required) to: Dr John Powell "Information Survey", Institute of Health Sciences, FREEPOST (OF97), Old Road, Headington, Oxford OX3 7LF.

To be entered in the prize draw to win £100 of shopping vouchers please remember to write your details on the blue entry form and enclose it with the survey.

If you have any questions about this survey please contact Dr Powell on 01844 239363 or via email mhis@mhis.org.uk.

Turn the page to start the survey. Please note that there is also a separate sheet called the "General Health Questionnaire" which we would also like you to fill in and return to us with this survey.

Firstly we would like to know a little bit of background information about you.

Q. 1. Please indicate your age group ***(please tick one box).***

Under 18 .... ☐ 46 – 55 .... ☐

18 – 25 .... ☐ 56 – 65 .... ☐

26 – 35 .... ☐ 66 – 75 .... ☐

36 – 45 .... ☐ Over 75 .... ☐

Q. 2. Please indicate whether you are male or female ***(please tick one box).***

Male .... ☐ Female ...... ☐

Q. 3. Please indicate the <u>highest level</u> of educational qualifications that you have obtained ***(please tick one box).***

No formal qualifications .... ☐

O-levels or GCSEs **below grade C** or equivalent
(e.g. GNVQ foundation or GSVQ or NQ or SVQ level 1 or BTEC first certificate) .... ☐

O-levels or GCSEs **grade A - C** or equivalent
(e.g. GNVQ intermediate or GSVQ or NQ or SVQ level 2 or BTEC first diploma) .... ☐

A-levels or AS-levels or equivalent
(e.g. Highers or GNVQ advanced or GSVQ or NVQ or SVQ level 3 or BTEC national) ...... ☐

Higher education below degree level
(e.g. Diplomas in higher education, HNC, HND, higher level BTEC) .... ☐

Undergraduate degree or a degree-level qualification
(e.g. B.A. or B.Sc. or B.Ed. or PGCE or NVQ or SVQ level 4) .... ☐

Postgraduate degree
(e.g. Masters or Doctorate or NVQ or SVQ level 5) .... ☐

Other - please state: .... ☐

Thank you. Secondly we would like to know your views on sources of information about **mental health issues**. By mental health issues we mean those concerned with emotional or psychological issues. This includes problems such as depression, anxiety, schizophrenia, dementia, difficulties in relationships or difficulties caused by drugs or alcohol. It also includes information on how to cope with these situations and other stresses.

Q. 4. Please read the list below and indicate which of these sources of information in your view provide the <u>most accurate</u> information on mental health issues. ***(Please tick a maximum of 3 boxes).***

General Practitioner (GP) .... ☐

Television or radio programmes .... ☐

Mental health professional (e.g. psychiatrist, psychologist, psychiatric nurse)....... ☐

The Internet .... ☐

Someone else with the same mental health problem .... ☐

NHS Direct telephone helpline .... ☐

Other telephone helpline (e.g. SANELINE, MIND, The Samaritans)................ ☐

Newspaper or magazine articles .... ☐

Leaflets produced by the NHS or voluntary organizations or charities .... ☐

Home medical encyclopaedia or similar books .... ☐

Alternative or complementary therapist .... ☐

Friend or family member .... ☐

Other - please state: .... ☐

....

We are interested in the Internet as one source of information. These next 5 questions are about this. If you have not used the Internet please jump to Question 10 on the facing page.

Q. 5. Have you ever used the Internet? *(Please tick one box).*

Yes (If you have used the Internet please go to question 6) .... ☐

No (If you have not used the Internet please jump to question 10 on page 5) .... ☐

Q. 6. How often do you use the Internet? *(Please tick one box).*

Never .... ☐

Once a month or less often .... ☐

Up to several times a month.. ☐

Up to several times a week .... ☐

Every day .... ☐

Q. 7. How many times have you ever used the Internet to find out about any aspect of health or healthcare? (not just mental health issues) *(Please tick one box).*

Never .... ☐

Once or twice .... ☐

A few times (three to ten times).. ☐

More than ten times.. ☐

Q. 8. How many times have you ever used the Internet to find information about a <u>mental health issue</u>? *(Please tick one box).*

Never .... ☐

Once or twice .... ☐

A few times (three to ten times).. ☐

More than ten times.. ☐

Q. 9. Have you ever used the Internet <u>to chat to other people</u> about mental health issues? *(Please tick one box).*

Yes........... ☐ No .... ☐

> Thank you. Question 10 is about attitudes to mental health problems. Please indicate if you agree or disagree with each statement. There are no right or wrong answers.

Q. 10. Do you agree or disagree with the following statements? *(Please tick one box for each statement).*

	Agree	Disagree	Not sure
"It is embarrassing to have a mental health problem"	☐	☐	☐
"In general most people have negative attitudes towards people with mental health problems"	☐	☐	☐
"If I had a mental health problem I would not want my friends to know"	☐	☐	☐
"Other people's attitudes to mental health problems would stop me from looking for information on mental health issues"	☐	☐	☐
"People who have had a mental health problem understand this problem better than the mental health professionals"	☐	☐	☐

The next 2 questions ask about finding information on mental health issues. These questions ask you to imagine what information you would want to know and where you would get it from if you had a mental health problem. We want everyone to answer these questions. You do not need to have ever experienced a problem to answer them.

Q. 11. If you had a mental health problem what sources of information would you be <u>most likely to use</u> to find out more about this?
(Please tick a maximum of 3 boxes).

I wouldn't look for information .... ☐

General Practitioner (GP) .... ☐

Television or radio programmes .... ☐

Mental health professional (e.g. psychiatrist, psychologist, psychiatric nurse)....... ☐

The Internet .... ☐

Someone else with the same mental health problem .... ☐

NHS Direct telephone helpline .... ☐

Other telephone helpline (e.g. SANELINE, MIND, The Samaritans).................. ☐

Newspaper or magazine articles .... ☐

Leaflets produced by the NHS or voluntary organizations or charities .... ☐

Home medical encyclopaedia or similar books .... ☐

Alternative or complementary therapist .... ☐

Friend or family member .... ☐

Other - please state: .... ☐

....

Q. 12. If you had a mental health problem which areas of information would it be most helpful to find out about?
(Please tick a maximum of 3 boxes).

I would not be interested in finding out information on the problem .... ☐

What the problem is (the diagnosis) .... ☐

What has caused the problem .... ☐

How to help myself .... ☐

Where to get help from .... ☐

What treatments are available .... ☐

Side effects of treatments .... ☐

How to prevent mental health problems .... ☐

Finding out the results from research .... ☐

Finding out that I am not the only person with this problem .... ☐

Hearing about other people's experience of this problem .... ☐

What can cause the problem to get worse .... ☐

The future course of the problem (the outlook or prognosis) .... ☐

Other - please state: .... ☐

....

Thank you. Finally we would like to know about your current state of health. The answers to these questions are treated in the strictest confidence, and are used to help us understand if people's attitudes towards sources of information are affected by their current health.

Q. 13. Have you ever had a serious mental health problem that you consulted a doctor about? ***(Please tick one box).***

Never .... ☐

Once .... ☐

Sometimes .... ☐

Often .... ☐

Q. 14. Finally please would you complete the "General Health Questionnaire" which is included on the separate sheet. This is a standard health questionnaire used in surveys. Again the answers to these questions are entirely anonymous.

Thank you once again for taking the time to complete this survey. Please return the survey in the envelope supplied (no stamp required) to Dr John Powell: "Information Survey", Institute of Health Sciences, FREEPOST (OF97), Old Road, Headington, Oxford OX3 7LF.

Please remember to include this survey AND the General Health Questionnaire AND the blue form if you would like to be entered in the prize draw for £100 of shopping vouchers.

If you have any questions please call 01844 239363 or email mhis@mhis.org.uk.

NHS

Appendix 6: Covering letter with initial survey mailing

NHS

October 2002

Dear Sir / Madam

We are NHS researchers at Oxford Institute of Health Sciences, Oxfordshire Mental Healthcare NHS Trust, and London University. We are carrying out a survey about health information. We are looking at the information that people use to find out about their health and healthcare.

We are particularly interested in health information on mental health issues. This survey is being sent to a random sample of people who live in or near Oxfordshire. Your name was selected completely at random from a population list and we hope that you will agree to take part. We want to hear your views whether or not you have any experience of mental health problems.

The survey is enclosed with this letter. We would be very grateful if you could take the time to complete this and the short 'General Health Questionnaire' and return it to us in the freepost envelope provided.

This survey should help us to provide better information for health service patients and carers in the future. It should take no more than 10 minutes to complete.

All the replies that we receive will be entered into a prize draw with a chance to win £100 worth of Marks & Spencer vouchers.

All replies are anonymous and there will be no way of identifying individuals from the results. We have attached an information sheet to this letter with more details. If you have any further questions please do not hesitate to contact the lead researcher Dr John Powell on 01844 239363 or write to 'Information Survey', Institute of Health Sciences, Freepost (OF97), Old Road, Headington, Oxford OX3 7LF or email mhis@mhis.org.uk.

This research has received ethical approval from the Oxfordshire Psychiatric Research Ethics Committee (OPREC O02.021). The title of this project is "Mental health information needs: a survey of the general population".

Many thanks.

Dr John Powell	NHS Training Fellow in Health Services Research, London University. Honorary Clinical Research Fellow, Oxfordshire Mental Healthcare NHS Trust.
Dr Muir Gray	Director of the National electronic Library for Health, Oxford Institute of Health Sciences.

Appendix 7: Information sheet with initial survey mailing

NHS

Mental health information needs: a survey of the general population.
Oxfordshire Ethics Committee study number OPREC O02.021

INFORMATION SHEET

You are being invited to take part in a research survey. Before deciding whether to fill this survey in, it is important that you understand why the research is being done and what it will involve. Please contact us if there is anything that is not clear or if you would like more information.

What is the purpose of this survey?
This is an NHS research project aiming to find out what sources of information people use to find out about mental health issues.

Why have I been sent this survey?
This survey has been sent out to a random sample of the Oxfordshire population. You have been sent the survey as your name was randomly selected.

Do I have to fill it in?
It is up to you whether or not you decide to fill the survey in. This is a research project and has nothing to do with any usual care you receive from the NHS. Your answers will be used to find out more about how information about mental health issues should be provided for patients and for no other purpose.

I don't have any mental health problems, should I fill in this survey?
Yes please. We are interested in everyone's views on sources of information. It is very useful for us to find out whether people who have not had experience of mental health problems value different sorts of information.

Why are you surveying the general population?
Mental health problems are very common, and most people who want information on mental health issues do not see their GP or go to a hospital.

If I decide to fill the survey in, what would it involve?
The survey consists of 13 questions and a short health questionnaire. It will take about 10 minutes to fill in. We have enclosed a freepost addressed envelope for your reply.

What do you mean by mental health issues?
Mental health issues are those concerned with emotional or psychological issues. This includes problems such as depression or anxiety or schizophrenia or dementia or difficulties in relationships or difficulties caused by drugs or alcohol. It also includes information on how to cope with these situations and other stresses.

What do you mean by information?
We are interested in where and how people find out about mental health issues. This includes information on diagnosis, treatments and where and how to get help. We are interested in all sources of information including the Internet.

How do I enter the prize draw?
There is a blue form enclosed with the survey. Please enter your name and address on this form and enclose it with the survey to be entered in the prize draw. This information will only be used for the prize draw and for no other purpose. Your answers to the survey will remain anonymous. The winner will be notified by post by 31st January 2003.

Who is organizing and funding this research?
The NHS Research & Knowledge Management Programme.

What will happen to the results of this research?
The results will be analyzed and the findings will be put together in a report for the NHS which will be available for everyone to see on the study website www.mhis.org.uk. They will also be published in a medical journal. We hope that the results will lead to better provision of information for patients.

Who has reviewed this study?
The Oxfordshire Psychiatric Research Ethics Committee.

Who should I contact for further information?
The lead investigator Dr John Powell on 01844 239363 or by post (write to Dr John Powell, Honorary Clinical Research Fellow, University Department, Warneford Hospital, Warneford Lane, Headington, Oxford OX3 7JX) or by email at mhis@mhis.org.uk.

Appendix 8: Entry form for prize draw with initial survey mailing

ENTRY FORM FOR FREE PRIZE DRAW

If you want to be entered in the prize draw to win £100 of Marks & Spencer's vouchers please fill in your name and address on this sheet and return it with your survey and general health questionnaire in the freepost envelope provided.

The details for the prize draw are kept separate from the survey and general health questionnaire. These remain anonymous and confidential.

Your name:

....

Your contact details:
Please give your address OR telephone number OR email address

....

....

....

....

The winner will be chosen at random from all entries received and will be notified by January 31st 2003.

Appendix 9: Survey reminder postcard

NHS

Dear Sir / Madam

A short while ago we sent you a questionnaire about health information. We asked if you would be kind enough to fill this in for us. Please accept our apologies if you have already replied or if you have decided that you do not want to complete this survey. It is entirely up to you whether or not you choose to fill it in.

However it is important that we try to get the views of everyone we have written to, so that the NHS will have a better idea of what information should be provided for patients and the public. We would be very grateful if you could find the time to complete the survey and health questionnaire and return them to us in the freepost envelope. If you need another copy of the survey or if you have any questions please call 01844 239363 or email mhis@mhis.org.uk.

Many thanks
Dr John Powell NHS Training Fellow in Health Services Research

Appendix 10: Covering letter for survey reminders

NHS

November 2002

Dear Sir / Madam

We are NHS researchers at Oxford Institute of Health Sciences, Oxfordshire Mental Healthcare NHS Trust, and London University. We recently wrote to you about a survey we are carrying out. This asks questions about the information that people use to find out about their health and healthcare. We are particularly interested in health information on mental health issues.

It is entirely up to you whether or not you choose to fill in this survey. Of course the more replies we get, the more confident we can be that we have got a representative selection of people's views.

If you have already returned the survey, then thank you very much. If you have not done so then we wonder whether you might give it a second chance? If you need another copy please call 01844 239363 or email mhis@mhis.org.uk.

All the replies that we receive will be entered into a prize draw with a chance to win £100 worth of Marks & Spencer vouchers.

If you have any further questions please do not hesitate to contact the lead researcher Dr John Powell on 01844 239363 or write to 'Information Survey', Institute of Health Sciences, Freepost (OF97), Old Road, Headington, Oxford OX3 7LF or email mhis@mhis.org.uk.

This research has received ethical approval from the Oxfordshire Psychiatric Research Ethics Committee (OPREC O02.021). The title of this project is "Mental health information needs: a survey of the general population".

Many thanks.

Dr John Powell	NHS Training Fellow in Health Services Research, London University. Honorary Clinical Research Fellow, Oxfordshire Mental Healthcare NHS Trust.
Dr Muir Gray	Director of the National electronic Library for Health, Oxford Institute of Health Sciences.

Appendix 11: Covering letter for test-retest sample

NHS

November 2002

Dear Sir / Madam

Recently you very kindly completed a questionnaire and posted it back to us. Thank you very much for doing this.

As part of this research it is necessary for us to ask a small number of people to fill in one of the questionnaires again. We hope this will not cause too much inconvenience. We are doing this as we need to see whether the answers people give vary from day to day, or whether they remain the same.

We do not require you to fill in the 'General Health Questionnaire' again, just the 13 questions on the enclosed survey. As before please would you return it in the enclosed freepost envelope (no stamp required). If you have any questions please call 01844 239363 or email mhis@mhis.org.uk.

Once again, we are very grateful for your help. Please be assured that this is the last time that we will ask you to fill in this questionnaire!

Many thanks for your help.

Dr John Powell	NHS Training Fellow in Health Services Research, London University. Honorary Clinical Research Fellow, Oxfordshire Mental Healthcare NHS Trust.
Dr Muir Gray	Director of the National electronic Library for Health, Oxford Institute of Health Sciences.

Appendix 12: Confidence intervals for individual proportions related to Internet use

Table A.1 Univariate analyses of respondents' use of the Internet by age, sex, educational level, health status and psychiatric history, showing 95% confidence intervals (CI) for individual proportions (Clopper-Pearson) in brackets.

	All	**Sex**		**Age**		**Educational level**		**Health status**		**Past psychiatric history**	
	% of all respondents n=917 (95% CI)	% of men (95% CI)	% of women (95% CI)	% of younger (95% CI)	% of older (95% CI)	% of more educated (95% CI)	% of less educated (95% CI)	% of GHQ-12>1 (95% CI)	% of GHQ-12≤1 (95% CI)	% of those with past psychiatric illness (95% CI)	% of those without past psychiatric illness (95% CI)
Have you ever used the Internet?	58.8 (55.5 - 62.0)	59.9 (55.0 - 64.6)	58.2 (53.7 - 62.6)	84.5 (80.3 - 88.1)	42.9 (38.7 - 47.1)	85.0 (81.1 - 88.4)	37.9 (33.1 - 42.8)	66.0 (60.5 - 71.3)	55.0 (51.0 - 59.1)	65.1 (57.3 - 72.3)	57.8 (54.2 - 61.4)
Have you ever used the Internet to find out about health or healthcare?	37.4 (34.3 - 40.6)	35.8 (31.2 - 40.6)	39.3 (35.0 - 43.8)	55.4 (50.0 - 60.6)	26.3 (22.7 - 30.1)	56.6 (51.5 - 61.6)	21.3 (17.4 - 25.6)	34.5 (30.8 - 38.5)	42.9 (37.4 - 48.6)	45.8 (38.0 - 53.7)	35.8 (32.3 - 39.3)
Have you ever used the Internet to find information about a mental health issue?	10.6 (8.7 - 12.8)	9.1 (6.5 - 12.3)	12.1 (9.3 - 15.3)	15.8 (12.2 - 20.0)	7.3 (5.3 - 9.8)	16.5 (13.0 - 20.5)	6.7 (4.5 - 9.6)	15.1 (11.3 - 19.5)	8.3 (6.2 - 10.8)	20.5 (15.0 - 27.3)	8.5 (6.6 - 10.7)

Table A.2 Univariate analyses of use of the Internet to find information about health or mental health, among those who have ever used the Internet (n=539), showing 95% confidence intervals (CI) for individual proportions (Clopper-Pearson) in brackets.

	All	Sex		Age		Educational level		Health status		Past psychiatric history	
	% of those respondents who have used the Internet (n=539)	% of men	% of women	% of younger	% of older	% of more educated	% of less educated	% of GHQ-12>1	% of GHQ-12□1	% of those with past psychiatric illness	% of those without past psychiatric illness
Have you ever used the Internet to find out about health or healthcare?	63.6 (59.4 - 67.7)	59.8 (53.5 - 66.0)	67.6 (61.8 - 73.0)	65.6 (59.9 - 70.9)	61.3 (54.8 - 67.4)	66.6 (61.2 - 71.6)	56.2 (48.0 - 60.2)	65.0 (58.1 - 71.5)	62.8 (57.5 - 67.8)	70.4 (60.8 - 78.8)	61.9 (57.1 - 66.5)
Have you ever used the Internet to find information about a mental health issue?	18.0 (14.8 - 21.5)	15.3 (11.0 - 20.3)	20.8 (16.2 - 26.0)	18.7 (14.5 - 23.6)	17.1 (12.5 - 22.5)	19.4 (15.3 - 24.1)	17.6 (12.0 - 24.6)	22.8 (17.3 - 29.2)	15.0 (11.4 - 19.3)	31.5 (22.9 - 41.1)	14.7 (11.4 - 18.4)

Appendix 13: Logistic regression for general and health-related Internet use

1. Use of the Internet

Table A.3 Logistic regression to analyse the relationships between the predictor variables of sex, educational level, age group, past history of a serious mental health problem, and the presence of mental health distress; and the outcome (dependent) variable of use of the Internet. Calculated using SPSS statistical software.[542]

Factor	B	S.E.	P	Odds Ratio (95% CI)
SEX	-0.152	0.183	0.405	0.859 (0.600 to 1.229)
EDUC_LEVEL	2.061	0.187	<0.001	7.850 (5.437 to 11.333)
AGE_GROUP	-1.847	0.205	<0.001	0.158 (0.105 to 0.236)
PAST_HISTORY*	-0.006	0.240	0.980	0.994 (0.621 to 1.590)
GHQ_CASE*	0.117	0.205	0.567	1.124 (0.7535 to 1.678)
Constant	0.998	0.360	0.006	2.714 (1.340 to 5.495)

*As past history and GHQ-12 caseness correlate with each other, the regression was also run with the omission of each of these variables in turn. This had no effect on the findings for age group and educational level in relation to Internet use.

2. Use of the Internet for health information

Table A.4 Logistic regression to analyse the relationships between the predictor variables of sex, educational level, age group, past history of a serious mental health problem, and the presence of mental health distress; and the outcome (dependent) variable of use of the Internet for health information. Calculated using SPSS statistical software.[542]

Factor	B	S.E.	P	Odds Ratio (95% CI)
SEX	0.173	0.197	0.380	1.189 (0.808 to 1.750
EDUC_LEVEL	0.453	0.204	0.026	1.572 (1.057 to 2.346
AGE_GROUP	-0.128	0.201	0.522	0.879 (0.593 to 1.303)
PAST_HISTORY*	0.280	0.245	0.252	1.324 (0.819 to 2.140)
GHQ_CASE*	-0.003	0.201	0.987	0.997 (0.672 to 1.479)
Constant	-0.036	0.391	0.926	0.965 (0.448 to 2.076)

*As past history and GHQ-12 caseness correlate with each other, the regression was also run with the omission of each of these variables in turn. This had no effect on the findings for age group and educational level in relation to Internet use for health information.

Appendix 14: Confidence intervals for responses to attitudinal questions

Table A.5 Percent agreement with attitudinal statements, showing 95% confidence intervals for proportions (Clopper-Pearson) in brackets.

	All	Sex		Age		Educational level		Health status		Past psychiatric history	
	% of all respondents n=917 (95% CI)	% of men (95% CI)	% of women (95% CI)	% of younger (95% CI)	% of older (95% CI)	% of more educated (95% CI)	% of less educated (95% CI)	% of GHQ-12>1 (95% CI)	% of GHQ-12≤1 (95% CI)	% of those with past psychiatric illness (95% CI)	% of those without past psychiatric illness (95% CI)
In general most people have negative attitudes towards others who have mental health problems	75.8 (72.9-78.5)	74.7 (70.2-78.8)	78.6 (74.7-82.2)	79.9 (75.3-83.9)	74.9 (71.1-78.5)	79.2 (74.8-83.1)	74.0 (69.4-78.2)	82.5 (77.8-86.5)	74.0 (70.3-77.5)	80.6 (73.7-86.3)	75.9 (72.7-79.0)
It is embarrassing to have a mental health problem	33.5 (30.4-36.6)	36.4 (31.8-41.3)	32.4 (28.3-36.8)	30.0 (25.3 - 35.1)	36.7 (32.7 -40.9)	35.7 (31.0-40.7)	30.6 (26.1-35.4)	38.8 (33.3-44.5)	31.6 (27.9-35.6)	51.8 (43.9-59.7)	30.0 (26.7-33.5)
If I had a mental health problem I would not want other people to know	25.2 (22.4-28.1)	26.3 (22.1-30.8)	25.0 (21.2-29.1)	25.3 (20.8-30.2)	25.7 (22.1-29.5)	22.2 (18.2-26.6)	28.1 (23.8-32.8)	28.9 (23.9-34.3)	23.7 (20.4-27.4)	33.5 (26.4-41.3)	23.6 (20.6-26.8)
Other people's attitudes to mental health problems would prevent me from looking for information on mental health issues	5.3 (4.0-7.0)	4.9 (3.0-7.5)	5.4 (3.6-7.8)	5.4 (3.3-8.3)	5.5 (3.7-7.7)	2.8 (1.4-5.0)	7.6 (5.2-10.7)	6.8 (4.3-10.3)	4.7 (3.2-6.7)	6.1 (3.0-11.0)	5.2 (3.7-7.0)
People who have experienced mental health problems understand these problems better than the mental health professionals	27.0 (24.2-30.0)	26.0 (21.9-30.6)	28.7 (24.7-32.9)	23.2 (18.9-27.9)	30.1 (26.3-34.1)	20.6 (16.7-24.9)	34.2 (29.5-39.1)	27.5 (22.6-32.8)	27.3 (23.7-31.0)	34.5 (27.3-42.3)	25.8 (22.7-29.1)

Appendix 15: Investigation of item order response bias

The item order for responses in questions 4, 11 and 12 was reversed in 50% of the surveys sent out. Univariate analysis was used to investigate item order response by comparing the total responses for the item on one set of surveys, with the total responses for the item when its position was reversed. The total response proportions were treated as two independent binomial proportions, as different people received the questionnaires that had different ordering.

This showed significant ($P<0.01$) differences for:

- Question 4: items 1, 3, 6, 7, 10, 12.
- Question 11: items 2, 3, 4, 6, 11, 13.
- Question 12: items 2, 3, 4, 6, 10, 11, 12.

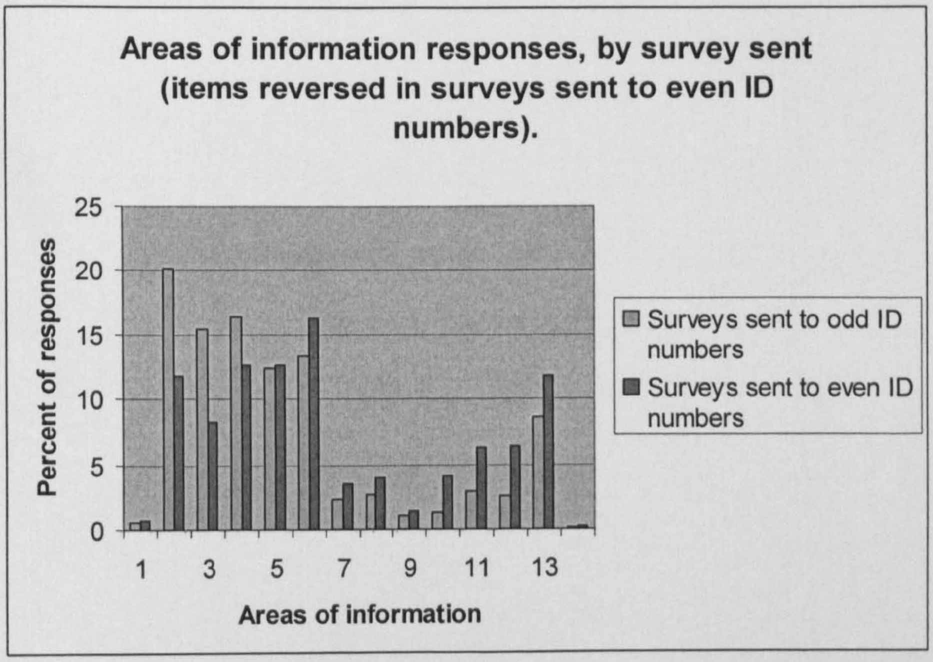
However, because the responses within each questionnaire are not strictly independent, the threshold probability (alpha) was reduced from 0.05 to 0.05/41 (Bonferroni correction) to allow for type I error due to simultaneous inference or multiple comparisons. Following this correction, there was still some order effect indicated ($P<0.01$) for the following:

- Question 4: items 3, 7, 12.
- Question 11: item 4.
- Question 12: items 2, 3, 4, 10, 11, 12.

Relative transposition, whereby the questions at the top and bottom of the list move more in their order than questions in the middle, was not considered, partly because the questions are not independent. This would have required multivariate modelling and would be very complex as simple logistic models do not fit the data.

Overall, the results showed that there were some minor order effects for question 4, and for one item in question 11, but for the most part these questions did not demonstrate a major effect of item order. However question 12 is potentially problematic, with items towards both ends of the list showing significant effects. This is demonstrated in Figure A.1 which shows the responses to both sets of surveys sent out.

Figure A.1 Areas of information by survey sent out (items reversed in surveys sent to even ID numbers). To allow comparison on the same scale the responses have been standardised to the order of items used in the surveys sent to odd ID numbers.



The responses in the figure have been standardised to the order of items used in the surveys sent to odd ID numbers, to allow them to be viewed on the same scale. The figure shows that the responses to the items 2, 3, 4, 5, and 6 appear to show a primacy effect in the decreasing frequency of responses in surveys sent to respondents allocated odd study ID numbers, compared with the increasing frequency seen in responses to surveys in which the order was reversed and these items appeared in positions 13, 12, 11, 10, and 9. Similarly there were relatively more responses to items 10, 11, 12 and 13 in the even ID number surveys in which these items appeared in positions 5, 4, 3 and 2. The implications of this are discussed in the text (Section 4.4.4.3).