Investigating service users’ views of health services:
An introductory resource for researchers

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Final report
23 August 2006

This draft has been submitted to the NHS SDO R&D programme
and will be subject to review and revision.
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EXECUTIVE SUMMARY

- An interest in research that investigates service users’ views has been fuelled by a number of developments including policy commitments to (a) develop health services that are responsive to the people they serve and (b) involve those people in the development process.
- Research that investigates service users’ views of health services can take many forms. Researchers from different backgrounds and with diverse interests have tackled a range of research questions using a variety of research methods and drawing on concepts and theories from various sources. Their findings have been put to a number of different purposes.
- Concerns have been expressed about the poor quality of some of the research that has been carried out to date to investigate service users’ views. Problems have been identified with:
  - The clarity and appropriateness of the aims of the research
  - The scope of the research, both in terms of which service users are involved and in terms of which aspects of services are considered
  - The clarity of the concepts employed, rigour with which data are collected and analysed, and the extent to which conclusions are justified
  - Service users’ experiences of the research and its impact on their lives
- This Resource aims to help those who plan to conduct research to investigate service users’ views about health services. It encourages researchers to:
  - Think carefully about the nature of ‘views’ and what can be known about them.
  - Pay careful attention to what is already known about service users’ views of health services.
  - Be as clear as possible about the meaning of terms that are used to describe types of views and aspects of health services.
  - Consider the potential implications of all aspects of their proposed research for service users’ experiences of research participation and for what comes to be understood about service users’ views.

The nature of views and what can be known about them
- Many fundamental issues regarding the working of human minds, the nature of views and what can be known about these remain poorly understood.
- A wide range of terms have developed to describe the various phenomena that can be grouped together under the heading ‘views’. These are not always applied consistently.
- People may have a complex and dynamic set of views about a range of situations and issues. A variety of factors might influence the views that people form and the views that they express. In addition to the information about those situations and issues that is available in their particular environments, these factors include automatic information processing activity in the brain and a number of social-psychological influences that may operate ‘automatically’ and/or through conscious thought processes. This has several implications. In particular:
  - Service users’ reports about particular health service encounters will inevitably be in some senses partial and there will be limits to the extent to which either service users or researchers can ascertain what influences have shaped them.
Researchers and their approaches to data collection may themselves influence the views that service users develop and express.

Researchers’ efforts to collect and interpret data and present research findings will be influenced by factors other than the views that service users’ hold and express.

- When service users are asked to indicate agreement or otherwise with statements that researchers offer, the statements might be about issues of more or less importance to service users, and responses might or might not be indicative of prior and stable views about the matter of interest.

Views about health services

- Researchers have considered, in a variety of ways, the views that service users have as they anticipate service use (expectations), proceed through health service encounters (experiences), assess the services they have used (evaluations), and consider what kinds of health services they would like to be available in the future (preferences).
- ‘Expectations’ have been defined and categorised in various ways. On a broad interpretation, they may include what people think is likely to happen, what they hope will happen or what they think ought to happen. On a narrower interpretation, they include only what people predict will happen.
- The formation and implications of expectations remain poorly understood, but it seems that people may have few and low specific expectations of services they have little experience of.
- Service users’ accounts of their ‘experiences’ of health services may include statements about what happened and what it was like for them. They may also incorporate interpretations, reflections and evaluative judgements.
- Attempts to elicit service users’ own evaluations of health services have traditionally focussed on their ‘satisfaction’ with services. Satisfaction is still poorly understood, but it is generally thought to represent an evaluation based in some way on the fulfilment of expectations.
- A number of problems have been identified with patient satisfaction surveys, including the fact that most people report being satisfied even if they have some negative experiences.
- There are several reasons for high levels of reported satisfaction. People may have low expectations of services. Also, when responding to questions about their satisfaction, they may
  - make global assessments that ‘override’ a few negative experiences
  - consider possible reasons for their negative experiences and express satisfaction if they think service providers are ‘doing the best they can in the circumstances’.
- Surveys of patient experiences are increasingly used as an alternative to surveys of patient satisfaction in attempts to assess health service quality. These surveys ask people whether specific things happened in the course of their care.
- A range of techniques have been developed to examine service users’ preferences for future service provision. These include deliberative group discussions and survey techniques that allow larger scale quantitative assessments of preference and investigations of the relative importance of different health service attributes to service users.
- The validity of the assumptions about rational decision-making that underpin some survey techniques has been questioned.
People are more likely to express preferences for service features that they have previous experience of or that are available locally. Efforts to reflect local preferences in health service planning may thus tend to support the status quo.

Views about quality
- Health care ‘quality’ and its attributes can be conceptualised and assessed in various ways. Researchers need to develop and use clear, well nuanced conceptualisations of those attributes and appropriate assessment tools.
- Researchers have good reason to pay attention to what service users think matters in terms of health care quality, and to how they conceptualise particular quality attributes because:
  - Quality attributes may be differently conceptualised by service users and service providers.
  - Service users’ views about what makes for quality are important in their own right;
  - Service users’ views about quality attributes may reveal matters of importance that are not evident from providers’ perspectives.
  - If researchers do not appreciate the meanings that service users attach to quality attribute terms, they may inadvertently misinterpret service users’ reports or assess quality attributes in ways that do not accommodate service users’ views about them.
- Studies of service users’ views often contribute to the assessment of quality in practice. Some aspects of health care quality are best assessed from the perspectives of service users.
- Service users’ views about the structures, processes and outcomes of health care can also be regarded as among the processes or outcomes of health care. Researchers need to think carefully about how they need to treat these views in any particular project.
- Service users’ assessments of health service quality are inevitably shaped to some extent by their interpretations as well as what health services do. They should thus be used with caution as indicators of the performance of health care providers.

Research processes and service users’ experiences
- Services users’ experiences of research that is intended to investigate their views are important both in their own right and because they affect the views that researchers hear and come to understand service users to hold.
- Service users, broadly defined, vary significantly in a number of ways. Individuals may be very differently affected by particular research processes and differently able and willing to express their views in particular data collection contexts.
- Some groups of people are regularly excluded from research studies that aim to canvas the views of a broad population because these studies are usually conducted in the majority language, take place in social contexts that tend to disable and marginalise people who do not conform to dominant norms, and use methods that require significant cognitive, communication and sometimes literacy skills on the part of participants.
- People who tend to be excluded from mainstream research are also likely to have problems using general health services. Some are the intended beneficiaries of particular health and social care services. It is thus important that their views about services can be investigated.
• Broad-based research studies might be made more inclusive by improving the design of invitations and data collection instruments so they are more broadly accessible and acceptable, and/or by providing assistance or modifying approaches to groups with special needs.

• Efforts to improve service users’ experiences of research might improve participation rates and the quality of data collected. However, they might also sometimes be in tension with efforts to improve the robustness of understandings that can be generated about service users’ views.

• Carers may play a number of roles in relation to research to investigate the views of the people they care for. However, carers have their own agendas in relation to the health and social care services provided to the people they care for, and the extent to which they understand and agree with those people’s views is variable. Researchers are thus encouraged to find ways to enable people to express their views for themselves.

• Service users’ experiences and interpretations of invitations to participate in research, of data collection approaches, and of communication from researchers about study findings may all have implications for the views that researchers come to hear.

• Research teams may be better able to ensure that their approaches are well-tailored to their particular study populations if they include members of those populations and/or consult with them as they consider how to invite people to participate, how and when to collect data, and how to provide feedback relating to study findings.

• There are still a number of methodological questions to be answered in relation to studies of service users’ views of health services. Researchers are encouraged to make use of and to contribute to critical reflections on and formal comparisons of different approaches to the study of service users’ views.
PREFACE

In recent decades, efforts to develop health services that are responsive to the needs and preferences of the people they are intended to serve have prompted a significant interest in research that generates knowledge about service users’ views.

The National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCC SDO) pays careful attention to the views of service users as it develops the agenda for the NHS Service Delivery and Organisation R&D Programme (SDO Programme).\(^1,2\) NCC SDO has commissioned research projects that have used a variety of different methods to investigate service users’ views on a range of issues including, for example, the implications of changes in the professional workforce, approaches to chronic disease management, the sharing of information between health professionals and carers of people with mental health problems, and continuity of care (see http://www.sdo.lshtm.ac.uk/commissionedprojects.htm). It has also commissioned research to investigate issues relating to the roles of service users in the management of change in the NHS \(^3,4\)

A scoping exercise commissioned by NCC SDO to examine methods for eliciting users’ views of the processes of health care highlighted concerns about the quality of some of the research that is undertaken to investigate service users’ views of the processes of health care.\(^5\) Poor quality research wastes the time and effort of research participants and raises the worrying possibility that health service development may be influenced by misleading representations of service users’ views.

The authors of the scoping exercise recommended, among other things, that the NCC SDO could play an important role in ensuring improvement in the quality of research in the area of eliciting service users’ views. This Introductory Resource for Researchers forms part of the SDO Programme’s response to the recommendations of the scoping exercise, building on work undertaken for the Programme by Anthea Innes and colleagues at Stirling University. The Resource draws on the author’s own experience of conducting and reviewing research relating to service users’ views, and on a broad (but by no means exhaustive) reading of the published literature, including reports of studies commissioned previously by NCC SDO.

I am grateful to Naomi Fulop for initiating this project, and to Pamela Baker, Nick Goodwin and Barbara Langridge (all of NCC SDO) who have provided patient encouragement along the way. I am also grateful to Jill Francis, Lorna McKee and Paul McNamee (all at the University of Aberdeen) for helpful discussions during the early stages of the project and for pointers in the relevant psychological, sociological and economic literatures respectively. Vera Araujo-Soares, Sara Joice, Thilo Kroll and Brian Williams provided helpful suggestions on early drafts of particular chapters, and three anonymous reviewers for NCC SDO all provided helpful comments on a draft of the Resource as a whole. Finally, many thanks are due to Alex Gordon and Rosanne Bell for help with document retrieval and referencing.

Vikki Entwistle
August, 2006.


Labelling people: a note about terminology

There has been much debate about the choice of words to describe the people who are referred to collectively in this resource as service users. The most obvious options, including ‘clients’, ‘consumers’, ‘customers’, ‘lay people’, ‘patients’, and ‘users’, all carry connotations that are, at least in some circumstances, inappropriate for some of those who are being referred to. One particular concern is that some terms, including ‘patient’ and ‘service user’ may imply that the people described play only passive roles in relation to their health care. This implication is not intended in this document, where the choice of the term ‘service users’ simply reflects a focus on views about health services from the perspectives of those who are intended to benefit from them.

A similar concern may arise in relation to the implied roles for service users in research. In this document, the term ‘service users’ is used to refer to people whose views are being or might be studied – to people who (do or might) contribute data, for example by completing questionnaires or talking about their views in research interviews. The term ‘researchers’ is used to refer to people who are primarily involved in the design and conduct of research projects (e.g. planning studies, collecting and analysing data, and reporting findings). This is not to deny that some of the people referred to as researchers will also be service users, nor that people who participate in research studies initially and primarily as data contributors may in some circumstances, wittingly or otherwise, contribute to the (re)shaping of a study.\(^1\)

However, in an attempt to avoid confusion, service users who, in a particular context, are involved by specific intent in the design, management or conduct of research projects will be included among ‘researchers’ and those who are primarily (potential) data contributors will be referred to as ‘service users’.

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CHAPTER 1:
INTRODUCTION

“We need to pause and think critically about our aims, assumptions and methods when trying to access user opinion”
(Carol Edwards and Sophie Staniszewska)

WHAT THIS CHAPTER INCLUDES
• A brief introduction to the context in which interest in research into service users’ views has flourished.
• An orientation to the aims and scope of this Resource and the way it is organised.
• A section that highlights the diversity of research into service users’ views and introduces some of the different perspectives from which these are studied.
• An outline of the main criticisms that have been levelled against some previous research into service users’ views.
• An initial set of general recommendations and a list of questions for researchers to reflect on before investigating service users’ views

1.1 BACKGROUND

In recent decades, national governments and health policy leaders from around the world have expressed and renewed commitments to develop health services that are responsive to the needs and preferences of the people they are intended to serve and to ensure that those people are involved in the processes of development (or redevelopment).2,3,4 These broad health policy commitments have tended to foster an interest in research into service users’ views for the purposes of supporting health service development, as we will consider further below.

An interest in service users’ views has also been fuelled by developments in public policy more generally. Consumerism and efforts to promote citizenship and participatory democracy both encourage – albeit in different ways - attention to the views of ordinary people. The broad social trend that has increased the extent to which the authority of specialist professional expertise is challenged while personal experience is privileged5 has also tended to support an enthusiasm for research into service users’ views.

Research into service users’ views may contribute to the development of health services in a number of ways. For example, an understanding of people’s views about health services and the ways in which these views influence how they use (or avoid using) particular services is likely to have important implications for health service planning (including resource allocation) and efforts to improve the accessibility or uptake of services (including marketing that aims to encourage particular groups of people to use or not use particular services in particular ways).

An understanding of service users’ perspectives on service use is also important for health care providers who aspire to deliver culturally appropriate patient- or client-centred services. It is increasingly recognised that health service staff do not usually,
in the course of their day to day work, acquire a good appreciation of what it is like to be on the receiving end of the services they provide. Service users rarely try to express their views about their care to those who provide care directly to them, especially if they think those care providers are rushed, disinterested, or prone to interpret expressions of concern as personal criticisms and possibly as cause for retaliation. Even when service users do try to express their views to staff, they may not be listened to or understood. Careful research is increasingly seen as a means of rendering service users’ views more accessible to health service providers.

Research into service users’ views is important in the context of evaluations of health service developments and of efforts to monitor health service performance. Service users are now recognised as an important source of ideas about what makes for good quality in health services. Their experiences of using health services and their own assessments of those services are increasingly regarded as important indicators of service quality. Service users’ views are thus important in relation both to the establishment of the criteria by which the quality of health services should be judged, and to the assessment of services against those criteria.

The use of research findings to inform the development of health services might also be seen as a way of fulfilling policy commitments to involve those people who contributed views to the research in the development process. However, many would argue that such an indirect form of involvement is insufficient, and that service users and local communities should have a more direct influence over decisions about health service development. Some would go further and say that such direct influence is more important than, and renders unnecessary, some of the research that is currently undertaken to investigate service users’ views. The development of this Resource clearly reflects an assumption that there is a need for good quality research into service users’ views. However, researchers should still consider carefully whether and why any particular project is justified, and research should not be seen as a substitute for appropriate user involvement in policy and service development.

While the factors noted above have contributed to the demand for research that investigates service users’ views of health services, there have also been several developments on the supply side of research. Knowledge production is no longer confined to universities. People with diverse educational backgrounds who work in a range of roles in government departments, health services, and commercial or voluntary sector organisations with interests in health care and/or research are increasingly encouraged by their organisations to undertake research. Technological and software developments have also made it increasingly easy to carry out some of the technical aspects of data collection and data management. Not surprisingly, then, there has been a proliferation of research into service users’ views.

However, concerns have been raised about the quality of some of the research that has been undertaken to investigate service users’ views. These concerns relate to the quality of participants’ experiences of research, the robustness and relevance of the knowledge generated, and the potential for decisions about health services to be influenced by misleading information.
1.2 ABOUT THIS RESOURCE

1.2.1 Aim

This introductory Resource aims to help those who want to conduct good quality research to investigate service users’ views about health services. It is intended as a ‘starter’ reader that:

- outlines some of the key conceptual, theoretical and methodological issues that are relevant to the design and conduct of research into service users’ views of health services
- introduces examples of previous research in order to:
  - illustrate the diversity of studies that have investigated service users’ views;
  - “feed creativity”;
  - offer insights that may usefully inform the design or interpretation of future studies;
- encourages researchers to reflect carefully on the nature of service users’ views, what can be known about them, and the implications of different approaches to investigating them.

1.2.2 Who is the Resource for?

The Resource is primarily intended for people who:

- seek to conduct research that will provide a robust contribution to knowledge about service users’ views of health services;
- have some familiarity with the methods used in health services research; but
- have little or no prior experience of conducting research into service users’ views about health services.

The Resource should be suitable for people whose interest in researching service users’ views has arisen from their academic studies, their work as health or social care providers or their personal experiences of health service use. It does not assume any particular educational background.

Although the Resource has been developed primarily for those who plan to conduct research into service users’ views, it may also be helpful to those who plan to use such research as they make or seek to influence decisions about the organisation and delivery of health services.

1.2.3 How the Resource is organised: an orientation

This first chapter highlights the diversity of research into service users’ views of health services, notes the main types of criticism that have been levelled against previous research, and suggests a number of questions that researchers might usefully consider before embarking on an investigation of service users’ views.
Chapter 2 considers the nature of ‘views’ and outlines the various factors that are known to affect the views that people develop and what people say about their views in particular circumstances. This chapter discourages complacency about our ability to identify, understand and appreciate the significance of service users’ views.

Chapter 3 considers some of the main types of views that have been investigated in efforts to understand service users’ perspectives on health services. It summarises important developments in recent thinking about the study of expectations, experiences, evaluations (including satisfaction) and preferences.

Chapter 4 highlights issues relating to attempts to elicit service users’ views on particular aspects of health services, including attributes of health service quality. It emphasises the importance of service users’ views in the conceptualisation of health service quality attributes.

Chapter 5 considers the implications of research processes for service users’ experiences of research and for the understandings that are generated about service users’ views.

Boxed summaries of examples of studies of service users’ views and of researchers’ reflections on their studies appear throughout the Resource. These examples were chosen to illustrate something of the variety of research methods that have been used to investigate service users’ views of health services. They also provide insights that may usefully inform the design or interpretation of other studies.

1.2.4 How might the Resource be used?

The Resource was written as an introduction to a number of key issues relating to research into service users’ views of health services. It is probably best read through in order, although ‘dipping’ is not prohibited!

The boxed summaries of study examples can stand alone as sources of ideas for reflection, but they should not be regarded as flawless examples of research. The summaries are inevitably selective in their presentation of the methods, findings and discussion points of the original studies. You are encouraged to turn to the source documents for more details.

The Resource is not a substitute for general textbooks and training relating to health services research and the use of particular research methods. It does not provide a step by step guide to the design and conduct of research, and does not consider in detail the various data collection methods and analytic techniques that might be used. By focusing on some key conceptual and theoretical issues relating specifically to the study of service users’ views of health services, the Resource aims to help you to apply advice about research methods in appropriate ways when investigating service users’ views of health services.
1.2.5 **Scope and focus**

Research into service users’ views about health services is conducted for a variety of reasons and encompasses a broad range of activities. For the purpose of putting boundaries around the subject matter, the terms that appear in the title of the *Resource* have been interpreted as follows:

- **Research:**
  This term is used broadly in keeping with the following definitions:

  Research “attempt[s] to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods”.

  “Health services research aims to produce reliable and valid research data on which to base appropriate, effective, cost effective, efficient and acceptable health services”.

  The *Resource* focuses on research that is designed primarily to generate knowledge that will be useful in more than one particular decision-making or service development situation. However, some of the issues it covers will also be relevant to (a) health service audits that elicit reports from service users to check the performance of particular health services and (b) emancipatory research or action research projects that seek primarily and directly to secure practical changes in a particular setting.

- **Service users:**
  This term is used in an extremely broad sense to refer to anyone who is using, who has used, or who might in the future use any form of service intended to help improve or maintain their health, and anyone who might be affected by a family member’s use of such a service. It includes, for example, people with particular health conditions, people living in particular circumstances, patients, family members, informal care-givers, members of particular demographic groups or local communities and ‘the public’. It also includes people who are deliberately *not* using health services that service providers intend to benefit them. Although the term ‘service users’ is clearly a misnomer for this latter group, its use in this *Resource* reflects a focus on efforts to understand the views of those people who are intended to benefit from health services.

  Although the term ‘service users’ is used in a broad, inclusive sense, this is not intended to imply that all of the various groups of people who are referred to as service users have similar characteristics. There are many different sub-groups of people among those referred to here as service users. They may have different concerns about and perspectives on health services and researchers may need to adopt different approaches when eliciting their views.
• **Views:**
This term is used as a non-technical umbrella to cover the complex range of things that might loosely be described as part of people’s ‘mental content’. The focus is primarily on the views or (broadly) thoughts that service users are somehow able to report, including, for example, their beliefs, judgements, opinions, lines of reasoning, preferences, and valuations.

The *Resource* focuses on research that examines the ‘content’ or ‘meaning’ of what people say, write or otherwise express about their own views. It thus relates primarily to ‘interpret(at)ive’ or ‘experiential’ research,\(^{12,13}\) rather than to forms of research, such as ethnomethodology\(^{13}\) and conversation or discourse analysis\(^{12,14}\) that focus on the actions and processes that are evident in practice and in talk.

• **Health services:**
The *Resource* focuses primarily on the views that service users have about issues relating to the organisation and delivery of health care, although it is important to recognise that these are likely to be influenced by, and may also influence, the views that service users have about health and illness, particular health care interventions (e.g. screening and diagnostic tests, medical and surgical treatments, rehabilitative or palliative therapies) and the impact of these on health status. It considers the views that service users may hold and express as they approach health service encounters, use health services (including those that advise them how to care for themselves), reflect on their experiences and evaluate the services they have used, and consider what future health services should look like.

The *Resource* was written with a particular eye on the context of the National Health Services of the UK, but includes examples of studies conducted in other health systems and should be broadly relevant to researchers studying the views of people using health services in any context.

### 1.3 THE DIVERSITY OF RESEARCH INTO SERVICE USERS’ VIEWS

Research into service users’ views of health services is funded and conducted by organisations and individuals with varied interests, motivations and allegiances. It takes a wide variety of forms, asking diverse types of questions about people and services with varied characteristics, and using a variety of study designs and methods for collecting and analysing data. The findings it generates may be interpreted from a range of perspectives and used for different purposes.

Box 1 illustrates something of the diversity of research that might incorporate investigations of service users’ views of health services. It lists just some of the types of research that might consider service users’ views about self-management programmes for people with long term conditions.
### Box 1

**Examples of research that might examine service users’ views about support for self-management of their long term conditions**

A survey to explore the views of people with chronic health problems about their ability to manage their conditions effectively, the extent to which their health care provider(s) facilitate that, and their self-reported likelihood of using a proposed self-management support programme.

An investigation of the delivery and acceptability of a particular self-management support programme in different settings. The investigation involves researchers observing the content of training sessions and interviewing programme participants about the session structure, session leaders, within-group interaction, supporting materials and perceived helpfulness of the training sessions.

A randomised controlled trial (RCT) comparing two self-management support programmes and ‘routine care’ to investigate their relative effects on people’s health service use, perceived self efficacy, preferences for health service support, and self-rated wellbeing.

A statistical analysis of data from the above RCT to examine whether the programmes have differential effects among people with different types of chronic health problem and from across different gender, age, and ethnic groups.

A qualitative study, nested within the above RCT, that uses diaries and interviews to investigate service users’ experiences of the two programmes and how, if at all, the programmes influence their interactions with health care providers.

An exploratory study that uses focus groups to gain insights into the acceptability of different features of the two programmes to people from cultural and linguistic groups that were under-represented among the original programme participants.

A study based on the Theory of Planned Behaviour to identify factors that might predict whether or not people will (a) join and (b) complete the programmes.

A survey incorporating a discrete choice experiment to explore the importance people attach to particular programme characteristics when expressing preferences between two programmes that differ in a number of ways.

A meta-ethnography to synthesise published qualitative studies of people’s experiences of participating in self-management support programmes.

A verbal protocol analysis to investigate how people understand and formulate responses to structured questions about the quality of support for self-management they receive from health care providers.
1.3.1 Diversity of interests and perspectives

As noted in section 1.1, research into service users’ views is increasingly carried out by people with diverse educational backgrounds who work in a variety of roles in different types of organisation. Researchers’ backgrounds, affiliations and roles are likely to shape their particular interests in service users’ views about health services. They may influence the kinds of issues that they see as important or problematic, the ways they think about these, and the ways in which they seek to ensure their research is used.

For example, hospital managers in England are increasingly aware that the introduction of a policy requiring that everyone who needs an operation is given a choice of four or five health care providers means that their hospitals will be competing to attract patients. They are thus encouraged to pay attention to service users’ views about different hospital characteristics. Two facilities managers ran a small focus group study to investigate the relative importance of factors that fall within the responsibility of facilities managers. They found that, while service users report placing more importance on clinical factors than service factors when choosing a hospital, they do regard cleanliness and food quality as important to their choices. They recommended that facilities managers who want their hospitals to be competitive should focus particularly on cleaning and catering services.15

People who have responsibility for implementing policies that promote patient and public involvement in service planning and delivery are likely to have a broad interest in service users’ views, but may also want to pay particular attention to service users’ views about their participation in service development. For example, the experiences of service users who serve as lay representatives on committees in health care organisation may be of particular interest.16

Service users have sometimes been motivated to initiate research themselves, particularly when they have been frustrated to find that ‘traditional’ (usually academic/medical) researchers have not addressed the issues of most concern to them, have used disempowering research approaches and have represented their experiences in ways that they are not happy with. These service users have been particularly concerned to conduct research that starts with definitions and understandings of their health problems that they are comfortable with and that enables them to report on their experiences of service use and their recommendations for future services in their own terms.17

Researchers in universities often conduct applied research that is commissioned and intended for use by health service policy makers. However, these researchers may also have an interest in and/or a remit to develop the knowledge base of their particular academic disciplines. Academic disciplines have their own main areas of interest and address the issues that fall within these areas with characteristic ways of thinking – although academics working within the same discipline may disagree about the appropriateness of particular concepts and the usefulness of particular theories.

Service users’ views of health services may be of interest to researchers working in a number of academic disciplines. For example, researchers in departments of politics and social policy may be particularly keen to consider whether and how service users’
views are influential in shaping health policy and health services. Those in departments of economics, psychology or sociology may be more inclined to focus on the content of service users’ views, but they vary in terms of which aspects of these they consider.

Whether or not you seek to contribute to the development of the knowledge base of a particular academic discipline, the social science disciplines have a wealth of concepts, theories and methodological tools to offer to studies of service users’ views. If you have had little or no prior exposure to these disciplines, the brief descriptions and examples below should serve to introduce you to the types of questions that researchers trained in the disciplines of psychology, sociology and economics will tend to ask, and to the kinds of concepts, theories and methods that these disciplines can contribute to studies of service users’ views.

**Psychology**

Broadly speaking, psychologists study behaviour. They tend to ask questions about why people behave as they do (for example, why do some people seek help for minor illnesses from accident and emergency departments rather than general medical practitioners, or why do people accept or decline invitations to join discussions about the way their health services operate?) and how they might be encouraged to change their behaviours (for example, what interventions would be most likely to increase the proportion of hospital visitors who wash their hands?).

Different branches of psychology focus on behaviours in particular contexts (e.g. educational psychology, health psychology, occupational psychology) or on particular types of factor that influence behaviour (e.g. cognitive psychology, evolutionary psychology, neuropsychology, social psychology).

A number of insights that originate from cognitive and social psychology in particular are relevant to studies of service users’ views of health services. For example, cognitive psychologists have studied sensory perception (including perceptual illusion), information processing, memory formation and retrieval. These all have relevance for our understanding of the development, retention and expression of views. They have also developed techniques for assessing and improving the communication of intended meaning in the context of survey questions and response options. Social psychologists have identified a number of contextual factors that affect whether and how people express their views. They have also been responsible for the development of the most commonly used approaches to attitude measurement.

Health psychologists have paid a lot of attention to service users views about illnesses and treatment interventions, and have developed and tested a number of theories about the relationship between these views and service users’ uptake of particular treatments (including self-treatment behaviours) and their health states. They have perhaps paid less attention to service users’ views about health services per se. The study summarised in Box 2 is an example of a study that investigated service users’ views using a psychological approach.
The organisation of antenatal screening and women’s views about tests.

Uptake of antenatal screening tests for Down syndrome is generally higher when it is conducted as part of a routine antenatal appointment than when women are required to make a separate clinic visit. It is not clear whether the higher or the lower rates reflect a greater proportion of women making informed personal choices. Susan Michie and her colleagues set out to investigate to what extent the differential uptake is due to testing during routine appointments being more convenient for women and to what extent it is due to women being more likely to think that their midwives or doctors regard screening as more desirable when it is offered as part of a routine appointment.

The researchers used the psychological Theory of Planned Behaviour to guide their study. This theory states that people’s behaviours are predicted by their intentions, and that their intentions are predicted by their attitudes towards the behaviour, their subjective norms (what they think other people think they should do) and their perceived behavioural control (the extent to which they think they can adopt the behaviour in practice).

The researchers used a questionnaire survey to collect data from 1499 women who were offered screening for Down syndrome at either of two hospitals. One hospital offered the screening as part of a routine appointment and the other required women to make a separate visit for the test. Women answered questions about their attitudes towards the test, their subjective norms (whether their partners, friends, midwives and doctors thought they should have the test), their perceived behavioural control (how easy it would be for them to go along and have the screening test), and their intention to have the test. The researchers used laboratory records to check screening uptake.

Women’s intentions were strong predictors of their uptake of the tests. Intentions were most strongly predicted by attitudes, followed by subjective norms for partners and friends, and then perceived behavioural control. Subjective norms for health professionals did not predict either intention or uptake.

When data from the two hospitals were compared, it was found that intention predicted uptake more strongly and attitude predicted intention more strongly in the hospital that offered tests during routine visits. The researchers suggest that this finding might be explained by there being more actual (as opposed to perceived) barriers to acting on intentions for women in situations where a separate visit is required for a screening test.

Since women’s perceptions of health professionals’ views were not predictive of their intentions or uptake, the authors concluded that offering to carry out the test in a routine visit is more likely to facilitate informed personal choices than offering to carry it out but requiring a separate visit.

Sociology

Broadly speaking, sociologists study people in society. They are interested in the social patterning of individual experiences, including experiences of health, illness and health service use. They ask questions, for example, about whether experiences differ for people of different ages or people from different cultural or socio-economic groups. Sociologists also tend to ask how the structures and features of society (e.g. asylums for people with mental illness, the proportions of people from different ethnic groups in particular social roles) influence individuals, and/or how individual behaviours (e.g. the efforts of women to care for the health of their families) influence society.

A number of branches of sociology have developed which focus on particular social groups or aspects of life. The sociology of health and illness, which may be regarded as either synonymous with or related to medical sociology, is a well developed area of interest. Sociologists have contributed significantly to the development of knowledge about professional and lay understandings of health and illness, and interactions between service users and health service staff.

A number of more general sociological concepts and theories, including, for example, those relating to culture and cultural norms, socialisation and social status, power relationships, and people and organisations are likely to be useful to researchers thinking about service users in relation to health services. These concepts and theories are also helpful when considering the social circumstances in which research to investigate service users’ views is conducted and used.

The study summarised in Box 3 is an example of a study that drew on sociological concepts and theories to examine service users’ views.
Box 3

Experiences of receiving health and social care at home

Jan Angus and her colleagues conducted an ethnographic study of long term home care. They carried out 16 case studies of households that had received at least two home care services a week for eight weeks. The case households were located in urban, rural and remote areas of Ontario, Canada. The care recipients included males and females whose ages ranged from 5 to 83 years.

In each case household, the researchers video-recorded tours of the home spaces that were used for care-giving, made systematic observations and carried out focused interviews with care recipients, family members and home care service providers.

The researchers’ analysis drew on a sociological theory of practice developed by Pierre Bourdieu. Bourdieu regarded activity as a product of the relationship between an individual’s *habitus* (deeply ingrained dispositions reflecting the social position and material conditions to which the individual was accustomed) and the *fields* (social contexts in which individuals’ positions are determined by the distribution of economic and cultural capital) within which the action takes place.

The researchers found that “although all the care recipients and their family caregivers indicated a strong preference for home care over institutional care, their experiences and practices within their homes were disrupted and reconfigured by the insertion of logics emanating from the healthcare field”. They identified three main themes:

- **The politics of aesthetics.** The aesthetics of home spaces differ from those of health care spaces. The introduction of health care aesthetics into their homes is often a challenge for care recipients, while home care providers may regard some home spaces as unsuitable to health care.

- **The maintenance of order and cleanliness.** The recipients of home care services often have limited capacity to manage their homes. Health care equipment may generate problems of clutter. Some people become embarrassed by the state of their homes as they decline.

- **Transcending the limitations of home.** For people with declining health status and mobility, the limitations of their home spaces become increasingly apparent, and they seek ways to transcend these.

Service users reported that individuals who provided home care services often tried to help them preserve a clean, orderly and homely home, and to transcend the limitations that their home spaces presented for them. Although these individuals were officially quite constrained by their employers in terms of what they could do, some did more than was permitted.

The researchers concluded that the implementation of home care policies that were ostensibly intended to preserve a meaningful place for people within their homes and communities could, particularly in the context of limited resources, ironically tend to dismantle and reconstruct people’s experiences of home.

(Health) economics

Health economics addresses a wide range of economic issues in health care contexts, but health economists have paid particular attention to the costing and valuation of health care. They ask questions such as ‘What is the relative value of this as opposed to that way of organising health care?’. Until relatively recently, health economists tended to consider the value of health services only in terms of their contributions to health (fairly narrowly defined). They thus focused on methods for eliciting valuations of (or utility for) different health states. More recently, health economists have recognised that service users derive benefit from other aspects and attributes of health care processes and outcomes including, for example, information provision, waiting times, continuity of care providers, dignity and reassurance.

Health economists have developed a number of techniques for ascertaining how much value people place on different aspects of health services and their relative preferences for these. Some of their techniques are underpinned by the normative assumptions of neoclassical economics, and thus appear to assume that service users follow particular rules of rationality when making decisions.

The study summarised in Box 4 is illustrative of an economic investigation of service users’ views.
Box 4

Waiting times, costs and preferences for place of surgery.

In the late 1990s, waiting times for elective surgery on the Isle of Wight were long. The island’s Health Authority was considering offering residents surgery on the mainland. This could reduce waiting times, but could also result in residents incurring additional travel costs and needing to stay away from home during treatment.

Mandy Ryan and her colleagues conducted a study to establish whether Isle of Wight residents would be prepared to travel to the mainland for elective surgery. They sought to explore how residents would value and make trade-offs between three different aspects of the service: location, waiting time and travel costs.

The researchers sent a questionnaire to a random sample of 1000 residents. The questionnaire included a series of nine questions that asked people to choose between two options for elective surgery. In each case, the choice was between surgery on the island and the mainland, but the waiting times and travel costs associated with these varied across the questions. The questions took the following form:

<table>
<thead>
<tr>
<th></th>
<th>Isle of Wight</th>
<th>Mainland</th>
</tr>
</thead>
<tbody>
<tr>
<td>Operation waiting time</td>
<td>18 months</td>
<td>6 months</td>
</tr>
<tr>
<td>Travel costs</td>
<td>£0</td>
<td>£100</td>
</tr>
</tbody>
</table>

Which option would you prefer? Prefer option A ☐ Prefer option B ☐
(tick one box only)

556 people, whose demographic characteristics were broadly representative of the island’s residents, replied. 21 of these people gave incomplete responses, and 37 gave logically inconsistent responses. These 58 were excluded from the analysis.

Of the 498 people who gave complete and consistent responses, 22% had dominant preferences for surgery on the island (or lower costs), 48% had dominant preferences for surgery on the mainland (or lower waiting times), and 30% made trade-offs between waiting times and travel costs (their choices between surgery on the island or mainland depended on what combinations of these were involved).

The researchers noted that the information from their study could help policy makers to predict how many people would choose to go to the mainland for elective surgery if this was offered as an additional option. It could also be used to predict how many people would choose to go to the mainland with different waiting time reductions and travel cost subsidies. However, if the policy makers were in a position of having to decide between offering elective surgery only on the island or only on the mainland, they would probably also want information about the strengths of the preferences of those people who had dominant preferences for either the island or the mainland. This information was not available from their study.

1.3.2 Diversity of study aims and purposes

Research is undertaken for various purposes and research findings may be put to diverse uses. Studies of service users’ views may serve, for example:

- to fulfil service requirements to consult service users;
- to render visible to policy makers and service providers the experiences and views of particular service user groups;
- to help policy makers or health service providers understand behaviours that they regard as problematic (e.g. non-use of services; non-attendance at scheduled appointments);
- to inform the development of services (scope, organisation and delivery, distribution);
- to inform the development of information about services;
- to identify groups of people who might usefully be offered additional support to enable them to make better use of services;
- to monitor, compare and evaluate the performance of different health services, or different ways of organising and delivering health services; and
- to test or develop (social, psychological or economic etc.) theories and to inform future research.

Study aims usually reflect the intended purposes of research. They can be thought of as specifying what the project itself will achieve (as compared with what can be done with the study findings). Researchers may aim, for example, to:

- investigate the distribution or social patterning of views across population sub-groups;
- examine the relationships between particular types of views and other variables, asking, for example:
  - Do or how do different ways of delivering services affect people’s views of those services?
  - Do or how do people’s expectations of health services influence their evaluations of those services?
  - Do or how do people’s beliefs about a health service affect the way they use that service?
- address methodological questions about the properties or implications of different approaches to studying service users’ views.

Depending on their aims, researchers will need to incorporate their investigations of service users’ views within different types of study design.

1.3.3 Diversity of Data Sources

Service users might express their views about health services in a variety of ways. When they intend to communicate these views, most will rely primarily on verbal or symbolic languages and that is what this Resource will concentrate on – although facial expressions, bodily gestures and creative art works may also, of course, convey important information.

Researchers might employ a variety of methods to collect verbal expressions of service users’ views. They might make use of what service users say or write about
health services without researchers’ prompting, by collecting and analysing for example:

- Personal writings (e.g. diaries, letters between friends) that relate to experiences or thoughts about health services;
- Published writings (e.g. letters, personal accounts or opinion pieces that appear in patient or consumer group newsletters, magazines, newspapers, websites etc.)
- Communications between service users and health services (e.g. written or recorded complaints, observations or recordings of service users’ conversations with, observations or recorded minutes of service user forums and other meetings in which service users participate)
- Communications among service users or between service users and other groups (e.g. entries on publicly accessibly internet discussion areas, observations or the recorded minutes of patient or consumer group meetings)

More commonly, researchers will ask service users to contribute their views specifically to a particular research project and will use dedicated data collection techniques, including:

- Questionnaires in which service users record their own answers to researchers’ questions;
- Interviews in which service users engage in spoken conversations with researchers, usually on an individual basis but occasionally with a close family member or friend;
- Group discussions or focus groups in which several service users discuss questions posed by researchers; and
- Diaries for research, in which service users record material for researchers on a more or less regular basis over a period of time.

Within each of these broad groups of data collection techniques there are many variations on a theme. Researchers may ask questions in a more or less structured way and give service users more or less flexibility in terms of the forms their responses can take. They may introduce different kinds of prompts (e.g. materials for discussion, written or acted scenarios, problem solving exercises or simulated decision making situations) to stimulate service users’ thoughts and discussions. The techniques can be administered via a growing range of information and communication technologies. For example, questionnaires may be completed using paper and pencil, computers (with keyboards, mice or touch screens), telephone touch pads, conference hall voting systems or interactive television screens. Interviews and focus groups may be conducted face to face, using telephone and/or various technologies that allow video-conferencing, or via e-mail. Diaries have traditionally been written, but could also be audio or video-recorded or kept as internet blogs.
1.4 RESEARCH QUALITY MATTERS: AN INTRODUCTION

The fact that research that investigates service users’ views can take many forms does not mean that any form of research can be regarded as appropriate in any particular situation. This section introduces some key issues relating to research quality by highlighting the types of criticism that have been or could be levelled against some previous research. The rest of the Resource is intended to help you avoid the potential pitfalls listed below.

1.4.1 Concerns about the clarity and appropriateness of research aims

Lack of attention to previous research
Resources for health services and research are limited so researchers need to think carefully about current research priorities and be careful not to ‘reinvent the wheel’ unnecessarily. Some research has been justifiably criticised because researchers failed to consider insights from earlier work as they planned their own studies and interpreted their findings, and thus failed to build effectively and efficiently on previous knowledge.

Failure to consider the relevance of proposed research
Some researchers have been criticised because they have not adequately demonstrated why their research is relevant, either to the concerns of health services and their users or to the development of social science theory and method.

Lack of clarity about research objectives and questions
Some research efforts are not as fruitful as they might be because researchers have been unclear about which particular questions they want to address and why. Sometimes researchers identify a general area of interest but do not invest sufficient time and effort to understand what is already known about this area, to identify where the most important problems lie or what questions policy makers need to address, and to clarify a realistic set of research objectives and questions, bearing in mind how and to whom the knowledge they will generate might be useful.

1.4.2 Concerns about the scope of the research

Limitations in terms of what is asked about
No one research project can be expected to address all possible questions, and researchers investigating service users’ views will usually need to focus in some way on particular types of views about particular aspects of services. However, a serious criticism of much previous research into service users’ views, especially that which has purported to investigate the overall quality of services, is that it has not given service users an opportunity to comment on some of the key issues that fall within the scope of what the researchers are claiming to study. For example, some of the surveys that were used in the past to investigate hospital patients’ satisfaction with their care asked about the quality of the food and the décor in the ward, but not about the way patients were treated by doctors and nurses. They thus only addressed a fraction of the issues of concern to most hospital patients.

Limitations in terms of whose views are studied
Again, no one research project can reasonably be expected to consider all service users’ views, and some studies focus with good reason on the views of particular
groups of service users. However, researchers who purport to present the views of (all) users of a particular service or (all) members of a particular clinical or demographic sub-group can be fairly criticised if the inclusion criteria, sampling strategy or data collection techniques that were used were likely to exclude certain groups, especially if these potential exclusions and sources of respondent bias are not considered in the interpretation of data and drawing up of recommendations. These criticisms will be particularly marked if research is being conducted with a view to identifying priorities for quality improvement. Some of the groups that are likely to be excluded by ‘mainstream’ data collection methods including, for example, people who do not speak the majority language and people with sensory impairments, learning difficulties or literacy problems, are also likely to have different and potentially more difficult experiences of health services.23

1.4.3 Concerns about clarity and rigour

Lack of conceptual clarity
Some research reports are difficult to interpret and use because researchers have not explained what they mean by particular terms. A number of important and widely used terms relating to service users’ views (e.g. ‘patient satisfaction’) and what those views are about (e.g. ‘continuity of care’ and ‘patient centred care’) refer to complex constructs that have been understood and operationalised in a variety of ways. Researchers may be criticised if they do not familiarise themselves with established conceptual nuances, do not take steps to ensure that they understand how respondents understand and interpret key terms when using or answering questions that contain these, and do not clarify their own intended meanings when reporting their research findings.

Failure to meet standards of methodological rigour
Some researchers have failed to adhere to accepted standards for the execution of the study design, data collection methods or analytic techniques that they have used, and have not explained why, or considered the implications of their deviance from those standards. Although narrow methodological dogmatism is problematic,13 and adherence to standard methodological procedures is not of itself sufficient to assure the validity of findings and the broader quality of research,9 an appreciation of the implications of different ways of doing things remains important, and there are good reasons for some of the prescriptions associated with particular study designs and research methods.

1.4.4 Concerns about service users’ experiences of research and its impact

Inappropriate interpretation and use of data
Researchers are sometimes prone to infer more than is justified from their data and to fail to specify the assumptions they have made when undertaking their analysis and generating their conclusions and recommendations. Researchers who start out with strong ideas about how services should be organised and delivered may be particularly prone to draw stronger conclusions than might be warranted. Researchers can be criticised if they fail in their analysis and interpretation of their data to take adequate account of, for example:

- the extent to which they have explored the range and distribution of views within the group(s) of health service users that they have studied;
• the potential impact of their own methods on the data they collected and the interpretations they arrived at;
• the extent to which they have been able to investigate the nature of the relationship between service users’ expressed views and features of the organisation and delivery of health services that they refer to.

Some research into service users’ views has been criticised for its uncritical acceptance and re-presentation of what service users say, and because researchers have failed to consider the contexts in which service users’ views were shaped and communicated, and the implications of these contextual factors for the interpretation of the views expressed. Rigorous research – even when it aims quite simply to find out what a group of service users think about a particular health service issue – involves more than identifying people with appropriate credentials as service users, asking them a few questions about the issue of interest, recording what they say and simply reporting a summary of their responses or a selection of quotations.

While it may be inappropriate for researchers to simply and unconditionally accept everything that service users tell them at face value, it is also important to note that researchers may warrant censure if they fail to adequately respect their respondents and the views they express. Exactly what it means to respect respondents and their views is difficult to pin down. The types of behaviours that exhibit respect may vary depending on the context in which views are elicited, the types of views that are expressed, and the purposes to which they are to be put. Respect for service users who contribute to research does not require researchers to condone, for example, expressions of sexism or racism from respondents. However, researchers may be deemed to lack respect if, for example, they are unduly suspicious about the veracity of service users’ reports, react with indifference to accounts of experiences that service users’ have found difficult, or deprive service user respondents of personal dignity by presenting themselves as having superior expertise and power.

Some research, particularly that which involves some form of evaluation of services, has been criticised for failing to consider adequately what service users themselves would like to suggest or recommend in order to improve services from their perspective. For example a study of residential institutions for people with physical impairments that was conducted in the late 1960s was subsequently heavily criticised by one of the residents. Although the researchers concluded in their report that segregated residential homes were oppressive to residents, describing them as “inherently pathogenic”, they did not suggest that they be abolished, and in their recommendations for changes within the institutions, did not suggest that residents should be given more say in their management. Almost a decade after the publication of the report, the resident accused the researchers of being biased against the residents’ interests, failing to take adequate notice of their experiences and views, and directing recommendations to practitioners alone, so that residents only featured as “objects about whose existence someone else is to be given greater knowledge and competence”.24

**Insensitivity to service users’ experiences of the research process**

Some research has been justifiably criticised because researchers have paid inadequate attention to the impacts they have on the lives of the service users they study. The processes that researchers use to invite people to participate in research, to
collect data about people’s views, and to communicate (or not) their findings might have both positive and negative implications, that may vary across different groups.

Users of health services vary greatly in terms of their health status, personal characteristics and social circumstances. However, health and health services are widely regarded as important, and current health service users in particular may be vulnerable because of their ill health and because of their sense of dependence on the continued provision of the health services they are using and on the good will and competence of the staff who deliver them.

While even the most vulnerable among service users may value the opportunity to participate in and contribute to research, researchers may cause discomfort or distress if they fail to anticipate and address the possibility that their invitations to participate in research and their data collection processes are interventions that may impact on service users’ views and subsequent experiences of health service use. For example, long term users of particular services have sometimes interpreted the fact that research is being conducted relating to those services as a sign that their continued provision is under threat. Questions about past experiences of health service use may require people to recall and relive difficult times, may draw their attention to aspects of services they had not previously considered, raise questions about the quality of their previous or subsequent experiences of service use, and cause them to re-think their previous evaluations of services. Questions about anticipated future service use may raise concerns and influence – for better or for worse – service users’ future interactions with and experiences of health services.
Zoe Skea and her colleagues studied women’s perceptions of various aspects of decision-making relating to hysterectomy, including information provision.

104 women who were due to be admitted to hospital for hysterectomy completed a questionnaire that asked, among other things, about whether they had been given information about particular issues relating to hysterectomy during their recent visits to hospital clinics, and what they thought about the amount of information they had been given.

The researchers were concerned that their questionnaire might alert women to the possibility that there was more information to be had about various issues relating to hysterectomy than they had been given by their consultants. However, the research team and the Research Ethics Committee agreed that the women should have been given information about these issues and the researchers sought to enable women to access information about issues they felt inadequately informed about by providing suggestions about sources of further information at the end of the questionnaire.

To investigate the issue, the researchers included an open-ended question at the end of the questionnaire that invited women to note any concerns or questions that the questionnaire had raised for them. Several women noted in response to this question that the questionnaire had highlighted gaps in their knowledge and/or inadequacies in the information they had been given by their hospital doctors. When the researchers interviewed a sub-sample of twenty women post-operatively, they found that the questionnaire had prompted several of them to seek further information from their doctors before their surgery.


Researchers can reasonably be criticised if they do not offer appropriate opportunities for those who participate in research to receive information about the findings. Service users who make an effort to participate in research studies but never hear back from the researchers after they have contributed their data and do not see any improvements in the services they use may understandably become disillusioned with both research and services.26

Lack of impact on health services
Not every research project that includes an investigation of service users’ views aims to produce directly actionable results that will lead to recognisable changes in the services that are or might be used by the people who contribute data to the project. Policy makers may be more likely to respond to good quality research27 and to draw on the ideas and insights that emerge from a broader body of research than to act in response to a single study.28 Depending on the nature of the research and findings, the implications of a particular project for broader policy and practice may not be obvious, and even if they seem to be so, a variety of contextual factors can limit the ability of health services to act effectively on relevant research findings.29 However,
researchers can be fairly criticised if they fail to make adequate efforts to disseminate their research findings and if, when they invite service users to contribute to their studies, they raise unreasonable expectations about the service improvements that might result from it.

There is, of course, some overlap between the problems that underlie these criticisms. For example, limitations in terms of what is asked about (a failure to explore all the salient dimensions of the aspects of health services that the research claims to focus on) may reflect a lack of attention to previous research and a failure to consider how the proposed research is seen as relevant by key stakeholder groups. It may imply to service users a lack of respect for their views, and may contribute to the lack of impact of research on health services.

1.5 BROAD RECOMMENDATIONS AND QUESTIONS TO REFLECT ON

In general terms, this Resource encourages you as researchers to:

1) Think carefully about the nature of ‘views’ and what can be known about them.

2) Pay careful attention to what is already known about service users’ views of health services.

3) Be as clear as possible about the meaning of the terms that you and others employ – particularly concepts relating to the types of views that service users have and the aspects of health services that they have views about.

4) Consider the potential implications of all aspects of your proposed research for:
   a. service users’ experiences of research;
   b. the views that are collected and the ways they are understood.

The material in the following chapters is intended to help you in these respects. It should help you develop answers to the following questions, which you might find it helpful to consider before embarking on any particular study to investigate service users’ views.

1. What types of views, on what types of issues, are of interest and why?

2. Are service users likely to have these types of views on these types of issues?

3. When and how might people develop the views that you are interested in? In particular:
   i. How do these views relate to their encounters with health services?
   ii. How might research processes shape these views?
4. Are the views of interest susceptible to change? Under what circumstances?

5. How well can people recognise, recall and articulate their views?

6. What might influence whether and how people will express their views?
   i. Are people willing to answer questions about the issues of interest?
   ii. How do people go about answering questions?

7. How might research processes affect what people are willing and able to say about their views?

8. How else might research processes affect those whose views are studied?

9. How might your own views affect your interpretations of the data you collect?

10. Will your answers to the above questions vary across different groups of service users, and if so, what are the implications of this?
SUMMARY OF KEY POINTS:

- An interest in research that investigates service users’ views has been fuelled by a number of developments including policy commitments to (a) develop health services that are responsive to the people they serve and (b) involve those people in the development process.
- Research that investigates service users’ views of health services can take many forms. Researchers from different backgrounds and with diverse interests have tackled a range of research questions using a variety of research methods and drawing on concepts and theories from various sources. Their findings have been put to a number of different purposes.
- Concerns have been expressed about the poor quality of some of the research that has been carried out to date to investigate service users’ views. Problems have been identified with:
  - The clarity and appropriateness of the aims of the research
  - The scope of the research, both in terms of which service users are involved and in terms of which aspects of services are considered
  - The clarity of the concepts employed, rigour with which data are collected and analysed, and the extent to which conclusions are justified
  - Service users’ experiences of research and its impact on their lives
- This Resource aims to help those who plan to conduct research to investigate service users’ views about health services. It encourages researchers to:
  - Think carefully about the nature of ‘views’ and what can be known about them.
  - Pay careful attention to what is already known about service users’ views of health services.
  - Be as clear as possible about the meaning of concepts relating to types of views that service users have and the aspects of services that they have views about.
  - Consider the potential implications of all aspects of their proposed research for service users’ experiences of research participation and for what comes to be understood about service users’ views.
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CHAPTER 2:

ABOUT ‘VIEWS’ AND THEIR EXPRESSION

Going on inside me all the time is a complex and dynamic flow of ever-changing awareness, mood, response, reaction, feeling, emotional tone, perceptions of connections and differences, back references, side references, with flickering thoughts and glimpses and half-memories darting in and out of the various interweaving strands, all flowing endlessly on in some richly reverberating echo chamber of resonance and connotation and implication. I might be able to imagine this being translated into some kind of orchestral music, but certainly not into words. (Bryan Magee)

We can try to describe our thoughts and feelings to each other, of course, but we have no way of knowing whether the words we use are referring to the same thing. (Timothy Wilson)

WHAT THIS CHAPTER INCLUDES

• An introduction which notes that many important issues relating to the nature of views and what we can know about them remain contested.
• A section that highlights the range of types of views that people may have, and the ways these are characterised.
• A section that considers factors that influence whether and how people form and express views on particular issues.

2.1 INTRODUCTION

As noted in Chapter 1, the word ‘views’ is used in this Resource as a non-technical term to cover a complex range of things that might loosely be described as ‘mental content’.

Before we try to investigate service users’ views about health services, we might usefully reflect on:
• what views are (the nature or ontology of views);
• what we can know and how about our own and others’ views (the epistemology of views);
• the different types of views that have been identified;
• how people develop views and how their views relate to what goes on in the world;
• how what people say about their views on a particular occasion relates to:
  o the views they hold, have held and might hold at different times
  o what they say about their views on other occasions; and
• how people interpret what others say about their views.

In fact, many important questions about the ontology and epistemology of views are highly contested. We still know relatively little about the nature of our mental content and how human minds work. Research into the philosophy and science of mind has not yet resolved, for example, whether and how our thoughts are related to the
material features of our brains, or what we can know and how about other people’s
minds. There is an ongoing dispute about the source of meaning and the nature of the
relationship between thought and language.

Some scientists and philosophers, especially those who think it will eventually be
possible to explain human behaviour purely in terms of physical events in our brains,
have adopted a position known as ‘eliminativism’ with respect to concepts such as
beliefs and desires. They reject the suggestion that these concepts refer to real entities,
dismissing them as posits of a misguided theory that they call ‘folk psychology’.
Their position is, however, vigorously contested by their peers who hold a variety of
views about what views are.3

In the practical worlds of public policy formation, health service provision and health
services research, talk about service users’ views seems set to continue for a good
while yet. For the purposes of this Resource, therefore, we will assume that (most)
people can or have inherent potential to:
• form, and in some senses have, various types of views about things;
• recognise and reflect on at least some of these views;
• use language to communicate something about their views to others; and
• understand something of other people’s views on the basis of what they are told
about them.

However, important questions remain about what we can infer about people’s views
from what they say about them. As the quotations that open this chapter suggest:
• even the most articulate people may struggle to identify and describe their views;
• people’s ability to identify and describe their views may depend in part on the
language(s) and communication tools available to them and those with whom they
communicate; and
• there are limits to the extent to which researchers can justifiably claim to
understand service users’ views on the basis of what service users say about them.

It is entirely appropriate for health services researchers to make some pragmatic
assumptions and avoid getting waylaid by efforts to get to the bottom of the long-
standing questions about minds that keep the world’s leading philosophers occupied.
However, we would also do well to pause from time to time to reflect on our
assumptions and uncertainties about how the mind works and what it is possible for us
to know about our own and others’ views.

2.2 FEATURES OF ‘VIEWS’

2.2.1 Talking about types of views and their properties

A wide range of terms are used to describe the various phenomena that we are
grouping together and calling ‘views’. These include, for example, ‘attitudes’,
‘utilities’ and ‘values’. Many of these terms are familiar and widely used—although
not always consistently. Psychologists, philosophers of mind and others have, over
the years, defined them in a sometimes confusing variety of ways.
Researchers need to be aware that the terms used to describe different types of views can carry several possible meanings. You should consider carefully what these terms refer to when they appear in documents about service users’ views, when they are used in questions that are put to service users, and when they feature in service users’ reports about their views. (The next sub-section emphasises this by considering potential distinctions and areas of overlap between attitudes and values).

Thinking activity:
How many meanings can you think of for the phrase “I imagine that…”?

(What kinds of things might be involved in imagining? What could the phrase “I imagine that…” convey in a conversation, and how would you know what the speaker intended to convey?).

Discussion:
You might have thought of (imagined?) a number of possibilities. “I imagine that…” might be used, for example, to convey notions of fantasing, speculating, thinking tentatively that something is the case, supposing, thinking of something that does not exist, and visualising, among others. 4

The intended meaning of “I imagine that…” in a particular instance might be fairly obvious once the sentence is completed. However, it is often the case that several reasonable interpretations remain, and these might be significantly different. For example, a researcher could come to quite different conclusions depending on whether they interpreted a service user’s statement “I imagine that when I go into hospital…” as (a) an indication of what the service user tentatively thought likely to happen but was uncertain about and reluctant to express using more confident terms such as “I believe” or “I know” or (b) part of a description of their strategy for controlling their anxiety.

Views that are *about* something are sometimes called ‘propositional attitudes’. 5 The content of a propositional attitude can be expressed as a statement that something is the case. In the following examples, different types of propositional attitude are printed in italics and the statements that describe or form their content are underlined.

Annie *believed* that the nurse was working a double shift.

Bert *hoped* he would be seen by the same therapist at his next appointment.

Clare *anticipated* that there might be no free spaces in the clinic car park.

David *feared* that the student nurse would struggle to insert the needle correctly into his vein.
Elizabeth intended to check that the hospital staff involved in her care washed their hands before they inspected her wound.

There is a long established practice of dividing mental content, including propositional attitudes, into three broad types: cognitions, affects and conations. Roughly speaking, cognitions are thoughts (e.g. attributions, beliefs, reasons), affects are feelings (e.g. fear, happiness), and conations are closely associated with behaviour (e.g. desires, intentions). However, the boundaries between the three categories are variably drawn and some types of mental content are difficult to categorise. For example, emotions are sometimes regarded as affects, sometimes as having a cognitive basis, and sometimes as both.6

The question of whether the various types or categories of view form natural classes (groups that can be defined by real world properties) warrants some attention, although the answer remains contested. When we use phrases such as ‘having a positive attitude towards something’ or ‘having a belief about something’, we tend to think of ‘attitude’ and ‘belief’ as terms that denote something real - perhaps something that is discretely represented in the brain. However, the terms might also be thought of as referring to hypothetical constructs and we might not want to commit ourselves to the belief that they refer to things that scientists will eventually be able to detect in our brains in the same kinds of ways that they can detect particular cell types or molecules.

Some of the terms that we use to describe particular types of view are more intuitively recognised as referring to hypothetical constructs than others. Economists who were trying to quantify the benefit associated with particular goods or services introduced the concept of ‘willingness to pay’ and researchers now quite routinely ask people how much they would be willing to pay, for example, for particular features within health services. Although people are (sometimes) willing to answer these questions,7 it would seem odd to talk of service users as having a type of view called a ‘willingness to pay’ as if it were something they carried around in their heads.

We associate a number of different properties with views. For example, views may be regarded as more or less relevant in the context of particular discussions, and they may be more or less enduring in their holder’s memory. The range of properties that it is meaningful to attribute to views varies according to the type of view envisaged. For example, it makes sense to talk about the certainty of beliefs, but not about the certainty of fears. It makes sense to talk about the intensity of feelings, but not about the intensity of reasons.

2.2.2 Attitudes and values

Attitudes and values are often of interest to policy makers and health service developers. This section briefly highlights a few issues relating to their definition and identification with a view to highlighting the need for researchers to be as precise as possible when investigating and describing different types of views.

The word ‘attitude’ has been widely and variously used. In the 1950s and 1960s it was used quite broadly to refer to cognitive, affective and behavioural responses (or
predispositions to respond) to stimuli. A tripartite classification of attitudes still persists in some discussions (especially philosophical discussions about propositional attitudes), but most psychologists and health services researchers now talk about attitudes in a narrower sense, regarding them as evaluations that, for example, “denote a person’s orientation to some object, or attitude referent” or “locate ‘objects of thought’ on ‘dimensions of judgement’”.

Examples of statements that express attitudes include:

- Appointment systems for NHS outpatient clinics are inefficient.
- When doctors don’t inform patients that there are treatment options other than surgery, that’s inexcusable.
- Continuity of care is very important to me.

There are some differences of opinion about how general an object of thought needs to be before someone could be said to hold an attitude about it, and also about how stable the evaluative orientation needs to be. For example, while most people would regard “Clinic receptionists are rude” as expressing an attitude, not all would regard “That clinic receptionist was rude to me today” as expressing an attitude. The latter statement clearly includes an evaluative judgement, but some would suggest it is better described as an opinion about a specific event – albeit one that is consistent with the attitude that regards clinic receptionists as rude.

Attitudes may involve various dimensions of judgement, including, for example, bad/good, early/late, appropriate/inappropriate, and worthwhile/not worthwhile. However, not all dimensions of judgment will be applicable to all possible attitude objects.

In service users’ talk, attitudes may be identifiable within a complex of descriptive and evaluative statements, even if they are not as obvious as those above.

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**Thinking activity:**

Consider the following paragraph from a hypothetical interview with a service user.

The follow-up care was wonderful. One of the nurses phoned me at home the day after I left hospital and again a few days later to check if I’d got any problems or questions, and I had a number to call in case I was worried about anything in between times. That gave me more confidence – it’s just such a sensible way of doing things. I didn’t have to stay in hospital longer than I needed to, but I wasn’t just kicked out and left to get on with it!

What attitudes or evaluative judgements do you think the service user expresses? What are their objects or referents, and what kinds of evaluative dimensions do they involve?

**Discussion:**
The service user’s first sentence conveys a positive evaluation of the follow up care the service user received (the object) on the dimension of wonderful/[not wonderful, awful]. The second sentence provides a brief description of something of what happened during the course of the follow up care. Two further evaluative-type statements in the third sentence refer either to the follow up care in general, to being telephoned and/or to being given a telephone number to call (the object of these evaluative judgements is not entirely clear). They evaluate this or these on the dimensions of confidence-enhancing/[confidence reducing] and being a sensible way of doing things/[or not]. The final sentence, which refers indirectly to the timing of hospital discharge, seems to express another positive evaluation of the follow up care received, perhaps on dimensions of appropriate/[inappropriate] or acceptable/[unacceptable].

Attitudes (at least, attitudes in the narrower sense) are formed during our early and ongoing socialisation. They may be shaped by various forms of direct and indirect experience, including deliberation and discussion (see Box 6). They may be held with more or less ambivalence, clarity, confidence and certainty, and may be more or less accessible in memory and more or less stable.
Paul Dolan, Richard Cookson and Brian Ferguson set out to investigate the extent to which members of the public change their views about priority setting in health care as a result of discussion and deliberation.

They convened 10 groups of about six men and women of various ages. Each group met twice, a fortnight apart, for discussions that lasted about two hours. Individual participants completed two questionnaires, one before the first discussion and one after the second discussion. These included questions about who should contribute to decisions about priority setting in health care and whether certain groups of people should be given more or less priority for treatment than others.

In their first meetings, the groups were given several hypothetical scenarios and asked to make decisions about setting priorities between different groups of patients. In their second meetings, they were asked to make three pairwise comparisons between groups of patients who differed in terms of their deprivation and ability to benefit from treatment, and to decide in each case who should be given priority.

On the first questionnaire, most respondents indicated that they wanted members of the public and doctors and nurses to have relatively more involvement in priority setting decisions than NHS managers, politicians and pressure groups. On the second questionnaire, 48% of responses shifted. Fewer respondents supported more involvement for members of the public, and more supported more involvement for NHS managers. The researchers suggest that this was because the discussions led people to realise the complexity of the issues involved in priority setting decisions.

On both questionnaires, about a third of respondents indicated that people who are deemed largely responsible for their own illnesses (e.g. smokers, heavy drinkers, illegal drug users) should be given a lower priority for treatment. However, 18 respondents changed the priority they gave to these people between the two questionnaires, 12 to a lower relative priority and 6 to a higher relative priority. The respondents who changed their views, and the direction of change of their responses, were not obviously associated with participation in any particular group.

One respondent characteristic was associated with holding particular views. People who were smokers were less likely to give a lower priority to smokers and others who might be deemed responsible for their own illnesses.

The authors suggested that if researchers are seeking the considered attitudes of the general public relating to health care priorities, they will need to give people time to reflect on their responses.

Attitudes can serve various functions, both as part of our individual lives and in our social discourse. They feature prominently in many current efforts to understand and predict service users’ health-related behaviours, especially their self-care practices and their use or non-use of particular health care technologies and services (see, for example, Box 2).

Service users’ ‘values’ are widely discussed but often poorly conceptualized and understood. Dictionary definitions of value tend to focus on the value of something as its worth, the extent to which it is held to be good, beneficial, worthwhile etc. They point out that value is often operationalised as a fair equivalent in monetary or other terms.

Psychologists sometimes regard values as general beliefs about desirable goals and behaviours (e.g. freedom, health, compassion, honesty). On this interpretation, values are like attitudes, but with more abstract or more fundamental objects or referents, and perhaps with a greater degree of stability and more of a quality of moral imperative about them. Values can serve to provide standards for, among other things, evaluating actions, justifying opinions, and presenting the self to others. Values may be conceived as having an influence over (and thus helping to predict) attitudes relating to more specific objects and behaviours. If we think, for example, that most members of the public value equity in service provision, or that most service users value their dignity, we would expect these values to be reflected in positive attitudes towards approaches to the organization of health services that seem to promote equity of access to people from different social backgrounds, and approaches to health care delivery that service users experience as preserving their dignity. Values are also more closely associated with social reference groups than attitudes are. However, it is difficult to say precisely where the boundary should be drawn between attitudes and values.

2.3 THE FORMATION, RECALL AND EXPRESSION OF VIEWS

Most people can be said to have a vastly complex and dynamic set of views. We readily recognize that we tend to develop views about the situations and issues that we are exposed to (or receive information about). Our views may also be shaped by a variety of neurobiological, cultural, linguistic, psychological and social factors. What we say about our views, too, may be subject to a variety of influences. In this section we consider three broad types of influences on the formation, recall and expression of views that are particularly relevant for researchers planning to investigate service users’ views of health services.

2.3.1. Automatic influences

The work of cognitive and social psychologists has led to a growing recognition that the human brain processes information and influences behaviour in many different ways. In particular, it is now widely accepted that our brains carry out a number of processing activities automatically, in ways that we are not aware or conscious of. These activities contribute to the ways in which we filter information from our environment, interpret, evaluate and respond to that information, selectively store information in memory, and retrieve information from memory.
Although it is not clear exactly how our ‘views’ are related to the material features of our brains, there is a reasonable consensus that humans can somehow store conceptual knowledge, evaluative judgements and so on, and that they can do so in a way that is abstracted from specific experiences. Studies of people’s responses to different stimuli have lent strong support to the notion that conceptual knowledge, evaluative judgements and other mental phenomena are stored in an organised way. Some groups of concepts are somehow connected and are likely to be activated (made accessible for mental processing and verbal reporting) together. These associated ideas are said to be stored within the same mental ‘schema’.

People are more likely to notice and attend to things that relate to their currently active schema, and more likely to interpret new concepts and experiences in ways that are easily accommodated within existing schema. Existing schema are thus important influences on the formation of new views.

Our tendency to stereotype people is one example of an effect of the operation of mental schemas. Stereotypes are social beliefs that lead us to categorise individuals on the basis of a few readily available characteristics. They provide a rapid way of forming an impression of other people. Stereotypes seem to result from automatic associations that we make, sub-consciously, between particular characteristics. For example, some people tend automatically to associate being overweight with being greedy, lazy and lacking in self-discipline. The stereotypes we hold, if activated in relation to a particular person or social situation, incline us to attend to information that fits our stereotype and to ignore most other information. For example, the sight of an overweight nurse might activate a stereotype that would lead a service user to notice aspects of the nurse’s behaviour that can be interpreted as signs of greed, laziness and a lack of self discipline. This might lead the service user to evaluate the quality of care provided by that nurse less positively than she would have done if the stereotype had not been activated, or if it had been overridden by a belief that the nurse’s weight problem had other causes.

The fact that there are non-conscious automatic influences on what we pay attention to, on how we interpret the world around us, on how we respond to people and events around us, and on what views we retain and can access from memory, means that we are not, and cannot be, aware of all the various influences on those thoughts and behaviours that we recognise. We do not know, for example, how our mental schema are organized. This has several general implications for researchers who wish to investigate service users’ views.

First, even if our primary interest is in service users’ conscious views about health services (the concerns and experiences that they recognise as such, the judgements they know they make, the preferences that they are aware of having, etc.), we must appreciate that service users’ reports about particular health service encounters and what they thought about them will only ever present partial pictures of what happened in the real world and how they responded to that. People do not attend to many of the detectable facts about their environments, and will not be aware why or even that they are not registering many of the things that they do not register. Their recall of memories is also subject to non-conscious influences, and their confidence about the accuracy of a memory is not a good indicator of their ability to describe an event accurately.12
Second, researchers’ own activities may affect the ways in which people form and recall views, without those people being aware of it. For example, researchers’ personal characteristics and interactions with service users may tend to activate particular schemas and prime respondents to focus on particular types of issue and/or to adopt more positive or more negative stances in relation to certain issues. The particular words they use as they invite people to participate in studies and as they seek to elicit their views might have a substantial effect on the data they collect.

Researchers who (perhaps unwittingly) put service users in situations that they find intimidating might inhibit those service users’ abilities to access their views about their recent health care experiences. If the service users’ attentional and information processing capacities are largely directed to the intimidating aspects of the research situation, their ability to access stored memory may be automatically inhibited.

Third, some of researchers’ best efforts to investigate how service users understand and respond to their questions have inherent limitations. Techniques such as asking people to ‘think aloud’ as they complete research tasks and/or to respond to verbal probes that invite them to explain how they have understood particular questions and response options are often used in the cognitive testing of survey questions and response options. These techniques rely on people’s recognition and recollection of, for example, how they interpreted particular phrases in researchers’ questions and why they responded to them as they did. They can hope only to access people’s conscious feelings and reasoning. This is not to say that cognitive interviewing techniques such as think aloud and verbal probing are not useful: people’s conscious feelings and reasoning processes do seem to influence their response choices, and the information they can give about why they responded as they did may prompt researchers to review the way they ask or interpret particular responses (see, for example, Box 7 below and boxes 13, 14, 25 and 26). However, we should be alert to the fact that the conscious information processing that people describe, even when these techniques are working at their best, may not fully explain their responses to researchers’ questions.
Box 7

Qualitative interviews offer insights into positive responses on structured assessments of health care quality

Zoe Skea and her colleagues used structured self-completion questionnaires and in-depth interviews to explore women’s perceptions of and satisfaction with various aspects of decision-making relating to hysterectomy.

104 women who were due to be admitted to hospital for hysterectomy completed a questionnaire about information provision, communication and decision-making relating to their hysterectomy during their recent visits to hospital clinics. 20 of these women, who had reported a range of views on their questionnaires, were also interviewed shortly after their surgery. They were asked first to describe the events that led to them having a hysterectomy, and then to discuss their reasons for selecting particular responses to some of the questions on the questionnaire.

On the questionnaires, most women gave positive responses to questions about the adequacy of information provision and the helpfulness of their doctor during decision making. In the interviews, however, even those who had given positive responses on the questionnaire identified problems and shortfalls in these aspects of their care.

The comments women made in interviews about their responses to the questionnaire suggested that some of those who had had some specific negative experiences had given positive responses on the questionnaire in an attempt to reflect their ‘overall’ assessment or experience of a particular aspect of care. This highlights the fact that even questions that focus on particular aspects of health care, such as support from doctors during decision making may require people to sum up a number of (often mixed) health care experiences in the selection of one response option. Some women reported choosing ‘agree’ rather than ‘strongly agree’, or ‘satisfied’ rather than ‘very satisfied’ responses because they had been only moderately impressed with the aspects of care they were asked about. They regarded their non-selection of a strongly positive response as reflecting the problems or shortfalls they had experienced in their care.

Women also gave a variety of reasons for choosing mid-point ‘neutral’ response options. These included: having mixed (positive and negative) experiences of the aspect of care in question; feeling unable to evaluate the quality of that aspect of care; not understanding the question or statement; being unsure whether the question or statement applied to them; and generally accepting that what was being done was inevitable.

Fourth, researchers’ own schema will tend to influence the ways in which they respond to study participants and interpret the data they elicit. Researchers’ attempts to recognise how their own views and ways of seeing things might influence the way they formulate questions, interpret responses, and form judgements about the views that they elicit – and the people that they elicit them from – will also only ever be partially successful. There are non-conscious automatic influences on researchers’ views and behaviours, just as there are on service users’. It is a recognition of this which leads to the recommendation that the interpretation and implications of what service users say should ideally be discussed within research teams with diverse backgrounds and perspectives.

2.3.2 The influence of researchers’ questions and the use of language

Whether or not we form views about particular phenomena or issues depends to a large extent on whether and how we are exposed to these (or associated) phenomena or issues - or to information about them - and whether and how we pay attention to them.

Sometimes people only express views on particular issues when they are asked to respond to researchers’ questions about them. Researchers thus need to consider carefully what they can infer about people’s views on the basis of what people tell them on demand. For example, if a researcher had approached me in the waiting room at my last clinic visit and asked me whether the following statements were true or false, I would probably have said they were true.

The receptionist is not a purple hippopotamus.

There is a handle on the door.

The plant near the window has 3 large white flowers open.

However, even if I was assiduously trying to fulfil a researcher’s request that I describe in as much detail as possible everything I could remember about my recent clinic visit, I would probably not mention these points. While I would agree with these statements and might agree to count them among my beliefs if I were pressed on the matter, I would not regard them as reflecting thoughts that I was conscious of having before I was asked about them, or beliefs that were useful or important to me – or indeed to the health service.

Even when we ask people about issues that they consider relevant, the answers we receive might lead us to overestimate the precision of the views they had previously ‘held’, as the philosopher Daniel Dennett explained with reference to the kinds of questions and answers that might be heard in restaurants.

“The capacity to express desires in language opens the floodgates of desire attribution. ‘I want a two-egg mushroom omelette, some French bread and butter, and a half bottle of lightly chilled white Burgundy.’ How could one begin to attribute a desire for anything so specific in the absence of such verbal declaration? How, indeed, could a creature come to contract such a desire without the aid of language? Language enables us to formulate highly
specific desires, but it also forces us on occasion to commit ourselves to desires altogether more stringent in their conditions of satisfaction than anything we would otherwise have any reason to endeavour to satisfy. Since in order to get what you want you often have to say what you want, and since you often cannot say what you want without saying something more specific than you antecedently mean, you often end up giving others evidence – the very best of evidence, your unextorted word – that you desire things or states of affairs far more particular than would satisfy you – or better, than would have satisfied you, for once you have declared, being a man of your word, you acquire an interest in satisfying exactly the desire you declared and no other.

‘I’d like some baked beans, please.’

‘Yes, sir. How many?’

You might well object to having such a specification of desire demanded of you, but in fact we are all socialised to accede to similar requirements in daily life – to the point of not noticing it, and certainly not feeling oppressed by it. [In the realm of belief, too] our linguistic environment is forever forcing us to give – or concede – precise verbal expression to convictions that lack the hard edges verbalisation endows them with.”

The upshot of all this is that when service users express or indicate agreement with statements that appear to describe propositional attitudes, researchers need to consider:

• whether service users’ agreement or disagreement with proffered statements can reasonably be regarded as reflecting their prior, currently ‘held’ or stable views about the matter;
• how important the views that service users appear to express about health services are to them, and why; and
• how and why any particular views that service users appear to express should be regarded as significant for health service development.

2.3.3. Some specific social psychological influences

It has been claimed that “People are attitudinally labile to an extraordinary degree, altering their ‘attitude’ to the same object according to the social context they are in”.

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Diana Rose and her colleagues conducted a systematic review of studies of the views of people who had undergone electroconvulsive therapy (ECT). They searched bibliographic databases and other sources to identify reports of relevant studies, then extracted data from each study report about: various aspects of the way patients’ views were collected (when, in relation to the receipt of treatment, the patients’ views were sought; where and by whom patients’ views were elicited; and how much scope the response format allowed for patients to express their opinions); and the proportion of patients who gave positive responses to questions about the effectiveness of ECT.

The researchers found that studies generally reported a higher proportion of patients expressing positive views about the benefits of ECT if patients were asked by doctors to complete questionnaires with a limited set of simple response options in clinical settings shortly after their treatment.

The authors also noted that studies conducted by or in collaboration with patients (as opposed to being conducted by academics or researchers based in psychiatric facilities) reported lower proportions of patients expressing positive views than those conducted by academics and researchers based in psychiatric facilities. This could have been due to the fact that these studies were less likely to elicit views soon after treatment, in clinical settings, using brief questionnaires with limited response options, administered by medical assessors. There may also have been different selection biases operating in the two sets of studies.


In this sub-section we summarise some of the specific social and psychological factors that have been identified as influences on whether and how people express particular views.

- **Social desirability response bias**
Social desirability theories suggest that people will tend to give researchers the responses that they think will be acceptable and helpful to those researchers and/or to others who may learn about their responses. For example, in cultures and societies in which racism is frowned upon, an individual might be careful not so say anything that might be construed as racist.

In relation to health services research, social desirability response bias is most often thought likely to prompt service users to speak positively about health services because they think this is what is expected of them. However, if service users are asked to contribute to a study being conducted by a group that claims to be lobbying for a particular type of service change to benefit service users, they might perceive the socially desirable response to be one that is critical of current services.

Social desirability response biases might also operate in contexts in which family members, informal carers or formal care providers are likely to hear or see service
users’ responses to researchers’ questions about their health care experiences – for example if these people are present as the data are collected, are asked to take questionnaires without envelopes to a collection point, or if services users are sent transcripts or summaries of what they have said.

Box 9
Service users report higher satisfaction to service reception staff than to ‘patient surveyors’

Diane Polowczyk and her colleagues used an experimental design “to determine whether psychiatric patients would respond differently to other patients than to staff when surveyed about the care they received”.

People attending any of 14 outpatient mental health care facilities in New York state, USA, were randomly allocated to be surveyed by reception staff from the facility they attended or by patient surveyors from another facility. Both reception staff and patient surveyors had attended a two day training programme on interviewing. The survey interviews were conducted in the reception areas of the mental health care facilities.

In general, patients in both groups reported a high level of satisfaction with the services they received. The mean of the satisfaction scores for the group interviewed by patient surveyors was lower than that for the group interviewed by reception staff, and the differences were statistically significant.

The researchers identified several possible explanations for their findings. It may have been that the service users surveyed by patient surveyors were significantly less satisfied with their care, but the random allocation procedure and the demographic similarity of the resulting two groups makes this unlikely. It may be that “patients surveyed by other patients may have felt more free to reveal their dissatisfaction” or that “among peers a socially desirable response set may have been to report more dissatisfaction than was actually felt”. The fact that reception staff surveyors may have had previous contact with the patients (and that patients were likely to have future contact with them) may have made positive responses to survey questions more socially desirable among those interviewed by reception staff.

This study, and the way it was reported, had several limitations. The researchers did not describe how the surveyors introduced themselves and described the survey to potential respondents, and they did not say whether the reception staff were clearly identifiable as such (for example because of their uniforms, badges or position behind a reception desk) when they asked service users to participate in the survey. They did not say who service users thought they were being interviewed by.


• Strategic self-interest bias
The views that people express may be influenced by their strategic considerations of how what they say is likely to serve (or not) their interests. For example, people who believe they need particular health services and suspect that those services may be
under threat may be inclined refer to them positively, stress how important and useful they are in order to help ensure their continuation.

- **Ingratiation response bias**
  This may be regarded as a particular type of strategic-self interest bias. The views that people express may be shaped by their concern to present themselves in a positive light and possibly to develop good relationships with those whom they believe will hear or learn about what they say. Again this suggests that service users will tend to comment positively on services that they are likely to use again in the future if they think that service providers will hear their responses and like positive comments.

- **Cognitive consistency effects**
  There are various theories of cognitive consistency. Perhaps the most famous is Festinger’s cognitive dissonance theory. This states that if a person holds two cognitions that are psychologically (not necessarily logically) discrepant, the person will find the discrepancy (dissonance) uncomfortable and will be motivated to reduce it, either by changing one or both of the cognitions, or by introducing a new cognition. Cognitive consistency may be more important to some cultural groups than others.

  It has been suggested that people who have had or are currently having negative experiences of a service they are (voluntarily) using might, in accordance with cognitive dissonance theory, be likely to report positively about the service in order to more comfortably justify (to themselves and/or to others) their continued use of it. However, they might also address the dissonance between their negative experience and their continued use of a service by adding in a belief to the effect that there is no better alternative than continued use of the service.

- **The fundamental attribution error and the actor-observer effect**
  These two related biases apply to attributions. Attributions are beliefs (or statements) about causes. Examples include:

  My wound became infected because the nurse was careless. She hadn’t washed her hands since she looked at the person before.

  The drug trolley hardly ever comes round on time in this ward because there aren’t enough nurses on duty.

  A distinction is made between dispositional type attributions and situational type attributions. Dispositional type attributions, of which the first statement above contains an example, cite personal characteristics (e.g. carelessness) as causal factors. Situational type attributions, of which the second statement above is an example, cite broader contextual factors (e.g. a shortage of nurses) as causal factors.

  The fundamental attribution error is a tendency to underestimate the impact of situational factors and overestimate the role of personal dispositional factors as influences on people’s behaviours. This bias has been demonstrated in a number of domains. However, as the example in Box 10 suggests, there is some evidence that service users may, at least in some circumstances, be particularly reluctant to attribute problems they experience in their health care to individual care providers. They are more likely to focus carefully on mitigating situational factors when asked to account for these problems. However, this does not rule out a possible tendency for service
users to make inferences about the abilities and personalities of health care providers on the basis of their observed behaviours without taking adequate account of the context of those behaviours.

The *actor-observer effect* is the name given to a tendency for people to attribute their own actions to situational factors and other people’s actions to stable personal dispositions. This commonly observed tendency would suggest, for example, that if a patient and a doctor were both asked why the patient did not ask the doctor a question that she had previously planned to, the patient would be more inclined to refer to situational factors, such as the doctor’s intimidating manner and apparent impatience for the consultation to finish, while the doctor would be more inclined to refer to the patient’s personal characteristics, such as timidity or forgetfulness.

Neither the fundamental attribution error nor the actor-observer effect are universal or universally strong influences on the attributions that people make. Martha Augoustinos and Iain Walker have suggested that a wide variety of data are consistent with ‘weak’ forms of both the actor-observer effect and the fundamental attribution error. Their understanding is that:

[A]ttributers use *both* dispositional *and* situational factors in constructing causal sense of the events surrounding them, but tend to rely on one relatively more than the other depending on their perspective on events. While there is evidence that changing people’s point of view alters their attributional accounts of events in that view, this does not imply any hard-wired, innate, psychologically or cognitively necessary attributional mechanisms. Developmental and cross-cultural evidence suggests that people must learn the attributional accountsfavoured by their social milieu. This learning is likely to be so efficient that particular attributional accounts become automatic and unthinking."
Box 10

Initial expectations of a service may be tentative.
Service users are reluctant to criticise care providers on whom they depend

David Owens and Claire Batchelor interviewed 60 elderly people about their views of a District Nursing Service (DNS) that provided nursing services to them in their own homes on the basis of a referral from a general practitioner or hospital consultant.

The sample of service users was constructed to be representative of the population of users of the DNS in terms of gender, type of condition being treated, residence in rural or urban areas, presence of an informal carer, and use of day, evening or night services. The interviews were conducted in the service users’ own homes. They included some structured questions “to facilitate the measurement of some Health Service Standards”, but also explored people’s expectations of and satisfaction with the service in more open ways. The researchers asked the service users what they had initially expected District Nurses to do for them, to describe what the District Nurses actually did, and to identify anything that they had expected the District Nurses to do that they had not done.

The researchers identified three categories in terms of people’s initial expectations of the DNS: people who had a good idea of what to expect either because they or someone they cared for had received care from the service in the past, or because their GP or a member of hospital staff had told them what to expect; people who had little or no idea about what to expect because they had been told little more than that a district nurse would visit; and those who had misconceptions about what to expect (for example, thinking the district nurses would provide substantial social as well as nursing care). However, over the course of their care from the service – which some had been receiving for many years – all respondents had learned what to expect.

All but one of the service users interviewed expressed satisfaction with the overall care provided by the DNS. This satisfaction did not seem to result largely from the fulfilment of their initial expectations and did not necessarily imply that respondents had been fully approving of the care they received. Indeed, the researchers inferred from their data that “areas of dissatisfaction existed despite protests of satisfaction”.

The researchers noted that some respondents were reluctant to criticise or make suggestions for improving the DNS because they feared their future care would be compromised, were concerned about adding to the nurses’ workload, or did not think anything would be done as a result of what they said. They also suggested that respondents’ expressions of satisfaction were influenced by their dependence on the district nurses (who enabled them to preserve their independence in their own homes), and by their sense of loyalty to, and friendship with, nurses with whom they had often built up personal relationships over a period of time. Respondents were more willing to criticise aspects of the service that were not the nurses’ responsibility.

Source: Owens DJ, Batchelor C. Patient satisfaction and the elderly. Social Science and Medicine, 1996; 42: 1483-1491.
• **Hawthorne effect:**
  People may, consciously or otherwise, respond positively to the fact that they have
  been asked for their views and are given attention in the context of the research study.
  In contexts in which health services are asking and promising to listen to service
  users’ views, the Hawthorne effect would usually be understood to predict that service
  users’ views would be influenced in a positive direction (people might feel more
  positive about a service that seems to be interested in their views and to be intent on
  making improvements by attending to service users’ views). However, this effect
  might be negated if service users think that they are repeatedly asked about their
  views but that health services never do anything as a result.

• **Acquiescent responses**
  These are usually associated with structured questionnaires that include relatively
  long series of questions using one response format. Acquiescent responders tend to
  give the same response (or tick the response option in the same position on the page)
  for all of the questions in the series.

  Other factors that may affect people’s responses include their mood and the level of
  apprehension that they experience (some people feel anxious about participating in
  research because they associate it with being tested).

The operation of these social-psychosocial effects has not been thoroughly
investigated in relation to the expression of service users’ views about health services.
As suggested above, the influence of the different effects may vary across cultural
groups and across health care and research contexts. They may also be more or less
likely when different approaches are used to data collection.

Researchers should be aware that their own views, as well as the views of those they
study, may be influenced by social psychological factors. They need to be sensitive to
this as they collect and interpret their data, and as they present their findings. For
example, awareness of the fundamental attribution error should alert researchers to the
possibility that they might themselves be inclined to make hasty inferences about the
personal dispositions of particular service users on the basis of their observed
behaviours or responses. Awareness of the possibility of social desirability and
strategic self-interest biases should give cause to check carefully on motivations for
presenting and publishing findings in particular ways.
SUMMARY OF KEY POINTS

- Many fundamental issues regarding the working of human minds, the nature of ‘views’ and what can be known about these remain poorly understood.
- A wide range of terms have developed to describe the various phenomena that can be grouped together under the heading ‘views’. These are not always applied consistently.
- People may have a complex and dynamic set of views about a range of situations and issues. A variety of factors might influence the views that people form and the views that they express. In addition to the information about those situations and issues that is available in their particular environments, these factors include automatic information processing activity in the brain and a number of social-psychological influences that may operate ‘automatically’ and/or through conscious thought processes. This has several implications. In particular:
  - Service users’ reports about particular health service encounters will inevitably be in some senses partial and there will be limits to the extent to which either service users or researchers can ascertain what influences have shaped them.
  - Researchers and their approaches to data collection may themselves influence the views that service users develop and express.
  - Researchers’ efforts to collect and interpret data and present research findings will be influenced by factors other than the views that service users’ hold and express.
- When service users are asked to indicate agreement or otherwise with statements that researchers offer, the statements might be about issues of more or less importance to service users, and responses might or might not be indicative of prior and stable views about the matter of interest.
References


CHAPTER 3

ABOUT VIEWS ABOUT HEALTH SERVICES (I):
EXPECTATIONS, EXPERIENCES, EVALUATIONS AND PREFERENCES

It would be wise not to underestimate the complexity
of users’ responses to their health care experiences
(Carol Edwards and Sophie Staniszewska)

WHAT THIS CHAPTER INCLUDES

• There are four main sections in this chapter. They consider, broadly, the views
that service users may have as they anticipate service use (expectations), proceed
through health service encounters (experiences), assess the services they have
used (evaluations), and consider what kinds of health services they would like to
be available in the future (preferences).

• The sections consider how expectations, experiences, evaluations and preferences
for future services have been conceptualised and investigated in previous research.
They also highlight insights into factors that may affect whether and how people
express these views.

3.1 EXPECTATIONS ABOUT HEALTH SERVICES

3.1.1 Definitions and types of ‘expectation’

Most dictionaries offer several definitions of ‘expectation’. For example:

Expectation: the act or state of expecting; the prospect of future good; that
which is or may fairly be expected; that which should happen, according to
general norms of custom or behaviour; the degree of probability; the value of
something expected.2

A variety of meanings of ‘expectation’ can also be discerned in writing about service
users’ views of health services, although authors have not always been clear about
what they mean in particular contexts. The term ‘expectations’ might be used to
describe people’s beliefs about what is typical, or what they anticipate as likely,
would consider appropriate, fear, hope for, and prepare for as they approach and move
through health service encounters.

Expectations relating to health services have been categorised in a number of ways
over the years. A few illustrative examples should serve to highlight the need for
researchers to be careful to think through what types of expectation they want to find
out about, what types of expectation they might elicit in practice, and what the
implications of these might be for health services.

Richard Kravitz distinguished two broad types of expectation:3

• Probability expectations or expectancies are beliefs or judgements about the
likelihood that something will occur.
• **Value expectations** are attitudes that can be further sub-divided into expressions of desire (what is wanted); necessity (what is perceived to be needed); entitlement (what is owed to someone); normative standards (that which should be); and importance (“a hybrid category, because wants, needs and rights may all be rank ordered in importance”).

Andrew Thompson and Rosa Sunol categorised expectations as ideal, predicted and normative:

• **Ideal expectations** are aspirations, desires, preferences or wants reflecting ‘the user’s perspective of the potential for a service’. They represent what service users think might, hopefully, occur as they use a service. Statements about ideal expectations might be elicited as responses to questions such as “If you were in this situation, what would you like to happen?” or “If the service were to be provided exactly as you would like it, what would you expect in relation to…?”.

• **Predicted expectations** are beliefs about what is realistically likely to happen in practice, about what is probable. Statements about predicted expectations might be elicited as responses to questions such as “If you were in such and such a situation, what do you think would actually happen?”.

• **Normative expectations** are views about what should or ought to happen. They may be related to what people consider to be deserved, due to service users by right, or socially endorsed. Statements about normative expectations might be elicited as responses to questions such as “If you were in such and such a situation, what do you think should happen?”.

(Thompson and Sunol also proposed a fourth category, unformed expectations, which is important to note, but perhaps better considered separately (see section 3.1.3, below)).

Jennifer Janzen and colleagues have recently suggested that ideal and normative expectations should perhaps not be regarded as expectations at all but as hopes and normative preferences. They advocate that expectations should be understood as predictions about consequences that guide subsequent behaviour. They point out that there is no clear relationship in practice between these predictions and Thompson and Sunol’s ideal and normative expectations.

Whether researchers prefer to follow Janzen and colleagues and reserve the term ‘expectations’ for predictive associations, or to allow that ‘expectations’ may refer to a variety of types of views, they need to recognise that expectations might associate diverse phenomena with any of a range of conceivable consequences. Service users might develop expectations that link, for example, news about financial problems in the NHS with a cut or deterioration in quality of a particular local health service, or the care provided by particular types of health care worker with their own future health status.
3.1.2 Why are service users’ expectations important?

In general, expectations are regarded as important because they may influence how people behave and how they understand and evaluate occurrences. Service users’ expectations may influence their use (or non-use) of particular services, what they try to do for themselves as they use (or avoid using) those services, and how they experience and evaluate the health care they receive. Expectations about health-related phenomena, possibly including issues relating to the organisation and delivery of services, may also play a role in the so-called placebo response.6

In some senses, the fulfilment of service users’ expectations is one of the goals of health services. When policy makers and health service leaders aspire to develop services that are responsive to service users’ views, they might be thought of as aspiring to fulfil what in Thompson and Sunol’s terms are service users’ normative and ideal expectations - or at least those normative and ideal expectations that the policy makers and service leaders consider legitimate and achievable. However, the question of which types and which specific examples of expectation health service providers should appropriately aspire to fulfil is open to debate. While service users’ expectations about health services are sometimes regarded as unrealistic (especially if they are high and rising), it remains unclear whether the appropriate response to this is to try to modify expectations in a downward direction or to try to harness the high expectations to stimulate quality improvement.7

Health service providers who are aware of and understand the kinds of expectations that are held by the people they aim to serve, and who appreciate the behavioural implications these expectations may have, will probably be better placed to support or try to modify people’s (variable) inclinations to use services and to help themselves. For example, if service providers know that people who are about to use particular services for the first time often have negative predicted expectations based on widely held misconceptions, they might judge it important to provide information to address these misconceptions and expectations in order to improve attendance at the service and to enhance service users’ overall experiences of needing and receiving care.

It may also be important for researchers to try to elicit service users’ expectations in order to be better able to interpret and consider the implications of their reported experiences and evaluations of services. (Although there is no clear pattern of relationships between expectations, experiences and evaluations, and these are now acknowledged to be highly complex).4,8,9

3.1.3 The formation and expression of expectations

People’s expectations about particular aspects of health services, may lie on a spectrum from non-existent, through amorphous, to well-formed.3 They may be more or less confidently held and expressed, and more or less stable.

The formation and modification of expectations about health services may be influenced by a variety of factors, including people’s health concerns, their perceptions of their own and others’ capabilities and roles relating to health care
provision, their prior experiences of health services, and information about health services that they have received from other sources, including for example the mass media. Janzen et al recently proposed a model of the processes by which (predicted) health expectations are formed. According to this model, a person experiences a precipitating phenomenon that triggers a process which leads the phenomenon to be interpreted in the light of the person’s knowledge and beliefs, and compared with their experiences of similar phenomena. Cognitive processing then leads to the development of a sense of probability, a sense of temporality and a sense of causality relating to the phenomenon of interest and its possible consequences. A sense of self efficacy and perceptions of expected subjective utility develop, and then a set of goals. All these factors combine to produce an expectation.

The Janzen model has not yet been subject to rigorous critique and testing, but is consistent with its simpler predecessors in that it suggests that the formation of expectations involves both experiences and beliefs, and might be influenced at least to some extent by the provision of information.

Although most people probably have some general expectations about health services, they may lack or have only tentative expectations relating to particular types or aspects of services that they have little or no prior knowledge or experience of. The studies summarised in Box 10 (see Chapter 2) and Box 11 highlight the fact that service users often do not know what to expect from services to which they are newly referred. In another study, Sophie Staniszewska and Laila Ahmed interviewed people before a scheduled hospital admission for cardiac procedures and found that their expectations relating to their own involvement in their care were more hesitant than their expectations relating to the care that would be provided by doctors or nurses. The researchers suggested that this was not only because their involvement had probably not been discussed with them in advance, but because they were less likely to have experience of being involved in their care in hospital contexts.
Mark Avis, Meg Bond and Antony Arthur set out to explore service users’ evaluations of their first outpatient clinic appointments. They interviewed 55 people with angina before and immediately after their first appointment at a cardiology clinic, and 34 people with obstructive airways disease before and immediately after their first appointment at a respiratory medicine clinic. They also observed the consultations, asked study participants to complete a standard satisfaction questionnaire, and interviewed sub-samples of 23 people at follow-up appointments and 10 people 4-6 months after their first appointment.

Prior to their appointment, service users identified between zero and four things that they expected to happen during the appointment, but these expectations were tentative and not clearly expressed. The service users were not well informed about how the system worked. Some explained that they were wary of setting their hopes too high in case they were disappointed. Some were anxious, for example that they would be unable to communicate effectively with the consultant, and between them they had a stock of ‘horror stories’, including grossly overdue clinic appointments, being mistaken for another patient, and public humiliation at the hands of a doctor, which seemed to affect their expectations.

Immediately after their appointments, the researchers noted recurrent expressions of relief among the service users’ comments. Service users were relieved, for example, that the consultation had not been as bad as was feared, that something was being done about their problem, and that they had felt confidence in the consultant. On the satisfaction questionnaire, 85% of participants expressed satisfaction with the consultation, although some said that they were not yet in a position to express satisfaction or otherwise, as this would depend on what happened to them over the coming weeks and months. In interviews, 38% acknowledged some disappointment with the consultation, but some service users blamed themselves for disappointments, for example relating to not getting their questions answered.

After follow-up consultations, the sense of relief was absent from service users’ evaluations, which now included judgements about what had been achieved by attending the clinic. Some service users were still waiting to see what would happen as a result of the investigations and treatments they had undergone. Although they acknowledged that they were pleased with some aspects of the service, they found it difficult to separate their satisfaction with care from the progress of their treatment. Also, some were hesitant about expressing evaluations because they had limited knowledge and were not convinced that their own experiences were a sufficient basis for judgement.

Expectations often develop and change as people use health services. David Brody and his colleagues asked people awaiting a general medical consultation about a new symptom which of a number of things they considered “necessary for [their] doctor to do today”, “realizing that it is not possible for [the] doctor to do everything during a single visit”. They gave respondents a list of interventions to choose from, including performing an examination, ordering tests, educating the patient about their health problem and its management, and discussing the patient’s ideas about how to manage the health problem. After the visit, they gave people the same list of interventions and asked them to indicate what they would want if they visited the doctor again for the same set of problems. A higher proportion of people endorsed each of the interventions as necessary after the visit, and the correlations between what people thought necessary before and after the visit were only modest.

Changes in expectations over the course of service use may occur as people’s condition and understanding of their condition develops, or because they become aware of the presence or absence of features of care that they had not previously thought of, realise potential implications of aspects of care that they had not previously recognised, or are given information during the course of their care that makes them change their mind about what forms of care are desirable, likely or feasible in their case. People often emerge from health care encounters in a different position in relation to the problems that they went into the encounter seeking help for.

Service users’ expectations about particular aspects of health services are likely to vary depending on the specific situations that they have in mind when they consider them. For example, ideal expectations about the length of consultations with general practitioners might vary depending on considerations of whether or not the general practitioner is familiar with the patient and their health history, the nature of the problem the patient is consulting about, statements in the public domain about targets for consultation times, and the number of people waiting for a consultation.

The social and psychological effects on the expression of views noted in Chapter 2 might operate in a variety of ways in relation to expectations. For example, people may be reluctant to express tentatively held expectations about a service if they are concerned these might make them appear foolish, or if they believe that talking optimistically is somehow unlucky and may jeopardise the chances of things going well for them. As the study summarised in Box 11 found, expectations about services expressed prior to service use may tend to be low or pessimistic. It is plausible that anticipatory self-protective coping mechanisms might, consciously and/or unconsciously, lead people to develop less optimistic expectations about their care. This would allow them to avoid serious disappointment or regret if their experiences of care, or their outcomes, are poor.

Given that expectations are changeable, situation specific and vulnerable to various social and psychological influences in the course of their expression), researchers need to think carefully about the timing and context of any attempt to elicit them. Awareness of these issues is also likely to be important for an appropriate interpretation of the significance of people’s expectations.
3.2 EXPERIENCES OF HEALTH SERVICES

3.2.1 Definitions and types of ‘experience’

The word ‘experience’ can be used with several different but related meanings. For example, one dictionary offers:

Experience: practical acquaintance with any matter gained by trial; long and varied observation, personal or general; wisdom derived from the changes and trials of life; the passing through any event or course of events by which one is affected; such an event; anything received by the mind, such as sensation, perception or knowledge; test, trial or experiment.2

Discussions about service users’ experiences may range over a number of these meanings.14 When service users are asked to talk about their experiences of a particular service, or during a particular occasion of health service use, their narratives tend to include at least three components:

- Accounts of what happened (the ‘facts’ about ‘events’ as they saw them)

  For example:

  “The doctor told me I had cancer”

  “I asked the nurse to explain what I might expect to feel like after my surgery, and whether I could ‘phone the ward if I was worried about anything”

  “I was discharged from hospital two days after my surgery”

- Descriptions of what it was like for them (their ‘feelings’)
  These include statements about what they were aware of thinking and feeling, and how they were affected by what happened.

  For example:

  “I felt devastated”

  “I was worried the nurse was going to think I was being unduly demanding. I dreaded being labelled a ‘difficult patient’, but I really did want to know.”

  “I was glad to be going home, but a bit worried about how well I would cope”

- Interpretations, reflections and evaluations.
  These include statements and questions about the significance of particular events and experiences, and reflections on what happened and what it was like for them, including their evaluations of these and of the services they used.

  For example:

  “The doctor was very good when he told me”
“I think now that they should have just given me that information, without me having to ask for it – without me having to work myself up to ask for it. Although having said that, I think my experience was fairly typical. Perhaps they just don’t have the time or resources…”

“I think that two days in hospital was probably long enough – given that I seemed to be recovering well. But if I hadn’t have got the information it would have been too soon. I wouldn’t have known what to do…”

These different types or aspects of ‘experience’ may be more or less easily differentiated within an account. For example, a statement such as “I really trusted that doctor” might incorporate elements of all three.

3.2.2 Why are service users’ experiences important?

Policy makers have increasingly regarded service users’ experiences of health services as important in their own right and also as potential indicators of the quality of care. They have aspired to ensure that service users’ experiences are as positive as possible, and to incorporate service users’ reports of these experiences in health service audits and evaluation studies.

An understanding of any or all of the different types or aspects of experience can be useful, but they each raise particular issues and may have different kinds of significance for those wanting to learn from service users’ views to inform health policy and health service development. We consider them briefly below.

3.2.3 Accounts of what happened

Descriptions of what happens in health service encounters can be obtained from both health care providers and health service users, as well as by using observational techniques. Service users’ reports of what happens in the course of their care are increasingly elicited in the context of surveys that are used both to monitor health service performance and to identify areas for improvement. These surveys are discussed in section 3.4 so they can be seen in their historical context and as instruments for evaluating health services.

Service users’ reports of what service providers did clearly derive from a particular standpoint. There are some types and aspects of events that service users are well placed to notice, and some that they are poorly placed to recognise. Service users, like any observers, may succumb to a variety of perceptual illusions, may interpret events in ways that are heavily influenced by their prior understandings and attitudes, and may struggle to remember things clearly. In addition, some health conditions and health care interventions, including, for example, psychoses and anaesthetics, may have a dramatic impact on what service users think happened. Service users’ reports of health care processes may also be influenced by their self-perceived health status, and particularly on how this has changed as a result of health care provided. For example, Ullabeth Larsson and colleagues found that people who had undergone elective orthopaedic surgery were more likely to report that they had been involved in
the decision to undergo that surgery if the outcomes of their surgery had been positive.¹⁵

This is not to deny that service users’ accounts of what happened have value. Service users clearly have a unique – and arguably uniquely important - view of what happens in the course of their care, and it will often be important to understand this if we are to make good sense of how they experienced their care in the ‘what it was like for me’ sense and of how they evaluated their care. It is these latter senses of ‘experience’ that are often of more interest to policy makers and health service leaders who are keen to assess the quality of health care from service users’ perspectives.

3.2.4 Descriptions of what was it like

It is widely accepted that descriptions of what it feels like to be a service user in a particular situation are best obtained from people who have been service users in that situation. We seem to have privileged access to our own feelings which gives us a unique authority to describe “what it was like for me”.

Service users’ accounts of (or answers to structured questions about) their experiences are obtained retrospectively – often some time after the health care events of interest. Depending on the aims and purpose of their research, researchers may want to try to focus on service users’ experiences as they were at the time, their reflections on these experiences and whether/how they think these have changed over time, or their experiences as currently recalled. However, people may vary in their ability to make these distinctions. People differ in the extent to which they are and feel able to remember what they felt like during particular health care episodes. Memories of more recent health care episodes may be clearer than memories of those that took place longer ago, but people may still retain strong memories of events from long ago if they were significant to them. Health problems and health care incidents can be highly memorable, but they also have a significant impact on people’s self-understanding and identity, and memories of what it was like for them at one point in time are filtered through intervening experiences. When asked retrospectively about their experiences, service users may sometimes ‘remember differently’ (or forget) particular aspects of their experiences-at-the-time. Their accounts may incorporate insights acquired as a result of their reflections on, or previous discussions about, their experiences at the time. These incorporations may not be readily discernible to either the service user or the researcher.
Box 12

Relatives’ experiences of a family member’s move to a care home

Sue Davies and Mike Nolan considered the issue of the roles and the needs of family caregivers when an older relative moves to a long term nursing home. They aimed to explore family caregivers’ experiences of helping their relative to move and of continuing to support them after the move. They were particularly interested in caregivers’ views about the support that nursing homes give to family caregivers and the ways in which they encourage (or discourage) their involvement in the care of their relatives.

The researchers carried out 37 semi-structured interviews with 48 people who had helped a close relative (spouse, parent, aunt or uncle) move into a care home. They used an inductive approach to analysis.

The researchers identified five main themes among family caregivers’ accounts of how they had tried to familiarise their relative and themselves with the nursing home, establish relationships with staff, and help staff become familiar with their relatives’ and their own needs. The researchers presented these themes as continua:

- Feeling no pressure / feeling under pressure (to make decisions quickly, to conform, to conceal their own needs).
- Working together with / working apart from health and social care staff to ensure the best care for their relative.
- Feeling supported / unsupported in terms of others being concerned about their own and their relatives’ feelings.
- Being in the know / working in the dark in terms of being given information that might help them to play an active role in the life and care of their relative.
- Being in control / losing control in relation to decisions that might affect their own and their relatives’ future.

This study confirmed that a relative’s move into a nursing home can be very traumatic for family members and requires significant adjustments to changes in their relationship, caregiving role, and pattern of day to day life. The researchers stressed how the actions of health and social care practitioners have potential to make significant differences to experiences around this time. They suggest that more could be done to: prepare both residents and family caregivers for what to expect in terms of care home routines and staff roles; make use of relative’s experiences and knowledge as the resident settles in and during care planning; and ensure that family caregivers are able and encouraged to remain appropriately involved in the care of their relatives.

3.2.5 Interpretations, reflections and evaluations

People may reflect in different ways and to varying degrees on health service happenings and their own feelings about these. They may, for example, ponder whether their own experiences were more or less typical, and consider what they represent or reflect in terms of health service quality. They may be inclined to consider the causes of particular events or feelings, to allocate responsibility or blame, to think about what they would have liked to have been done differently, and to plan ‘follow up’ action. They may consider the implications of their experiences and plans, for themselves and for others.

Policy makers and health service leaders are often particularly interested in the assessments, or evaluative judgements, that people form when they reflect on their experiences of using services. These are considered in the next section (where we focus on evaluations as a type of view) and in Chapter 4 (where we consider views about particular aspects of the quality of health services).

3.3 EVALUATION OF HEALTH SERVICES

3.3.1 Definitions and types of evaluation

An evaluation can be defined as “determination or estimation of the value of something.”

Our primary focus in this section is on the evaluative judgements that service users themselves make of health services, and particularly on the concept of ‘satisfaction’ which has dominated much research in this area. However, it is important to note that other types of service users’ views are also used in evaluations of health services. For example, services are sometimes evaluated on the basis of comparisons of service users’ accounts of what happened in their care with normative views about what should happen in their care. We will return to this issue in sub-section 3.3.4.

Dictionary definitions note several meanings of the verb ‘to satisfy’ and the associated noun ‘satisfaction’. For example:

Satisfy: to pay (a debt etc.) in full; to compensate or atone for; to give enough to; to be enough for; to supply fully; to fulfil the conditions of; to meet the requirements of; to make content; to free from doubt; to convince.

Satisfaction: … the state of being satisfied, contentment; payment; quittance; gratification; comfort; something which satisfies; atonement; reparation; the satisfying of honour, as by a duel; conviction.

Some of these senses are more apparent than others in discussions of service users’ satisfaction with health services. Although it has occasionally been noted that some service users associate satisfaction with positive feelings, for example of happiness or warmth, service user satisfaction has more often been regarded as some form of evaluative judgement about services based on an assessment of what happened and what it was like for the service user.
3.3.2 Satisfaction: potential and problems

The concept of ‘satisfaction’ appeared regularly in early attempts to elicit service users’ evaluations of health services in the past, and it remains popular in some quarters. Many of the insights that have emerged as researchers have critiqued and attempted to improve on satisfaction surveys will be more generally helpful for those who seek to understand service users’ perspectives on the quality of health services.

Surveys of service user ‘satisfaction’ typically ask people to indicate how satisfied they are with their health care by choosing one from a set of response options that range from very satisfied through to very dissatisfied. They usually include a series of questions similar to those below, asking about ‘overall’ satisfaction and satisfaction with particular aspects of care. For example:

**Overall, how satisfied were you with your care during this hospital stay?**

<table>
<thead>
<tr>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

**How satisfied were you with the cleanliness of the ward?**

<table>
<thead>
<tr>
<th>Very satisfied</th>
<th>Satisfied</th>
<th>Neither satisfied nor dissatisfied</th>
<th>Dissatisfied</th>
<th>Very dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

Many such surveys have been developed and used over the past few decades,8,17,18 and they have, at least until recently, dominated attempts to elicit service users’ views about health services. This dominance can be attributed to a number of factors, including increased efforts to monitor and compare the performance of health care providers (and thus to develop quantitative summaries of service users’ evaluative views), the fact that satisfaction surveys are easy and cheap to administer, and early optimism about the range of uses to which satisfaction surveys could be put.

Service user satisfaction has been viewed in several ways in relation to the quality of health care, including:

1. as a predictor of good health care outcomes (e.g. because people who express satisfaction with their health care may be more likely to continue to attend for health care and to comply with prescribed treatment regimes);
2. as an outcome of health care provided; and
3. as an indicator of the quality of care.19

As indicators of the quality of care, satisfaction ratings have been used in various ways. For example, in the USA, where health care provider organisations compete for service users and the income these bring in, high satisfaction scores (high proportions of service users expressing satisfaction) have been publicised in health service marketing literature to encourage people to use particular services. Some
organisations set levels of reported satisfaction as audit standards or targets, and many hoped that information about the distribution of satisfaction ratings could serve as a means of identifying aspects of health care that should be targeted for quality improvement.

However, a number of problems have been identified with traditional satisfaction surveys. Questions have been raised about the appropriateness of satisfaction scores as indicators of health care quality, and satisfaction surveys have not fulfilled the potential they were once believed to hold for contributing to improvements in the quality of care from service users’ perspectives.

One problem is that satisfaction scores are almost always high. Most service users report being satisfied with their health care, even in contexts where there are known shortfalls in the quality of care and respondents are known to have found their experiences of care difficult. A number of reasons for this are explored in subsection 3.3.3.

A second problem, which is hopefully less common now than it was in the early days of satisfaction research, is that the surveys have not always asked about aspects of care that matter to service users, either because health care providers and survey developers have been interested in other issues or because service users have been deemed unable to provide meaningful evaluations of some aspects of care that matter to them (e.g. technical quality). By restricting the range of aspects of care that service users are invited to assess, some satisfaction surveys may preclude service users from expressing opinions about issues that they think warrant attention – potentially censoring service users views in the course of efforts intended to elicit them.

A third problem is that ‘satisfaction’ is not a word that service users often employ when talking spontaneously about their health care. Several researchers have noted that service users rarely refer to being satisfied or to their satisfaction when they are asked to discuss their health care experiences in the context of in-depth interviews. Service users sometimes struggle to explain what it means to them to be satisfied – although they may be quite able to identify services that they have been more or less satisfied with, and to identify what it was about particular services that lay behind their responses to questions about their satisfaction.

A fourth, and perhaps the most fundamental problem, is that the conceptual basis of satisfaction surveys, which has been challenged for over 20 years, is still not fully understood and accepted. It is still not clear what satisfaction is and what surveys actually measure, although the notion of satisfaction as, broadly, an “evaluation based on the fulfilment of expectations” has gained quite widespread acceptance.

Various theories have been proposed that postulate different causal pathways linking expectations, experiences and satisfaction. However, the empirical evidence about expectations, experiences and satisfaction that might have shed light on the relative merits of these various theories is difficult to interpret for a number of reasons. These include:

- Researchers have measured different types of expectations (often not clearly specified) about different aspects of care and at different points in time in relation to both health care experiences and assessments of satisfaction.
Researchers have, for the most part, neglected to take into account any shifts in expectations that might have occurred between the time that they were measured and the time that satisfaction was assessed.

Service users may focus on different aspects of care when they are asked to indicate their overall level of satisfaction with a particular service or health care episode, and may refer to different expectations when judging how satisfied they are with any given aspect of that service or episode (“a person evaluates or measures an experience against personal yardsticks, and feels satisfied or dissatisfied depending on how well the experience met her criteria”).

Thus the relationships between service users’ various and changeable expectations about health care, their experiences in the course of a health care episode, and their expressed satisfaction with various aspects of that episode are still poorly understood.

However, people do continue to be asked for and to provide answers to questions about how satisfied they are with various aspects of health services, so it is important to consider how and why they answer as they do – and thus how their expressions of satisfaction should be interpreted. In recent years a number of studies have investigated how service users understand and respond to questions about their satisfaction. These are discussed in the next sub-section.

**3.3.3 Why are satisfaction scores high when experiences are often poor?**

Studies of how service users go about responding to satisfaction surveys have provided useful insights that, among other things, help to explain why satisfaction surveys often find that high proportions of people express satisfaction even though we know that some of them have (at least some) negative experiences in the course of their care. Some of these studies are summarised in boxes 7 (see Chapter 2), 13 and 14.

When service users are asked to make global assessments of their overall satisfaction of health services, a few negative experiences in the context of those services may be ignored or outweighed by consideration of more positive experiences. As the study in Box 7 illustrates, service users may ignore a few negative experiences when answering questions about their satisfaction with a particular aspect of care (such as information provision) as well as with their overall care. Further support for this explanation can be claimed from the findings of a national survey of UK residents that 8% reported being dissatisfied or very dissatisfied with the quality of care they received at their dentist but 12% reported having either complained or having felt like complaining about their dentist or about the treatment they received at their dentist.

The study in Box 13 suggests service users tend to consider any ‘mitigating factors’ that might reduce the blameworthiness of health services and health care providers in situations in which their experiences of care were negative. This tendency was also illustrated in an example reported by Philip Newsome and G.H. Wright. They describe a woman who was nervous about visiting dentists. She always found her visits to dentists difficult and stressful (she evaluated her experiences negatively). However, she only blamed this on the dentist (evaluated an aspect of the service negatively) when she felt that the dentist did not care about her anxieties. When
dentists showed concern and acted with understanding and empathy, she apportioned the blame for her negative experiences to herself.

**Box 13**

**High satisfaction ratings might not reflect good experiences**

In the context of a wider study of the experiences of people seeking help from a community mental health team, Brian Williams, Joanne Coyle and David Healy asked 15 current users of the service and 8 people who had recently stopped using it to complete a standard satisfaction questionnaire and then to participate in a face to face interview. The interviews were conducted in two sections. The first was a discussion of the users’ experiences and their views of the service they had received. The second was a more structured consideration of the individuals’ responses to questions on the satisfaction questionnaire.

In the interviews, all the service users reported some negative experiences. However, many had indicated on the relevant questions on the satisfaction survey that they were either ‘satisfied’ or ‘very satisfied’ with their care.

The researchers found an explanation for this in their analysis of the interview data. As they considered what service users told them about what it had been like to use the service, they made a distinction between service users’ evaluations of their own experiences of a service and their evaluations of the service itself.

Although service users often used positive or negative value terms during the first sections of the interviews, these terms usually related to their own experiences. When they were specifically encouraged to evaluate the service (or aspects of it), they considered their experiences in the light of what they thought it was the service’s duty to do. If their experiences of using the service were negative, they considered whether the service was culpable, and whether there were any mitigating factors that might explain their experiences, before they formulated an evaluative judgement of the service.

When service users were asked to comment on apparent discrepancies between what they said in the interviews about their negative experiences of care and what they had said on their questionnaires about their satisfaction, they confirmed that when they responded to the satisfaction questions they considered their experiences in the context of their views of what the service ought to have done, and of what factors might have affected service providers’ ability to do this.

The researchers concluded that “high satisfaction ratings do not necessarily mean that patients have had good experiences in relation to the service; rather, expressions of satisfaction may more often reflect attitudes such as ‘they are doing the best that they can’, or ‘well, it’s not really their job to do…’”.


The findings of the study summarised in Box 14 suggest that people may have a relatively high tolerance for negative experiences when reporting that they are
‘satisfied’ with aspects of their care, but that negative experiences do preclude people from saying that they are ‘very satisfied’ with their care (see also Box 7).

**Box 14**

**The difference between being satisfied and being very satisfied**

Karen Collins and Alicia O’Cathain considered whether and how patients make a distinction between being very satisfied and being satisfied.

They interviewed 30 people who were participating in a randomised controlled trial comparing conventional and telemedicine consultations for dermatological problems and who had completed a patient satisfaction survey in the context of this trial. Seventeen of the people had reported being very satisfied with their care, nine had reported being satisfied, three neither satisfied nor dissatisfied, and one dissatisfied.

The interviews focused on the participants’ recent health care experiences. In the course of the discussion, participants were asked to describe what the term ‘satisfied’ meant to them, and whether there was a difference between being satisfied and being very satisfied with their health care.

Most participants were able, in the course of the interviews, to distinguish between services that they were satisfied with and services that they were very satisfied with. They used a variety of terms, including metaphors and similes, to characterise the differences. The authors identified three themes that were particularly significant in people’s inclination to describe themselves as being very satisfied rather than satisfied with their care: the perception that some kind of extra effort had been made in the delivery of their care; the sense that there had been nothing missing from their care; and the perception that their care had been better than average, or outstandingly good.

Four participants, however, did not think there was a difference between being satisfied and being very satisfied. One acknowledged that any distinction he might make between the two on a questionnaire was ‘fairly arbitrary’.

Collins and O’Cathain judged that “enough respondents to patient satisfaction surveys can articulate a difference between being very satisfied and satisfied for us to consider the implications of it”. In the light of their findings, they suggested that the common practice of merging very satisfied and satisfied responses should be stopped. They proposed that “the concept of very satisfied may itself be a standard which audit and evaluation could aim for and thus reporting of very satisfied against all other categories might be an appropriate way forward for all those undertaking future patient satisfaction surveys”.

These studies and others have thus suggested a variety of reasons why service users may tend to be reluctant to express dissatisfaction with (or otherwise comment negatively on) their care. Service users themselves may or may not be able to recognise and articulate these reasons. In addition to the psychosocial tendencies that have been observed to influence people’s expressions of their views in a variety of contexts (see section 2.3.3) there may be other influences operating in (particular) health care settings that make people less likely to express negative evaluative judgements. These include:

- **Dependence on services**
  Service users may feel highly dependent on the health services and health service providers that they are asked to assess, and may worry that these services will be reduced or withdrawn if they make critical comments about them.

- **Vulnerability to retaliation**
  Service providers have significant power over service users in some contexts. Especially in situations in which service users recognise that they need or cannot refuse services, and realise that those who provide their care could make their experiences of care very unpleasant, service users may be cautious about saying anything that their health care providers might hear and interpret as criticism.

- **Gratitude and loyalty**
  Service users in some contexts feel indebted and grateful to particular health service providers and the efforts they have made on their behalf. Gratitude and loyalty may deter them from commenting negatively, for fear this might count against or be taken personally by the individuals with whom they have positive relationships.

- **Concern not to criticise when blame seems inappropriate**
  As the study summarised in Box 13 highlighted, service users may consider the scope of what a health service’s duty is (possibly narrowly conceived) and factors that might impede service providers’ abilities to do their jobs well before they are willing to express dissatisfaction or criticism.

- **Concern not to make difficulties for health care providers**
  Service users who think that individual service providers are working hard and in difficult conditions, or who hold general beliefs to the effect that there are insufficient health care professionals for the work they are required to do, may hesitate to make critical comments that they fear would result in adding to the burdens of already over-burdened health care staff.

- **Self protection**
  Service users might consciously or otherwise avoid holding negative views about health services in the interests of self-protection. Thinking positively about health services might play an important role in promoting positive responses to health care. (See Box 15)

- **Good health care outcomes**
  Service users whose health problems resolve or improve significantly as a result of their health care may tend to comment positively on processes that might not
have been ideal, but, in the context of the good outcomes can be seen not to have had adverse consequences.32

Box 15

Psychosocial pressures to re-interpret health care experiences positively

Carol Edwards, Sophie Staniszewska and Nicola Crichton sought to explore how service users reflect on their health care experiences, and why and how they sometimes transform negative perceptions of care into positive summary assessments.

They interviewed 19 men and women of varying ages who were scheduled for elective orthopaedic surgery. Where possible, each participant was interviewed at home on three occasions: between their pre-surgical assessment visit and their admission to hospital for surgery; shortly after their discharge from hospital following surgery; and approximately three months after their surgery. The interviews were relatively unstructured: participants were encouraged to reflect on their experiences of, and opinions about, their health care.

The researchers chose to interview each person on several occasions in order to allow them to become used to participating in the project, to encourage them to be open about their experiences and feelings, to give them a chance to mention things they thought about after earlier interviews, and to allow the researchers to get some feedback on their initial interpretations of data from earlier interviews.

The researchers noted that their participants showed varying levels of reflection on their experiences. One stuck essentially to ‘bare facts’ about his treatment, while others provided a lot of interpretation in their accounts, and raised a number of questions about their care.

The interview data included numerous examples of care that participants described negatively, but proceeded to summarise more positively. The researchers examined the rationales that lay behind the positive summary assessments. They identified three interacting areas of psychosocial pressure that, at least in the context of elective orthopaedic care, tended to promote a positive re-interpretation of negative experiences: the dependent position of patients on health care providers; social etiquette (oriented to maintaining constructive social relationships with care providers, and to considering one’s own needs in relation to those of others in a broader social context); and patients’ interests in maintaining a positive outlook in general (oriented to psychological self-care). These three areas of psychosocial pressure were not explicitly mentioned by the participants themselves, but were identified by the authors as they studied the descriptions of events, expressions of apparently contradictory feelings, rationales, and re-interpretations of experiences that were evident in the interview data.

Source: Edwards C, Staniszewska S, Crichton N. Investigation of the ways in which patients’ reports of their satisfaction with healthcare are constructed. Sociology of Health and Illness, 2004; 26: 159-183.
The fact that service users who have problematic health care experiences may express satisfaction with health services because they can identify mitigating factors that tend to explain or excuse poor quality care suggests that satisfaction surveys will be of limited use in identifying aspects of health care that might be improved.

“What the user deems to be mitigating circumstances, and how he or she assigns duty and culpability among the health care team, may not reflect how the service provider would view the situation. Therefore, some of the poor care the user rationalises away in this process may be exactly what the inquirer would like to hear about in order to plan changes in practice”.1

The fact that individual service users are likely to apply different criteria and use different processes when they consider how satisfied they are with their health care means that high levels of reported satisfaction are difficult to interpret in terms of their implications for the assessment of health care performance. They are not directly and straightforwardly related to service users’ experiences of health care, and should not be interpreted as objective indicators of a good quality health service (people may report being satisfied even if the care they receive would be judged poorly against most other quality standards). Some of the factors that influence satisfaction ratings are beyond the control of the health care providers whose services are being considered.

3.3.4 Other approaches to eliciting evaluations

A number of other approaches have been used to elicit evaluations of care from service users’ perspectives.

One approach involves asking people to indicate their willingness to recommend the services to others. However, responses to questions like this are likely to be influenced by service users’ considerations of the extent to which those to whom they might recommend services have a realistic choice between services, and of the extent to which services might differ in terms of the aspects of quality that matter to them.

Another approach involves the elicitation and analysis of narrative accounts of health care experiences. This can clearly be useful when a more in-depth understanding of service users’ evaluations is required, but it is impractical for large scale assessments. Also, if they wish to access the more negative as well as the positive evaluations of care, researchers may need to pay careful attention to the ethos they create in the interview, to use judicious probing during the interview, and to look very closely at what is said, as the findings of the study reported in Box 16 suggest.
Box 16  Service users’ strategies for expressing negative evaluations

Sophie Staniszewska and Lorna Henderson sought to explore how service users express negative evaluations in the context of semi-structured research interviews about hospital outpatient visits.

The researchers interviewed people between one and three days prior to their outpatient visit (n=41), one to three days after the visit (n=37), and again within six weeks of their appointment (n=7). The interviews were conducted in the service users’ homes and the researchers emphasised that they were not employed by the hospital and were not health professionals. The researchers used generic questions such as “how did things go at your outpatient appointment?” were used to encourage service users to talk openly about aspects of care that mattered to them.

The researchers noticed that service users were able to report positive aspects of their care very easily, but were a lot less comfortable reporting direct criticisms of their care. Service users sometimes sought to check that their negative comments were acceptable and appropriate, and were careful to provide rationales or justifications for these negative comments.

In their analysis, the researchers identified four strategies that service users used to express negative evaluations of health services. They suggest that service users may:
- Indicate what they would have preferred, in comparison to what happened;
- Add provisos at the end of broadly positive accounts;
- Give detailed narratives in which negative evaluations are implicit; and
- Have spouses or partners express negative comments if they were present in interviews.

The researchers offer some methodological recommendations to facilitate service users’ expression of negative evaluations.


Yet another approach is to consider the content of complaints registered against health services or other forms of service-user ‘initiated feedback’. These can obviously provide important insights into problems that service users perceive with health services. However, only a small proportion of service users who experience significant problems and form negative evaluations of their care get as far as making a complaint to the health services they had the problem with or to other agencies set up to handle complaints about those services. Reasons for not complaining include: a lack of awareness of to whom to complain and how; the complexity of complaints procedures and the burden they place on respondents; and scepticism about whether health services would respond adequately.

The study summarised in Box 17 focused on people who had expressed dissatisfaction with health services and explored the basis for this dissatisfaction.
Box 17

The meaning of ‘dissatisfaction’ with health care:
the importance of personal identity threat

Joanne Coyle used in-depth interviews to explore the meaning of dissatisfaction with health care. Her study was linked to an earlier survey of householders and she drew a sample of 41 people from the subset of survey respondents who had expressed dissatisfaction with some aspect of health care. The sample was purposively constructed to include men and women of a range of ages, from across the spectrum of ethnic and social class groups, some of whom had and some of whom had not proactively made complaints about their experiences.

The interviews took place in respondents’ homes. The researcher used open questions to encourage people to provide detailed accounts about the problems they had experienced with health care, and whether or not and why they would describe themselves as dissatisfied.

Respondents described an average of six instances of dissatisfaction with health care. These included problems with various aspects of care across a variety of health care sectors. Coyle’s analysis of their accounts led her to identify the concept of ‘personal identity threat’ as key “for understanding the meaning of dissatisfaction with health care from the point of view of health service users”, suggesting that it “highlights the basis of people’s disappointment or dissatisfaction with health care, and helps to capture the complexity of the feelings and views expressed”.

Coyle’s paper illustrates how personal identity threats could take the form of perceptions of being dehumanised, disempowered, and devalued. These perceptions arose in situations in which, for example, health professionals broke ‘taken for granted’ rules of social interaction; treated people as typical cases, objectified them and ignored their subjective experiences of pain and discomfort; appeared to stereotype people, for example as unintelligent, infantile, incompetent, dishonest or ‘unbalanced’; or did not provide information or assistance that would have helped people to help themselves.

This study highlighted a need for health care providers to be sensitive to issues of personal value, and to understand how particular health care situations and practices can either contribute to or undermine service users’ sense of self-worth.


There are, thus, a variety of methods that can be used to explore service users’ evaluations of health services. Whatever method is used, it will be important to remember that these evaluations will depend in part on the criteria that individual service users apply and the reference points (other experiences and/or normative considerations) against which they consider their experiences.32,34
3.3.5 Assessing patient experiences for evaluative purposes

In recent years, there has been a significant investment of effort and resources into the development and validation of structured surveys of service users’ experiences of health service episodes for use in health service quality assessments.\(^{36,37}\) Patient experience surveys represent an important alternative to satisfaction surveys and other attempts to elicit service users’ own evaluations. They are used both to monitor and compare the performance of particular service providers, to help evaluate service changes, and to identify aspects of service delivery that are in need of improvement.

There are various examples of patient experience surveys. One group, based on SERVQUAL approaches,\(^{38}\) elicit individual service users’ ratings of the importance of particular indicators of health care quality (such as that health care providers keep appointments punctually, are easily accessible by telephone, show understanding about service users’ contacts with alternative medicine providers) and their assessments of how well those indicators were achieved in their care. Examples of the questions from the QUOTE series (QUality Of care Through the patients’ Eyes) include:\(^{39}\)

<table>
<thead>
<tr>
<th>Importance item</th>
<th>Not important</th>
<th>Fairly important</th>
<th>Important</th>
<th>Extremely important</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health and social care organizations and care providers whose services I use… should always take me seriously</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Performance item</td>
<td>No</td>
<td>Not really</td>
<td>On the whole, yes</td>
<td>Yes</td>
</tr>
<tr>
<td>The GP I have seen during the past year … always takes me seriously</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The most high profile example of patient experience surveys in the UK is the Picker Patient Experience Questionnaire. This has been used, in several variant forms tailored to different types of service, in the context of national patient surveys for the NHS in England, as well as in a range of smaller scale surveys.\(^{40,41}\)

The Picker Patient Experience Questionnaire was developed after a significant body of work (literature reviewing, consultation with experts in patient centred care, and focus groups and in-depth interviews with a wide range of service users) had identified the issues that mattered most to health service users in their health care encounters.\(^{42}\) The questionnaire was then drafted, tested for comprehension using cognitive interviewing techniques, redrafted, and piloted before it was used in any large scale surveys. It continues to be revised and refined for use in different contexts (see, for example Box **).\(^{43}\)
The questions on the Picker Patient Experience Questionnaire generally ask service users about what happened in the course of the health care episode of interest, although they are sometimes worded so that they ask about what happened relative to the service user’s preference. Examples include:

When you had important questions to ask a doctor, did you get answers you could understand?
1. ☐ Yes, always
2. ☐ Yes, sometimes
3. ☐ No
4. ☐ I had no need to ask

Sometimes in hospital one doctor or nurse will say one thing and another will say something quite different. Did this happen to you?
1. ☐ Yes, often
2. ☐ Yes, sometimes
3. ☐ No

Responses are coded according to whether or not they indicate that, from the service user’s perspective, there was scope for improvement in that aspect of care. For example, in the first question above, responses 2 and 3 would be coded as indicating a problem, and in the second question, responses 1 and 2 would be coded as indicating a problem.43

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**Thinking activity:**

Do you think the responses coded as indicating a problem in the above questions should be interpreted as indicative of problems in health services? Why?

**Discussion:**

In the first question, responses 2 and 3 might well be indicative of problems, but the question and response options do not allow for the possibility that patients had important questions to ask but did not ask because they did not feel able to do so.

In the second question, responses 1 and 2 might well be indicative of problems, but service users might report that one doctor or nurse said one thing and another said something quite different if their doctors and nurses talked to them about different issues without giving conflicting information or advice, that is, without the service user interpreting this as problematic.

The performance of these questions might require further investigation.

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When the same survey questions are used in surveys carried out in different countries and in repeated surveys of similar patient populations within countries, they can be used to make comparisons or monitor trends in patient experience. For example, the Picker Institute highlighted the following observations, among others, on the basis of
an overview of fifteen surveys carried out on a national scale in England between 1998 and 2004:

“Patients’ experience has improved significantly in those areas that have been the subject of central initiatives and co-ordinated action, such as hospital waiting times, cancer care and coronary heart disease. The trends are less encouraging for patients in other groups”.

“Support for carers shows some signs of improvement, but many patients still report that staff are not always available when needed to talk to their relatives”.

While these surveys can usefully identify trends and persistent problem areas in terms of patients’ experiences, the survey findings themselves cannot explain what underlies these trends or why some problem areas remain. There is plenty of scope to use the findings from these surveys to identify areas for further research.

3.4 PREFERENCES FOR FUTURE SERVICES

3.4.1 Definitions and types of preference

Preference might be understood as:

“the choice, favouring, liking of one rather than another, estimation of one above another; the state of being preferred; that which is preferred; priority”

In this section we consider the general preferences that service users express for health services in the future, and the relative priority that they are inclined to give to particular services and to particular features of service organisation and delivery. The ideal and normative expectations considered in section 3.1.1 might also be regarded as preferences.

Preferences as we are discussing them here are, or incorporate, attitudes towards possible future states of affairs. They might vary in a number of ways, for example being based on more or less accurate understandings of what particular states of affairs entail and being formulated after more or less careful consideration.

When formulating preferences about future health services, people might invoke a variety of considerations. For example, they might or might not take resource constraints into account, and they might tend to think of what is likely or good for themselves alone or for a particular community, group of services users, or population. The content of the preferences they express may vary significantly depending on these considerations. People often realise that their own preferences are not universally shared, and they might appreciate that what is best for them as an individual is not necessarily best for the broader social group(s) to which they belong.

This issue has not been well investigated and may be an important area for future research. Until it is better understood, researchers might be advised to specify a particular set of considerations before asking about people’s preferences, or to ask
service users what kinds of considerations they had in mind when they expressed particular preferences.

3.4.2 Approaches to investigating preferences

A wide range of approaches have been developed to investigate attitudes, and a reasonable proportion of these have been used to investigate preferences relating to health services – particularly to inform the setting of health care priorities.

One notable group of approaches lends itself particularly well to the investigation of informed preferences, albeit of relatively small numbers of people. This group of approaches, which includes citizens’ juries, deliberative panels, and focus groups, emphasises the involvement of service users in deliberative discussions.44,45 Some uses of these approaches have been closely aligned to policy formulation and health service planning activities.

Another important group of approaches is used to survey larger groups of people and develop quantified estimates of preference. Many of these approaches have been developed by health economists who have drawn on concepts and techniques used in more commercially orientated consumer- and marketing- research. They include various rating, ranking and hypothetical resource allocation exercises, as well as attempts to elicit individual service users’ utilities or willingness to pay for particular types or features of services. Discrete choice experiments of the kind illustrated in Box 4 have gained particularly in popularity in recent years because they have potential to explore the relative importance that people attach to different attributes of health services.

The strengths and weaknesses of these various approaches have been reviewed by several researchers recently.45-47 It is important to note that the validity of the assumptions that some of the quantitative techniques make about service users’ decision making is open to challenge (they reflect the norms of neoclassical economics).48,49,50 As the study summarised in Box 18 illustrates, some service users find it difficult to answer questions in the ways researchers expect them. Some, particularly those who are not used to paying directly for their health care, may be troubled by techniques that ask them to indicate how much they would be willing to pay for particular features of care.
Box 18

**Acceptability and validity of questions about willingness to pay for services**

Susan Taylor and Carol Armour set out to compare the proportion of useable responses they obtained with two question techniques to assess willingness to pay (contingent valuation and a discrete choice experiment). They also sought to assess the acceptability of these techniques to service users.

The researchers sent a questionnaire about different approaches to the induction of labour to pregnant women attending public sector antenatal clinics. The questionnaire included descriptions of two techniques and asked about the women’s preferences for these. It then asked them first (contingent valuation) to indicate the maximum amount of money they would be willing to pay for each of the two treatments, on a scale from AUSS0-1500, and second to indicate which treatment they would prefer in each of 18 pairs of scenarios that varied in terms of several attributes, including treatment cost. Respondents were invited to write any comments they had about the questionnaire or the information it contained at the end of the questionnaire.

68% of respondents provided valid responses to the contingent valuation question (they made a choice between the two approaches, indicated the amount they were willing to pay for each, and were willing to pay a higher amount for the preferred treatment). A further 4% of respondents indicated that they were willing to pay AUSS0 for both approaches.

72% of respondents provided valid responses to the discrete choice experiment (they did not make a particular choice that would have been irrational given their other choices, and they completed at least 15 of the 18 scenarios). 59% of respondents completed both willingness to pay exercises successfully.

In their comments on the questionnaire, some women expressed an objection to questions that asked service users how much they were willing to pay, because they were committed to publicly funded health care or were concerned about what they or others could afford. Some found it difficult to put a monetary value on health care procedures and benefits. Comments about the discrete choice evaluation scenarios were mixed: some found them interesting, while others found them repetitive or difficult to complete, and became concerned about the possibility that they had given contradictory answers.


### 3.4.3 The issue of ‘conservative’ preferences

A number of studies have shown that people tend to be conservative in their preferences relating to health services in the sense that they are more likely to express preferences for services or aspects of services that they have previously experienced than for services or aspects of services that they have not previously experienced.
For example, as described in Box 19, Maureen Porter and Sally MacIntyre found that pregnant women tended to be more negative about innovations in the organisation and delivery of antenatal care until they had experienced those innovations.\(^5\) 

**Box 19**

**Preferences about services are often conservative**

In the context of an evaluation of new schedules for the organisation, delivery and content of antenatal care visits, Maureen Porter and Sally MacIntyre interviewed 232 pregnant women about their antenatal care and particularly about their responses to the innovations recommended in the new schedules. The interviews were conducted by sociologists in the women’s homes when the women were 36 weeks pregnant. They involved structured questions (most with fixed response options).

Over 80% of the women expressed satisfaction with their antenatal care overall, and most of the remainder reported ‘mixed feelings’ rather than dissatisfaction. Levels of reported satisfaction were similar among women who received most of their antenatal care from their GP and women who received most of their care at the hospital. However, the complaints women made about antenatal care experiences and the suggestions they made for improvements tended to focus on hospital care.

The researchers analysed women’s expressed preferences for different aspects of care in relation to whether or not the women had experienced those aspects of care. They consistently found that women who had experienced particular aspects of care were more likely to express a preference for those forms of care than women who had not experienced them. For example, among women who had received antenatal care from their GP, those who had attended special antenatal clinics were more likely to express a preference for special antenatal clinics than those who had received their antenatal care during ordinary GP surgery times. Women who had seen only one GP in the course of their antenatal care were more likely to express a preference to see the same GP at each visit than women who had seen several GPs for their antenatal care.

The researchers focused on three innovations in the new antenatal schedules: seeing a midwife instead of a doctor; not undressing at every visit; and not being palpated at every visit. They asked women who had experienced these innovations what they had felt about them, and women who had not experienced them how they thought they would feel about them. In each case “those who had not experienced the innovation were considerably more negative about it than those who had”.

The researchers suggested that women were inclined to accept the status quo of the antenatal service they received, tending “to assume that whatever system of care is provided has been well thought out and is therefore likely to be the best one”.


Although this study was conducted over twenty years ago and it is possible that service users are now less likely to “assume that whatever system of care is provided has been well thought out and is therefore likely to be the best one”, more recent
studies have found a similar tendency for the distribution of expressed preferences for particular forms of care to reflect patterns of receipt of those forms of care.

For example, Mandy Ryan and colleagues reported that people who experienced the introduction of a patient health card in the context of a randomised controlled trial valued this significantly more than those who did not experience it.\textsuperscript{52} Glen Salkeld and colleagues found that people who had previously used a particular bowel scan test kit (BowelScan) demonstrated a preference for this current kit over other hypothetical kits.\textsuperscript{53} In their discrete choice experiment, the kit that the respondents had experience of using was labelled BowelScan, and its attributes were described consistently in each of the 16 choices that people were asked to make. The options with which service users were asked to compare this, which had various attributes, were labelled Bowel Test. People chose BowelScan significantly more often, even when differences between the attributes of the kits were controlled for.

Within the general economics literature, the fact that experience of an attribute may lead respondents to value this attribute more highly has been called the ‘endowment effect’ or ‘status quo bias’. Suggested explanations for it include: aversion to loss; attempts to minimise feelings of regret and disappointment; having less information about the alternatives; and not considering the alternatives to be realistic.\textsuperscript{54} The question of which of these explanations apply in different health care contexts has apparently been little explored. Other explanations may also arise in this context. For example, as the study by Porter and MacIntyre suggests, people may have a preference for familiar rather than novel experiences.

People may also tend to express preferences for the types of service that are currently \textit{available} to them, whether they have personally used them or not, as the summary in Box 20 suggests.
Preferences for care may be influenced by the model of care on offer

Vanora Hundley and Mandy Ryan designed a study to consider the question of whether women using systems of maternity care with particular attributes (such as continuity of carer) value these attributes more highly than women for whom the attributes are not currently a realistic option.

They identified three geographic areas in which the organisation of maternity services differed, particularly in terms of continuity of carer. They asked women attending a booking visit for maternity care in each of these areas to complete a three-part questionnaire. In the first part, women were asked to indicate their preferences for different levels of each of six aspects of care during childbirth: continuity of midwife carer; types of pain relief available; type of fetal monitoring used; physical appearance of the birth setting; involvement of medical staff; involvement of women in decision-making. They were then asked to rate the importance of each of these six aspects of care. In the second part of the questionnaire, women were asked to complete a discrete choice experiment, choosing one from each of eight pairs of descriptions of maternity services that differed in terms of the six aspects of care. The third part of the questionnaire asked for demographic data.

Of 301 women who responded, about two thirds rated continuity of carer as a very important aspect of care, and about 15% said it was the most important of the six aspects of care considered. Most women expressed a preference to have a midwife who they had met during their pregnancy be with them throughout labour and delivery. However, women in the area with least continuity of carer were less likely to express a preference for having one midwife whom they met during pregnancy care for them throughout labour and delivery. This difference was statistically significant. The findings from the discrete choice experiment suggested a similar trend (women from the area with greatest continuity of carer seemed more likely to choose services with higher levels of continuity), but the differences were not statistically significant.

One possible explanation for the finding was suggested by an unsolicited comment that one respondent added to her questionnaire: that people might be less likely to express preferences for services that they do not think are realistic. As the authors note, further qualitative research, perhaps using verbal protocol analysis techniques, would be useful to explore what respondents are aware of as influencing their state preferences and choices.

Source: Hundley V, Ryan M. Are women’s expectations and preferences for intrapartum care affected by the model of care on offer?, 2004; 111: 550-560

These studies highlight the possibility that efforts to ensure that local people’s preferences are reflected in health service planning decisions may tend to perpetuate differences between health care systems in different localities – and thus possibly to increase inequalities in access to high quality care. Researchers and policy makers need to consider such possibilities carefully when making recommendations as to how service users’ views should be gathered, interpreted and used in decision making about the future of health services.
SUMMARY OF KEY POINTS:

- ‘Expectations’ have been defined and categorised in various ways. On a broad interpretation, they may include what people think is likely to happen, what they hope will happen or what they think ought to happen. On a narrower interpretation, they include only what people predict will happen.
- The formation and implications of expectations remain poorly understood, but it seems that people may have few and low specific expectations of services they have little experience of.
- Service users’ accounts of their ‘experiences’ of health services may include statements about what happened and what it was like for them. They may also incorporate interpretations, reflections and evaluative judgements.
- Attempts to elicit service users’ own evaluations of health services have traditionally focussed on ‘satisfaction’. Satisfaction is still poorly understood, but it is generally thought to represent an evaluation based in some way on the fulfilment of expectations.
- A number of problems have been identified with patient satisfaction surveys, including the fact that most people report being satisfied even if they have some negative experiences.
- There are several reasons for high levels of reported satisfaction. People may have low expectations of services. Also, when responding to questions about their satisfaction, they may
  - make global assessments that ‘override’ a few negative experiences
  - consider possible reasons for their negative experiences and express satisfaction if they think service providers are ‘doing the best they can in the circumstances’
- Surveys of patient experiences are increasingly used as an alternative to surveys of patient satisfaction in attempts to assess health service quality. Patient experience surveys ask people about specific occurrences in the course of their care.
- A range of techniques have been developed to examine service users’ preferences for future service provision. These include deliberative group discussions and survey techniques that allow larger scale quantitative assessments of preference.
- Some of the techniques for preference assessment that have been developed by economists allow researchers to quantify the relative importance of different health service attributes to service users. However, the validity of the assumptions that underpin these techniques has been questioned.
- People are more likely to express preferences for service features that they have previous experience of or that are available locally. Efforts to reflect local preferences in health service planning may thus tend to support the status quo.
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CHAPTER 4:

ABOUT VIEWS ABOUT HEALTH SERVICES (2):
ASPECTS OF HEALTH SERVICES AND HEALTH CARE QUALITY

WHAT THIS CHAPTER INCLUDES

- An introductory section that considers:
  - the distinction between health service structures, processes and outcomes; and
  - the concept of quality in health care
- A section that considers how studies of service users’ views can contribute to efforts to define and assess health service quality
- Two sections that focus on particular aspects of health care quality (continuity of care and patient involvement in decision-making) and illustrate:
  - The potential for differences between service users’ and health care providers’ understandings of concepts of health care quality
  - Issues that arise in attempts to assess health care quality on the basis of service users’ reports.

4.1 INTRODUCTION

Research projects that examine service users’ views often focus on particular aspects of health services, addressing questions such as:

- Which of two possible configurations of accident and emergency services would city residents prefer and why?
- What do people with asthma think of the care provided by nurse specialists as compared with the care provided by family doctors?
- How does the introduction of a new appointment booking system impact on service users’ perceptions of the accessibility of a service?
- From parents’ perspectives, how ‘family centred’ is the care provided on paediatric oncology wards?

Service users may be more or less well placed to express views on particular aspects of health services. As we will discuss in this chapter, their views are in some senses products and parts of what health services do and achieve.

We will use a conceptual framework developed by Avedis Donabedian to help organise our thinking about different aspects of health services and service users’ views about these. Although other conceptual frameworks have been developed, Donabedian’s work on health care quality has been particularly influential and can serve well to highlight key issues relating to the study of service users’ views. In the following sub-sections, we review the distinction Donabedian made between the structures, processes and outcomes of health care, and then turn to the account he gave of health care quality.
4.1.1 Health care structures, processes and outcomes

In making his now famous distinction between structure, process and outcome in relation to health care, Donabedian defined them as follows:¹

- **Structure** is “the relatively stable characteristics of the providers of care, of the tools and resources that they have at their disposal, and of the physical and organisational settings in which they work”. Structure also includes health service financing arrangements.

- **Process** comprises the “set of activities that go on within and between practitioners and patients”. It includes, for example: the making of appointments and referrals; thoughts, discussions and exchanges of written information relating to the patient’s care; and the administration of tests and treatments.

- **Outcome** is the “change in a patient’s current and future health status that can be attributed to antecedent health care”. Donabedian used a broad definition of health that included social and psychological functioning and also “patient attitudes (including satisfaction), health-related knowledge acquired by the patient, and health-related behavioural change” which, he argued, can all be seen “either as components of current health or as contributions to future health”.

Structure, process and outcome are related because the structural characteristics of care tend to influence the process of care, and changes in the process of care influence outcomes. However, the distinction between them is not as clear cut as it may first appear, and it can be difficult to classify some phenomena exclusively under one of the three headings. As Donabedian explained, “This is because the three part division is a somewhat arbitrary abstraction from what is, in reality, a succession of less clearly differentiated but causally related, elements in a chain that probably has many branches. In such a chain, each element is, at least to some extent, a cause of the element that follows, while it is itself caused by the elements that precede it.”¹

Whether we regard a particular link as a process or an outcome depends on which stretches of which branches of the chain we look at.

The structure-process-outcome framework is, of course, not the only one that can be useful in the context of health services research. Another framework that is used particularly for evaluations of social programmes treats the outcomes of an intervention as the product of the context into which the intervention is introduced and the mechanisms by which it works in that context.²

4.1.2 Health care quality

Most people would readily agree that the quality of health care matters, but it is harder to reach a consensus about just what matters for health care quality. Quality is a complex concept that is tricky to define. However, if we are to communicate effectively about it and make comparable judgements about the quality of different health services, we need some kind of agreement about the attributes of quality and
about criteria and standards for assessing whether and to what extent particular services have these.

Donabedian regarded quality as property that health care could have in varying degrees. He outlined three broad approaches for identifying and defining its attributes:

- An ‘absolutist’ approach based on (relatively narrow) professional definitions of health status, professional knowledge of what different health care interventions contribute to health status, and professional judgements of how the contribution of health care interventions should be measured.
- An ‘individualist’ approach that takes into account each patient’s objectives in seeking care, their judgements of what contributes to their welfare and their valuations of services provided.
- A ‘social’ approach that aggregates the factors identified using the individualised approach and additionally considers the social distribution of health care benefits.

There are advantages and disadvantages to each of these approaches. Definitions of quality derived using any of them may be more or less useful depending on the aspects of health services and the kinds and groupings of service users that are of interest.

Drawing to some extent on each of the three broad approaches to defining quality, Donabedian proposed seven key attributes of health care quality:

- Efficacy: the ability of care, at its best, to improve health;
- Effectiveness: the degree to which attainable health improvements are realized;
- Efficiency: the ability to obtain the greatest health improvement at the lowest cost;
- Optimality: the most advantageous balancing of costs and benefits;
- Acceptability: conformity to patient preferences regarding accessibility, the patient-practitioner relation, the amenities, the effects of care, and the cost of care;
- Legitimacy: conformity to social preferences concerning all of the above; and
- Equity: fairness in the distribution of care and its effects on health.

Other sets of key attributes have also been proposed subsequently. For example Robert Maxwell modified the above list by removing efficacy, optimality and legitimacy and adding access and appropriateness. Others have since suggested extending Maxwell’s list, for example by adding respect, choice, availability of information and technical competence. More recently, the (United States of America) Institute of Medicine produced a list of six dimensions of quality that health services should urgently attend to. It argued that health care should be:

- Safe – avoiding injuries to patients from the care that is intended to help them.
- Effective – providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and overuse, respectively)
- Patient centered – providing care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions.
- Timely – reducing waits and sometimes harmful delays for both those who receive and those who give care
- Efficient – avoiding waste including, for example, waste of equipment, supplies, ideas and energy
- Equitable – providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location and socio-economic status.

There is clearly a reasonable consensus about some of the kinds of properties of health care that belong in what we might call the major league lists of quality attributes. However, these properties are complex and they can be conceptualised and operationalised in different ways. For example, a number of conceptions of patient centred care have been evident in discussions and in research, and assessments of the patient centredness of the same health care consultations have been found to vary depending on the measures that are used. This is not surprising if we think about the various questions we might ask about a service in order to form a judgement about its patient centredness. The outline definition provided in the Institute of Medicine’s list suggests a need to consider whether care was (a) respectful of and (b) responsive to individual patient preference, needs and values, and also whether patient values guide clinical decisions. Attempts to consider these raise further questions, for example about what it means for care to be respectful of individual patient preferences, needs and values, and about how we might ascertain whether patient values have guided clinical decisions.

In addition to the properties that feature in the major league lists, a number of other attributes might be important to judgements of health care quality, and these may stand in various relationships to the major players and to each other. For example, family centredness may be regarded as either an extension of or an alternative to patient centredness, and the respectfulness that was mentioned above as a component of patient centredness might be regarded as a quality attribute in its own right. In practice, efforts to improve health services on some attributes may conflict with efforts to improve them on others. For example, considerations of effectiveness and efficiency might suggest that accident and emergency departments should be concentrated in large units, but considerations of access, acceptability, equity or timeliness might suggest smaller local services would be preferable.

Before we focus more specifically on the roles that investigations of service users’ views play in efforts to understand and assess health service quality, we should briefly note how quality relates to structure, process and outcome. Because he regarded quality as a property that health care might have to a greater or lesser degree, Donabedian thought that health care quality assessment should focus primarily on the process of care. However, he stressed that the basis for the judgement of health care quality lay in the relationship between process and outcome, and he thought that information about both the structure and the outcomes of health care could also serve to provide indirect assessments of quality – with information about outcome usually being the more useful of the two. Other authors have had different ideas – there is an ongoing debate about whether in particular circumstances it is more appropriate to assess whether health services are doing what they should (complying with normative views about structures and processes) or to monitor what health services are achieving and give more or less recognition to the fact that what we usually consider to be health care outcomes are not solely and entirely attributable to health service activity.
4.2 SERVICE USERS’ VIEWS AND ASSESSMENTS OF HEALTH CARE

Service users’ views about health services may usefully contribute to quality assessment in a number of ways, including:

- The development of understandings of what makes for quality in health services (what we identify as attributes of quality, how we conceptualise and operationalise these, and how we rate their relative importance)
- The practical assessment of health care quality (when service users’ ratings or reports are used to monitor or evaluate services or service changes, or in the context of studies designed to investigate the relationships between different aspects of health services, including quality variables).

We consider issues that arise in the context of each of these separately in the next two sub-sections.

4.2.1 Service users’ contributions to definitions of quality

Health service quality attributes are complex constructs that might be conceptualised and operationalised in a variety of ways. Particular conceptualisations and approaches to measuring these attributes might be more or less compatible with, and more or less accommodating of, service users’ own ideas about them.

Researchers have several good reasons to be interested in how service users identify and conceptualise quality attributes. First the ‘individualised’ approach to identifying quality attributes that was outlined by Donabedian is increasingly recognised as important, particularly in relation to the less technical aspects of health care. Second, service users’ experientially informed conceptualisations of quality attributes may differ from those of health service providers and researchers and may be quite revealing of matters of importance in the delivery of care. Third, if researchers ask service users to report on services in terms of particular quality attributes but are unaware of the meanings that service users attach to quality attribute terms, their interpretations of service users’ reports may be misleading.

Investigations of service users’ understandings of quality attributes may take a variety of approaches, including, for example, asking direct questions about the meanings of terms, asking for examples of situations in which a quality attribute had or had not been judged to be present, and asking for reflection on other people’s suggestions about a quality attribute. The study summarised in Box 21 used a number of these approaches (see also Box 24).
Box 21  

What makes for personal care?

Carolyn Tarrant and her colleagues aimed to explore (a) patients’ and health care providers’ perceptions of the features of personal care in general practice contexts; (b) whether a continuing provider-patient relationship is essential for care to be personal; and (c) the circumstances under which a continuing provider-patient relationship is important.

The researchers interviewed a demographically mixed sample of 40 patients recruited from 6 general practices as well as 13 GPs, 10 practice and community nurses, and 6 practice administrative staff. They sought to explore the meaning, value and priority that respondents gave to personal care in the context of their own experiences. They also investigated the factors that facilitated or inhibited personal care. The researchers checked their initial interpretations of their data by running focus group discussions with patients and general practice staff, asking participants to discuss statements relating to the identified themes and to give examples of any opposing beliefs.

The researchers identified three main features of personal care from participants’ accounts: human communication (good interpersonal skills on the part of the provider, evidence of empathy, and the perception that providers listened and ‘had time’ for the patient); individualised or tailored care (appropriately reflecting differences between service users); and holistic care (taking the patient’s family and social circumstances into account). The three features were evident in the accounts given by each of the participant groups, but patients focused particularly on human communication.

Although they usually described personal care in the context of a continuing provider-patient relationship, both patients and providers indicated that personal care could occur in the context of a single consultation with an unfamiliar provider (if, for example, they had a pleasant manner, didn’t rush, and spoke to the patient in a way that made them feel at ease), and in the context of the practice as a whole.

Some continuing relationships were not perceived to include personal care. If a care provider who was seen on multiple occasions did not refer back to and build on previous consultations, or if the patient did not feel they were being responded to appropriately, a continuing relationship was not associated with personal care.

A continuing relationship was considered important for making care personal if such a relationship had already been established (patients with such relationships emphasised their importance more) and if the consultation was about a complex, emotional and/or long term problem. Patients who saw themselves as busy or had chaotic lives were less likely to see a continuing relationship as necessary for personal care.

4.2.2 Service users’ assessments

Some health care processes and outcomes, and some attributes of health care quality, are best assessed from service users’ perspectives. Indeed some, such as patient satisfaction, can only be assessed via self-report. However, service users’ views about particular aspects of health care may not always be easy to obtain and their reports may be of limited use in some contexts and for certain purposes. In this sub-section, we consider:

- Whether and to what extent service users can and do focus on the particular aspects of health services that researchers ask them to
- The notion that service users’ views about particular aspects of health care are themselves parts and products of health care activity.
- The extent to which service users’ reports relating to health care quality attributes may be influenced by service users’ interpretations

**Focusing on particular aspects of health services**

Researchers often ask service users to focus on particular health care structures or processes. They might ask them to answer questions about particular organisations or services (e.g. mental healthcare partnerships, community pharmacies, the labour ward on which you gave birth, the fracture clinic you attended), particular professional groups (e.g. clinical nurse specialists, homoeopathic practitioners, psychiatrists), particular features of health service environments (e.g. car parking facilities, reception areas, hospital wards) particular systems (e.g. the system they have for calling patients from the waiting area to an assessment room, the way they give you the results of tests when these come back from laboratories) or particular episodes of care or health care encounters (e.g. your most recent hospital stay, any visits to the general practitioner you have made within the last year).

It is important to consider whether and how well service users can and do maintain a focus on the particular structures and processes (and consider the particular time frames) that researchers ask them about. Some service users might not be able to distinguish between particular types of organisation or health professional. For example, young mothers may have had no need to notice a difference between the general practice that they registered with so they could see a family doctor and the larger primary care organisation of which that subsequently became a part. Older people who are hospitalised with hip fracture might not be told or might not remember which of the various people who came to see them on the ward was the physiotherapist and which was the occupational therapist. People who consult several clinicians (or the same clinician on several occasions) about a long term health condition might not be able to recollect precisely in which consultation they were given a particular item of information. Even when service users can make these kinds of distinctions, the question remains of how consistently and persistently they can and will maintain a focus on the ‘correct’ one(s) if they are asked to give an account of their experiences in relation to a particular one, or to answer a series of questions about it on a questionnaire.

Sometimes, researchers’ assumptions (or the assumptions that are built into their questions and response options) do not give service users sufficient scope to distinguish between the care they have received from different service providers and
on different occasions. For example, as the study summarised in Box 26 illustrates, when asked to comment on the process by which a particular treatment decision was made, service users might need to consider discussions that occurred with several different health professionals at several different times. This highlights a need for researchers to be careful about assuming, for example, that the health care processes they are interested in are (from service users’ perspectives) completely and consistently contained within particular consultations or episodes of care.

**Service users’ views as parts and products of health care activity**

It is worth noting that service users’ views about the structures, processes and outcomes of care might also be regarded as among either the processes or the outcomes of care. For example, people’s thoughts about the different hospitals that they might go to for a hip replacement operation (which might include thoughts about the processes in place at those hospitals and the outcomes those hospitals achieve for hip replacements) can be regarded both as processes of health service use and as outcomes of (among other things) what people are told about the hospitals by their general practitioners and in information materials from other health service sources. (Similar observations can be made in relation to other evaluation frameworks. For example, in Pawson and Tilley’s framework, service users’ views might form part of the context into which a programme intervention is introduced, may feature among the mechanisms affecting how it works, and may serve among the indicators of its outcome). This has important implications. Researchers need to think carefully about how they want to consider and use service users’ views about particular aspects of care, and to select study designs and methods that will allow them to do this.

**Service users’ quality assessments depend on their interpretations**

When we recognise that service users’ views (as well as their behaviours) contribute to the processes of health care and are thus bound up in the generation of health service quality, we have to accept that attributes of health service quality may to a greater or lesser extent be influenced by service users’ interpretations. Service users’ interpretations will often be to a large extent outside a service provider’s control and this has important implications for the judgements that can reasonably be made of health services. Researchers may need to reflect on or investigate carefully the relationship between service users’ reports of their experiences or evaluations of care and what health services do.

To illustrate the issues discussed in this section, the next two sections present and discuss examples of research that has considered service users’ views in relation to two concepts that are often regarded as attributes of health care quality: continuity of care and patient involvement in decision making.
4.3 EXAMPLE 1: CONTINUITY OF CARE

‘Continuity of care’ is widely agreed to be a valued feature of health care that is not achieved as often as would be liked, and is therefore in need of attention.10 However, ‘continuity of care’ has not always been clearly or consistently conceptualised.

Thinking activity:

What does ‘continuity of care’ mean to you?
In what kinds of contexts is continuity of care an issue?
How might you recognise continuity of care if you saw or experienced it?

Discussion:
‘Continuity of care’ has been viewed and defined in a variety of ways, and different issues relating to continuity of care have been emphasised in work relating to different groups of service users and different types of health and social care settings. Attention has been paid in particular to problems with the continuation and consistency of care in situations in which service users are transferred from one health care provider organisation to another, or more generally when they receive care from several different health care professionals and organisations.

Recognition of continuity of care is likely to require a good awareness of what is and what has been going on in the care of particular individuals. It might be based on judgements of persistence and/or congruence of a variety of health care structures and processes.

Jeannie Haggerty and her colleagues undertook a comprehensive review of published accounts of continuity of care with a view to developing a common understanding of the concept.11 They identified two core elements that they deemed necessary although not sufficient for this understanding: continuity of care involved care of an individual and care over time. They argued that continuity should be seen not as an attribute of health service organisations and what they do, but as “how individual patients experience integration of services and coordination”.

Haggerty and colleagues identified three key types of continuity:

- **Informational continuity**
  This involves the use of information about an individual service user’s health problems, past care events, personal circumstances and preferences.

- **Management continuity**
  This involves the application of a consistent and coherent approach from all health care providers in a way that is responsive to an individual service user’s changing needs.

- **Relational continuity**
  This involves an ongoing therapeutic relationship between an individual service user and one or more health care providers.
They note that it may be appropriate to place more emphasis on the different types of continuity for service users in different situations. For example, management continuity is particularly important for service users with several chronic health problems who receive care from multiple professionals working for different health care organisations. The study summarised in Box 22 suggests that relational continuity may be particularly important for women from ethnic minorities as they go through pregnancy and childbirth.
Christine McCourt and Alison Pearce were concerned that women from minority ethnic groups had been under-represented among respondents to a questionnaire about experiences of care during pregnancy and childbirth. They therefore sought to interview women from these groups about their experiences.

The questionnaire had been sent as part of an evaluation study that compared caseload midwifery (which gives individual midwives responsibility for the care of particular women and thus gives women more continuity of carer) with the arrangements for care during pregnancy and childbirth that were then conventional. The researchers recruited to the interview study 20 women who had received conventional care and 20 who had received care from midwives working under caseload arrangements. The semi-structured interviews were conducted in English, but interpreters were offered (and were used by two women).

The researchers found that all of the women valued good communication, support and a sense of control in relation to decisions about pregnancy and birth. The experiences of women who received one-to-one care under caseload midwifery arrangements had been more positive in these respects than those who received conventional care.

In their accounts of the birth experience, women who received conventional care tended to focus on their pain and described feelings of fear and distress. In contrast, women who received one-to-one care gave more positive accounts. They referred to feeling supported and relaxed, and linked this explicitly with their knowing and being known by the midwife.

The caseload midwifery system seemed to facilitate good communication (women developed trust in their midwives and felt able to ask questions). The women who experienced it developed a sense of being cared for as a person by someone who got to know them and to understand their needs, and who was thus able to offer help congruent with their individual needs and expectations.

The researchers suggested that continuity of midwife “underpinned the woman-centred care” that was important to ensure good communication, support and a sense of personal control. They stressed that these features of care were valued by women from minority ethnic groups just as they are by women from the ethnic majority. They suggested that continuity of carer could be more important for women from ethnic minorities because under conventional care arrangements they tend to experience more problems with communication and control, and a greater dissonance between expectations and experiences.

When reviewing the literature, Haggerty and colleagues found that most previous attempts to assess continuity of care had focused on chronological patterns of care “without directly measuring experienced continuity or those aspects of care that translate into connected and coherent care”. This did not reflect their view that attempts to assess continuity of care should focus primarily on individual service users’ experiences.

The summary in Box 23 describes the development and piloting of a measure that aims to assess continuity of care from the perspective of people with diabetes. The summary illustrates how the meanings that service users attach to phrases such as ‘continuity of care’ may differ from those that prevail in current policy and research literature. It also suggests that attempts to assess particular attributes of quality might need to focus on different types of health care structure and process in different health care settings. In this particular study, the authors found that issues relating to self-care might be important in attempts to assess continuity of care for people with chronic health care conditions.
Lisa Dolovich and her colleagues developed and pilot tested a questionnaire scale to assess continuity of care from the perspective of people with diabetes. They were careful to ensure that the scale covered issues that people with diabetes considered important in relation to continuity of care.

To generate potential items for their scale, the researchers ran 7 focus groups with people with diabetes and 2 with health care providers. Participants discussed what continuity of care meant to them and researchers then gave them a definition of continuity of care as consistent and continued care and asked participants to describe their experiences of good and poor examples of this.

The researchers used transcripts of the discussions to identify issues relating to continuity of care that might be included in a questionnaire. They reduced their original list of 777 potential items by looking for items with similar concepts and deleting duplicates. For each of the 76 items remaining they wrote either a positively or a negatively phrased declarative statement. Questionnaire respondents were asked to indicate their agreement or otherwise with these statements using the options strongly agree, agree, no opinion, disagree or strongly disagree.

The researchers tested the face validity, readability and content validity of these initial questions by: asking five people with diabetes to explain the meaning of the statements; asking four diabetes experts to comment on their clinical sensibility; asking two health educators to comment on the language and readability of the questionnaire; and checking readability using a computerised programme. The number of questions was then reduced from 76 to 56 and the 56 items formed the preliminary version of the Diabetes Continuity of Care Scale (DCCS).

To test the construct validity and discriminative ability of the scale, and to guide the identification of its main domains, the researchers asked 60 people with diabetes to complete a questionnaire that contained the 56 DCCS questions and questions from other scales designed to measure continuity of care, satisfaction with care, and the effectiveness of diabetes management. To test the reliability of the scale, they asked the same 60 people to complete the DCCS again 2 weeks later.

Many of the concepts that people with diabetes identified with continuity of care were congruent with concepts that had previously been discussed in the literature. However, the patients also emphasised self-care and self-responsibility as integral parts of continuity of care. These issues were represented among the DCCS items, and self care emerged as one of the five main DCCS domains (the others were: care by doctor; care by other health professionals; access/getting care; and communication between health professionals). The scale had sufficiently good psychometric properties to warrant further investigation.

Source: Dolovich LR, Nair KM, Ciliska DK et al. The Diabetes Continuity of Care Scale: the development and initial evaluation of a questionnaire that measures continuity of care from the patient perspective. Health and Social Care in the Community, 2004; 12: 475-487.
Conceptually, self-care issues can probably be incorporated within the three types of continuity identified by Haggerty and colleagues if service users themselves are understood to be included among their health care providers as well as being the focus of health care providers’ attention.

The recognition that service users’ perspectives are particularly important for assessments of continuity of care, and that their conceptualisation of continuity of care may differ from that of health professionals, does not mean that health professionals’ perspectives are unimportant. Health professionals may also experience more or less continuity as they provide services, although in a different way to service users.

For providers, the experience of continuity relates to their perception that they have sufficient knowledge and information about a patient to best apply their professional competence and the confidence that their care inputs will be recognised and pursued by other providers.11

It is possible that service providers may be less able to ensure that service users experience continuity of care if they do not do so themselves. In order to test this hypothesis, researchers would need to design a study in which health care professionals’ experiences of continuity were measured among the independent variables and service users’ experiences investigated as dependent variables.

### 4.4 EXAMPLE 2: PATIENT INVOLVEMENT IN DECISION-MAKING

The involvement of patients in decisions about their health care is now widely regarded as a feature of good quality health care.6,12 Its status as an attribute of quality has been argued for using both ‘individualist’ and ‘absolutist’ type approaches: it is treated as valuable in its own right because it is important to patients and as instrumentally valuable because it is thought to contribute to improvements in more narrowly defined health status. However, there is no clear consensus about what it means for patients to be ‘involved’ in decisions about their health care, what might count as ‘good’ patient involvement, or whether the appropriateness of different possible forms of patient involvement might vary across different health care situations or according to individual patients’ preferences. It is unclear which forms of involvement matter most to service users and it is unclear which of the health care processes that might contribute to a judgement that they have been involved in decisions about their health care lead by which mechanisms and in which contexts to improvements in patients’ health status.13

Researchers’ two main preoccupations in investigations of patient involvement in decision making to date have been the roles played by individual service users and their health care providers in the selection of a course of action and the question of whether treatment decisions are consistent with the informed preferences of individual service users.

A significant body of work has focused on the micro-social aspects of clinician-patient communication about decision-making. This work has been underpinned to an important extent by a conceptual framework based on three models of communication that illustrate the different patterns of interaction and influence that service users and their health care providers might have over the choice of treatment. The three models,
as elucidated by Cathy Charles and her colleagues,\textsuperscript{14,15} start from the position of assuming the patient has a known diagnosis and there is a clear set of treatment options to choose from. The models differ in terms of how they envisage combining the health professional’s knowledge about the treatment options with the service user’s knowledge of her own preferences to make an informed decision that reflects the patient’s preferences (see Table 2).

Table 2: Models of treatment decision-making as outlined by Charles et al (1999)\textsuperscript{16}

<table>
<thead>
<tr>
<th>Information transfer</th>
<th>Paternalistic model</th>
<th>Shared decision-making model</th>
<th>Informed (patient) model</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctor provides patient with the minimum medical information necessary for informed consent.</td>
<td>Doctor provides patient with all medical information needed for decision-making. Patient provides doctor with information about preferences.</td>
<td>Patient provides doctor with all medical information needed for decision-making.</td>
<td></td>
</tr>
</tbody>
</table>

| Deliberation | Doctor (alone or with other doctors). | Doctor and patient (possibly with others) | Patient (possibly with others) |
| Decision about implementing treatment | Doctor | Doctor and patient | Patient |

Although these models were developed as descriptive rather than normative devices, it is now widely assumed that either the shared decision making model or the informed (patient) model represent more desirable approaches to decision-making, and efforts have been made to clarify the skills that health professionals and service users need and the processes they need to adopt to ensure these models rather than the paternalistic one are enacted in practice.\textsuperscript{16-18}

Another body of work relating to patient involvement in decision making focuses on the question of whether treatment decisions are consistent with the informed preferences of individual service users. This reflects a recognition that for many health problems there are a number of treatment or management options that are generally regarded as reasonable, but that individuals vary in their preferences relating to these. A broad consensus has emerged that when several reasonable options are legitimately available within a health care system, the choice between them in any particular case should reflect the individual service user’s preferences (rather than their health care provider’s).

A number of studies have sought to assess patient involvement in decision making from service users’ perspectives. These studies have been conducted with a view to monitoring health care providers’ performance in terms of facilitating patient involvement, and also, increasingly, to evaluate interventions that aim to promote the
involvement of patients in decisions about their care. Not surprisingly, the methods
they have used reflect the two preoccupations outlined above: they have generally
asked service users to report on the roles that they and their health care providers have
played in the making of treatment decisions and/or to indicate whether the decision
made was consistent with their informed preferences (or one that they were satisfied
with).

Although significant progress has been made in terms of understanding and assessing
patient involvement in decision making, some further development is likely to be
necessary. A concern has emerged that conceptual frameworks that have underpinned
the work undertaken to date may not incorporate all that is important in terms of
patient involvement in decision making,13 and problems have been identified with the
interpretations that have been made of service users’ responses to some of the
questions that have been used to assess their involvement, as outlined below.

There have been relatively few investigations of what matters to service users when
they think about their involvement in decisions about their care. The small study
summarised in Box 24 suggests that they may conceptualise such involvement (or
participation) more broadly than researchers have tended to do to date.
**Box 24**

**Participation from the perspective of people with chronic heart failure**

Ann Catrine Eldh, Margareta Ehnfors and Inger Ekman set out to explore the phenomena of participation and non-participation as experienced by service users in Sweden. They conducted narrative interviews with ten people with a diagnosis of heart failure, asking them to describe and discuss situations in which they had and had not experienced participation in their health care, and also to say what they thought participation and non-participation were.

Patients were found to associate participation with experiences of:

- **Being confident** (in themselves and their caregivers). For example, knowing their own goals, being able to interpret their body’s signal, knowing that their caregivers would listen and take an interest in what they feel and want.

- **Comprehending** (their body, the disease, the treatment, and information). For example, understanding the aim and consequences of treatments and being able to use information as a reason to act differently.

- **Seeking and maintaining a sense of control.** For example, initiating and checking care, and having a sense of control during health care planning and follow up.

They associated non-participation with experiences of:

- **Not understanding** (signals from their body, the disease, the treatment, health care structures). For example, not knowing how to interpret doctors’ instructions, not knowing who to turn to if they need assistance).

- **Not being in control** (of the disease, of the treatment, of access to care). For example, not knowing when and how symptoms might manifest, not having treatment plans, receiving orders from staff rather than having a dialogue.

- **Not having a relationship with caregivers.** For example, feeling isolated, experiencing little continuity and/or little co-operation from caregivers.

- **Not being accountable** (not being respected, being treated as though they lacked integrity or value, being treated as a body with a disease rather than as a person).

Each of these themes was judged to be present in at least eight of the ten interviews. Once they had identified the main themes, the researchers calculated the proportion of words in each interview transcript that were associated with each theme. On this basis, they found that ‘being confident’ was “the most central and common theme to participation” and ‘not understanding’ and ‘not being in control’ were most common to non-participation.


Reflecting the concern with the roles played in decision making by service users and their health care providers, a number of researchers have developed and used a menu set of different role descriptions. Service users (and sometimes health care providers) are invited to select one role that best describes how a treatment decision was made (sometimes by direct selection from the whole set, sometimes by a process of considering just two descriptions at a time). On the basis of their role selections,
service users are categorised as having experienced decision making that broadly conforms to the paternalistic, shared or informed (patient) models (or as having played passive, collaborative or active roles in their care). However, as the study summarised in Box 25 suggests, there may be problems with the validity of these categorisations, and the use of the role menu sets as indicators of patient involvement in practice (as opposed to patients’ preferences for involvement) may be problematic. (Other studies have also identified similar problems).19,20
Vikki Entwistle, Zoe Skea and Maire O’Donnell recognised several potential problems with some commonly used methods for assessing the roles that patients play in treatment decisions. They examined the performance of two instruments that were used to categorise people as playing active, collaborative or passive roles on the basis of their selection from a menu of several descriptions of doctor and patient roles.

The researchers conducted semi-structured interviews with 20 women who had recently undergone a hysterectomy as a treatment for heavy or painful periods. They first asked the women to describe the events that led to them having a hysterectomy, including the roles that they and their doctors had played in decision-making. They then asked women to think about the decision to have a hysterectomy, to pick a role description from each of the two instruments, and to explain why they thought the role descriptions they picked were the most appropriate ones in their case. The researchers considered how the selected role descriptions related to the women’s narrative accounts, compared selections from the two instruments, and analysed the reasons women gave for choosing particular role descriptions.

The narratives revealed that the women had all experienced menstrual problems for several years, had consulted general practitioners about these on a number of occasions, and had discussed treatment possibilities with various health professionals as well as family members and friends. This made it difficult to put a boundary around ‘the decision’ to have a hysterectomy and to determine which actions and interactions should be taken into account when assessing the women’s participation in that decision. Some women found it hard to pick one role description to sum up the roles that they and their doctor had played – and several questioned which doctor they should take the role descriptions to refer to. The question of what counted as part of the decision-making process was further complicated because some women recognised that the decision to have a hysterectomy necessitated other decisions, for example about what type of hysterectomy to have, and it was difficult to disentangle these. Most women described a range of behaviours and interactions with health professionals that could be regarded as indicative of different roles at different times in the lead up to their having a hysterectomy.

The researchers found that up to half of the women might have been differently categorised as playing active, collaborative or passive roles on the basis of the two measures. Women’s explanations for picking particular role descriptions varied. Some women who picked different role descriptions gave very similar reasons for their selections. The varied reasons women gave for selecting particular role descriptions helped to explain why women who told similar narratives about their decision making chose different role descriptions and would have been differently categorised as having played active, collaborative or passive roles.

The final issue that we shall consider with reference to patient involvement in decision making is that of the limitations of attempts to assess health service providers’ performance on the basis of service users’ assessments. The study summarised in Box 26 highlights some of the difficulties that might be faced during attempts to assess the quality of decision making in routine care. It also illustrates how service users’ assessments of the quality of decision-making may be influenced by factors that are not within the control of health service providers’ control. This reminds us that ‘good’ health care processes may not consistently lead to positive assessments by service users.
Vikki Entwistle and colleagues asked people attending routine consultations in five diverse clinical areas to fill in a short questionnaire that asked them to identify any decisions that had been made in their consultations and to complete a measure of their satisfaction for whichever decision they considered to be the main one.

The questionnaire was administered in the context of a broader qualitative study. The researchers were able to relate the responses people gave on the questionnaires to information obtained from recordings of their consultations and from interviews with the respondents themselves and the health professionals that they consulted. Most respondents also discussed what they had written on the questionnaire in an interview.

Service users identified a wide variety of decisions as having been made in their consultations, but the descriptions they wrote on the questionnaires were generally very brief and difficult to interpret. They were typically statements about what was to be done (e.g. blood test for thyroid, increase prescription strength) and revealed nothing about what other options they had been offered or had considered. Some people said in interviews that they had been unsure what counted as a decision or whether they should mention decisions that had been considered over the course of several consultations.

Service users’ explanations for the responses they gave to questions about their satisfaction with decisions revealed that they were sometimes evaluating decisions from a position of limited knowledge about the available health care options and their likely consequences. Their assessments of the quality of the decisions were not always made relative to what was realistically possible and were influenced by a number of factors, including, for example, their awareness of treatment policies in other health care systems. Some service users said that they might have assessed the chosen course of action differently depending on whether they compared it to the alternatives that had been discussed in the consultation or to other alternatives that were not discussed but that they might have preferred.

The researchers concluded that while service users’ subjective perceptions of decisions are important, they are not clearly attributable to health care providers’ actions and are not suitable as indicators of providers’ performance in terms of the facilitation of patient involvement in decision making. They suggested that assessments of health care providers’ performance in terms of facilitating ‘good’ clinical decision making should consider a range of factors and from several perspectives.

SUMMARY OF KEY POINTS

- Health care ‘quality’ and its attributes are complex constructs. They can be conceptualised and assessed in various ways. If research is to produce generalisable knowledge about health care quality attributes, researchers will need to develop and use clear, well nuanced conceptualisations of those attributes and appropriate assessment tools.

- Quality attributes may be differently conceptualised by service users and service providers, and approaches to assessment of quality attributes might be more or less compatible with, and more or less accommodating of, service users’ views about them.

- Studies of service users’ views might contribute both to the development of understandings of what makes for quality in health services and to the assessment of quality in practice. Some aspects of health care quality are best defined and assessed from the perspectives of service users.

- Researchers have good reason to pay attention to what service users think matters in terms of health care quality, and to how they conceptualise particular quality attributes:
  - Service users’ views about what makes for quality are important in their own right;
  - Service users’ views about particular quality attributes may reveal matters of importance that are not evident from providers’ perspectives.
  - If researchers do not appreciate the meanings that service users attach to quality attribute terms, they may misinterpret service users’ reports.

- Service users’ views about the structures, processes and outcomes of health care might also be regarded as among the processes or outcomes of health care. Researchers need to think carefully about how they need to treat these views in any particular project, and design their study accordingly.

- Service users’ assessments of health service quality are inevitably shaped to some extent by their interpretations as well as what health services do. They should thus be used with caution as indicators of the performance of health care providers.

- When attempting to assess health care quality using service users’ reports, researchers need to consider:
  - The extent to which service users maintain a focus on the particular aspects of health services that the researchers are asking about.
  - How well research instruments cover the issues of relevance to the quality domain(s) of interest.
  - The extent to which service users’ reports relating to health care quality are influenced by what health services do and the extent to which they are influenced by considerations beyond the control of health services.
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patients' participation and quality of decision-making: insights from a study of routine
CHAPTER 5

SERVICE USERS AND RESEARCH PROCESSES

“Research methods often suit the researcher and the organisation rather than the user” (McIver, 2005)

WHAT THIS CHAPTER INCLUDES

• A brief introduction that notes that service users’ experiences of research are important both in their own right and because of their implications for the views that researchers elicit and understand.
• A section that highlights the diversity of service users and outlines some key considerations relating to the inclusion of socially disadvantaged groups in research.
• A section that considers issues relating to recruitment and consent, data collection techniques, and feedback to services users about study findings, paying particular attention to the ways in which researchers’ approaches might impact on service users’ willingness and ability to participate, the content of the views they express, and their experiences of participation.
• A concluding section that stresses that much remains uncertain about the effects of different research approaches and encourages researchers to incorporate methodological research alongside their substantive investigations.

5.1 INTRODUCTION

Services users’ experiences as potential or actual participants in research intended to investigate their views can have important effects on what knowledge that research generates and thus on how useful it is. If service users are invited to participate in research but are unable or unwilling to respond because the forms of communication that researchers use make participation difficult or unattractive to them, then their views will not be heard. If service users who have agreed to participate in studies of service users’ views find the processes inappropriate or uncomfortable, the accounts they give of their views may be limited or misleading.

Service users’ experiences of research are also important in their own right. To the extent that researchers are committed to respect their participants as persons, a strong ethical tradition, following Immanuel Kant, suggests they should treat them not only as means to the end of knowledge generation but also at the same time as an ends in themselves. The process of participating in research should not undermine people’s status as moral agents.

Concerns about the failure of some previous research to adequately respect participants as persons has led, among other things, to increased efforts to enable members of the groups of people whose views are being studied to influence or control the research that is done, for example by shaping the research agenda and undertaking or managing research projects.
Some advocates of participatory or emancipatory research suggest that service users should routinely contribute to research as equal partners in or leaders of the research process. There is little doubt that members of the groups of people whose views are to be studied can in many circumstances improve the quality of research, for example by helping to ensure that communication with potential participants is clear and approaches to data collection are broadly acceptable. However, debates about the appropriateness of different forms of service user involvement in the conduct of research and in different circumstances continue.\(^5\)\(^6\)\(^7\) It is increasingly recognised that research-naïve service users are not well placed to lead research projects, that some people, even with training, will not be able to engage in some research tasks (for example, people with moderate to severe learning difficulties struggle with abstract reasoning), and that some attempts to give service users more power in research processes may both increase the costs of research and reduce the robustness of the knowledge generated.\(^7\)

This Resource focuses mainly on the experiences of service users as research participants and on researchers obligations to pay careful attention to these as they strive to generate socially useful knowledge. This chapter will note at several points that the inclusion of people with experience as service users as members of or advisors to research teams may be an important way of ensuring that research processes are respectful of and appropriate to particular service user participants. However, it is important to recognise that there may be a tension between efforts to ‘empower’ service users as researchers and efforts to ensure that research generates robust knowledge in a cost effective manner.

The aspects of research that most obviously have implications for service users’ experiences of research participation are the ways in which researchers identify and approach people to invite them to participate in studies, the data collection techniques that are used, and what research participants hear subsequently (from the researchers or other sources) about the study findings and what was done with these. It is these aspects that we focus on in this Resource. A broader range of aspects of research have implications for what comes to be understood (and by whom) about service users’ views as a result of the research, including the study designs within which data collection techniques are embedded, the ways in which researchers analyse and interpret their findings, and communication between researchers and policy makers and health service leaders. These issues have been well and widely written about in many general texts about health services and social science research and their methods,\(^8\)\(^9\)\(^10\)\(^11\) and are not covered further here.

Different groups of service users may be differently affected by particular research processes and differently willing and able to express their views in particular research contexts. The following sections consider the diversity of service users whose views might be of interest and then the three aspects of research noted above as most obviously having implications for service users’ experiences. They illustrate some of the key issues that may shape both those experiences of research and the understandings about service users’ views that research might eventually yield.
5.2 DIVERSITY AMONG SERVICE USERS

Service users, broadly defined, vary significantly in a number of ways. The range of people who fall within the sampling frame of any particular research project will vary according to the aims and focus of the research. At one extreme, studies of public opinion about health service issues aim to canvas the views of people from across the whole broad spectrum of society. At the other extreme, some studies focus on relatively homogeneous (usually minority) groups of people who share a number of attributes that differentiate them in some way from others.

There is a growing recognition that some people are, in practice, regularly excluded from most ‘mainstream’ research studies that aim to canvas the views of a broad population. This is because these studies are usually conducted in the majority language, take place in social contexts that have a tendency to disable and marginalise people who do not conform to dominant norms, and use methods that require significant literacy and/or spoken communication skills.¹

The groups of people who tend to be excluded from mainstream research are also likely to have particular problems in accessing and using general health services. Some groups are the intended beneficiaries of particular health and social care services, which may be more or less able to meet their self-defined needs in ways that they find acceptable. There are thus good reasons for wanting to investigate their views about both general and specialist services with a view to improving their experiences of these.
Conducting focus groups with people from ethnic minorities

Lai-Fong Chiu and Deborah Knight discussed experiences gained as researchers on two participatory action research projects that used focus groups to involve women from a range of minority linguistic groups in the identification of problems and development and evaluation of solutions relating to the delivery of cancer screening.

One project focused on breast cancer screening and recruited minority women from seven language groups. All were highly educated and (with the exception of the African-Caribbean group) bilingual. They included community workers, nurses and teachers of English as a second language. The focus groups were conducted in English, and the women were encouraged to discuss both their own views and the views of other women in their communities.

The other project focused on cervical cancer screening and recruited minority women from six language groups. These women had a limited ability to speak English. The focus groups were moderated by bilingual moderators (either the primary researchers or people who interpreted for them).

The researchers identified advantages and disadvantages to the two approaches. With bilingual participants, there was no obvious language barrier, no distortion or delays arising from the need for interpretation, and good group interaction. However, the researchers could gain only indirect access to the views of women who did not speak English and felt a need to be cautious about the distinctions that participants made between their own views and those of others in the community.

With bilingual moderators, the researchers felt more able to include directly those members of minority communities who were “most at need”, but were concerned about a possible distortion of the views they heard either because the moderators had not fully understood the research framework or because they did not share precisely the same dialect or culture as the focus group participants.

The researchers also observed that researchers or moderators who has the same or near same racial identity as the focus group participants were more likely to elicit concerns about racial discrimination.

Participants in the breast cancer screening project and bilingual moderators from the cervical cancer screening project were recruited and trained to serve as Community Health Educators for their communities.


There is a wide range of people for whom at least some ‘mainstream’ research approaches may be problematic. This includes people who may experience difficulties or be vulnerable in social interactions for any or several of the following reasons:
• Young age
• Old age and frailty
• Physical disabilities
• Cognitive and/or emotional difficulties (e.g. those associated with learning difficulties, mental health problems or dementia)
• Communication difficulties (e.g. those arising from visual, hearing or speech impairments, literacy problems, speaking a minority language)
• Membership of ethnic, cultural and linguistic minorities (to the extent that this renders engagement with members of the cultural majority and/or other groups problematic)
• Social isolation and/or stigmatisation (e.g. due to dependency within a disempowering relationship, engagement in behaviours that are widely disapproved of, poverty, disfigurement, or any of the above reasons)

People with different reasons for finding ‘mainstream’ engagement problematic will be differently able and willing to participate in particular types of research tasks, and need to be differently enabled to participate in research.

In the UK and a number of other countries, policy makers have been seeking in recent decades to address the problems of relative deprivation, alienation and social exclusion that have been faced by some minority groups. This has led to a proliferation of research into the experiences of people who are in some ways marginalised from mainstream society, of critical reflections on this work, and of advice about communicating and conducting research with people who tend to be excluded when researchers rely on traditional mainstream approaches. For example, in relation to people with learning difficulties, a government policy document *Valuing people* set out a strategy for improving the support that is provided to people with learning disabilities and their families, including in relation to health service use.12 This drew on and stimulated further research that examined issues from the perspectives of people with learning disabilities, and the Department of Health and other research grant-giving bodies required that people with learning difficulties were included in the research process.13 A number of reflections and advisory resources have been published about conducting research among and with people with learning difficulties.7,14,15

Advisory resources for researchers often draw on the experiences of both service users and the service providers and researchers who have sought to engage with them more effectively (and fairly). They may also incorporate insights from more formal evaluations of different ways of working among particular groups of people. They contain a wealth of insights into issues to be aware of and practical tips for different situations. There is not scope in this *Resource* to meaningfully review advice for each group and research issue, but a few broad themes are worthy of particular note.

Firstly, a social model of disability16 is gaining widespread acceptance, and it is increasingly recognised that many of the problems faced by people with physical and other impairments should be seen as arising at least in part from the social contexts in which they live.17,18 The emphasis in advice to researchers is thus usually on ways of modifying research processes so that they are more accessible and acceptable to potential participants. In the case of studies that aim to include a wide range of service users in their sample, efforts are concentrated on broadening access and appeal (see,
for example, Box 28). In the case of studies that focus on the views of particular groups of people who have face specific barriers to participation in research and other social activities, efforts are concentrated on ways of tailoring research methods as far as possible to remove those specific barriers (see, for example, Boxes 27 and 29).

Box 28

**Improving telephone surveys for people with disabilities**

Anne Ciemnecki and Karen CyBulski modified a telephone survey that was being used in the context of a large scale evaluation of the impact of reforms to the Medicaid system\(^1\) so that the evaluation could better include people with disabilities. The telephone survey consisted of a series of structured questions about access to care, use of health services, and perceived quality of care.

The researchers knew that the survey population included people with a variety of physical, sensory and developmental disabilities of differing degrees of severity as well as people with mental health problems. They recognised three broad categories of challenge that these people and the researchers would face in the survey:

- Communication challenges (e.g. hearing and speech impairments)
- Stamina challenges (e.g. physical and mental fatigue)
- Cognitive challenges (e.g. emotional disturbance, difficulty processing questions and responses, lack of complete or specific knowledge).

The researchers made four main modifications to the original protocol to make it more suitable for people with disabilities. They:

- Minimised high frequency sounds (by re-wording questions to avoid the use of high-frequency consonants);
- Introduced interviewer check points (to assess fatigue, offer a break if necessary, offer encouragement);
- Designed structured probes (to help clarify concepts or to rephrase questions in a standardised way); and
- Offered standardised response options if people were unable to provide precise answers to questions that asked for information about income, out-of-pocket medical expenses, waiting times etc.

They also made sure that interviewers were carefully selected and appropriately trained (e.g. to use text telephones, to adjust volume controls, to use a normal tone of voice), and eased usual interviewer performance measures (such as hours per completed interview) in recognition of the fact that more time might be needed to allow for questions to be repeated or for breaks to be taken.

Using the modified procedures, the researchers achieved higher response and cooperation rates among people with disabilities than the original survey had achieved among a general medical population. They suggest that the modifications they made would be suitable for a general population, and if more widely used, could make it easier for people with disabilities to participate in general population surveys.

1. Medicaid is the main source of funding for health care for US citizens on very low income with disabilities.

Second, there is a growing sensitivity to the power issues faced by people who are in some way dependent on particular services, and a concern that researchers do not (wittingly or otherwise) further disempower those who are already disadvantaged. As noted above, this concern has led many advocates for service users, as well as researchers, to ensure that members of the relatively disadvantaged groups that are being researched should be more closely involved in, and have more control over, research processes. More generally, however, it suggests that all researchers need to consider the impact of their interactions on (potential) research participants.19

Third, people are individuals and often will not fit the stereotypes associated with the group labels that are sometimes attached to them. Members of a particular group might be quite diverse in terms of their needs and preferences (for example, people with learning difficulties have varying degrees of cognitive and communicative ability, people who belong to a minority ethnic/cultural group may be more or less fluent and literate in the dominant language and more or less comfortable engaging with members of other ethnic/cultural groups). Also, individuals may belong to several groups and experience a number of difficulties (for example as a result of being an old, physically disabled, hearing impaired member of an ethnic minority who speaks limited English).

5.3 Carers

Family members and friends who provide various kinds of informal support, usually unpaid, to people who have health problems or who are vulnerable for other reasons, are often referred to as carers. However, not all appreciate that label, and the situation is often more reciprocal than the carer-cared for distinction implies.20 In relation to research to investigate service users’ views of health services, carers may play a number of roles and so warrant careful consideration.

The demands of caring are increasingly recognised, and formal service providers increasingly seek to offer support to carers as such. Carers are thus recognised as service users in their own right, and their views about services intended to benefit them are of interest in the same way that the views of any group of potential service beneficiaries are of interest.

Carers’ views about the services provided primarily to the people they care for are also of interest, because carers – and their caring contributions - are often significantly affected by these services. The study summarised in Box 12 is an example of an investigation of carers’ views about a service provided primarily for the people they cared for.

Carers may also play a variety of roles when researchers seek to elicit the views of the people they care for. These varied roles – and the ways in which they are negotiated – may have important implications for the service user’s and the carer’s experience of research participation, and for the nature of the views that researchers elicit.

Carers of particularly vulnerable people often act as gatekeepers to those people. They may do so in ways that are more or less helpful to the people they care for and to the researchers who seek to access their views. Carers’ actions sometimes tend to preclude vulnerable people from participating in research that they would otherwise
be willing and able to contribute to. More positively, carers sometimes assist researchers by facilitating introductions to the people they care for and offering information and insights that make it easier to elicit and interpret their views – especially if those people have cognitive and/or communication problems. For example carers might advise about communication techniques, suggest ‘ways in’ to discussion about particular topics, or explain what service users are referring to when they use particular names or terms.  

Carers may also help service users to express their views (e.g. by reading questions and writing service users’ answers, or by assisting with communication between a researcher and an interviewer). However, such help may also lead to some ‘distortion’ in the communication of the views of the person cared for, for example because:

- Carers are translating/interpreting what the people they care for say, and this is likely to involve some transformation;
- Carers may be inclined to add their own views to those of service users; and
- Service users may self-censor what they say when talking through their carers.

Carers sometimes prefer to accompany the people they care for during data collection even if they are not required in an assistive role. When interviews are conducted in people’s own homes, carers might find it more comfortable to sit in on the interview than to be shut out in another room, and researchers might find it difficult or inappropriate to exclude carers, for example because to do so might tend to imply that people living in intimate relationships have secrets that they withhold from each other. Carers’ presence may have varying influences on the views that the people they care for express – and indeed on the overall account that researchers hear.

Carers’ views have sometimes been used as ‘proxies’ for the views of the people they care for. However, this practice has become less popular as it is increasingly recognised that carers have different needs and agendas in relation to health and social care services than the people they care for, and that the extent to which they understand and agree with the views of the people they care for on particular issues is variable. Efforts are increasingly made to enable even the most vulnerable of people to express their own views where possible.

5.4 ASPECTS OF RESEARCH ACTIVITY

Research that attempts to elicit service users’ views is both complex and highly diverse. Many aspects of research activity have important implications. It is beyond the scope of this Resource to explore them all, but this section aims to highlight some general issues relating to the aspects of research that most obviously impact on service users’ experiences of participation and on the views they express: approaches to recruitment and consent, data collection techniques, and feedback of research findings to research participants.

When reading this section, you may find it useful to keep in mind the diversity of service users and to remember that:

- particular features of research processes may be more important to some service users than to others,
- features of research that are preferred by some may be dis-preferred by others, and
features of research that encourage and enable some people to express their views well may discourage and otherwise hinder others.

5.4.1 Identifying and approaching potential participants

Researchers must consider how they will identify the service users whose views they seek to study. This may be more or less challenging depending on the nature of the study’s eligibility criteria, the accessibility of information about which people meet them, and the ethical issues that might arise from using that information.

Regulations governing the sources and methods that researchers can use to identify and approach people with particular characteristics or people who have used particular services have become much more restrictive in recent years in the context of efforts to protect the privacy of people’s personal data and to ensure that vulnerable individuals are not unduly coerced to participate in research.23

When potential research participants are identified from service records, for example because they are registered with a general practice, are on the case list of a community mental health nurse, or are scheduled for a hospital outpatient appointment within the next 6 months, an invitation to participate in research must usually be given first by a health or social care professional who provides care within that service. The requirement that people actively opt in to research by contacting researchers may tend to reduce the total number of participants and to exacerbate the tendency of research to exclude people who experience more social disadvantage and are less vocal.24,25 The requirement that the first approach comes from a service provider may also reduce the clarity of any messages researchers might like to give about the independence of their research from the services from which they recruit people. This may influence the views participants subsequently express.

For some studies, it will be important to identify people who are not using particular services that are intended to benefit them (see, for example, Box 29). There are various strategies that might be used when the study population is not readily identifiable. For example, researchers might advertise in appropriate social settings and media outlets, and use ‘snowball’ contacting (starting from a few people who are known to meet the criteria and asking them to identify others whom they know).

It is important to think about the potential implications of different recruitment approaches in terms of who ‘hears’ the invitation, what initial impressions they form of the study, and how safe they feel in responding.

**Box 29**

**The use of ‘peers’ to access hard-to-reach groups**

Eva Elliott, Alison Watson and Ursula Harries were commissioned to investigate the experiences of parents who use illicit drugs, and to explore how, if at all, external support from formal services or informal sources impacted on their lives.

Illicit drug users are socially stigmatised and are committing criminal acts. They are thus understandably wary of being identified and of talking about their lives ‘on
record’. The researchers were able to identify some parents who were in touch with community drug team services, but they were also keen to explore the views of those parents who were not in touch with these services. They decided to use peer recruiter/interviewers to identify and elicit the views of these people.

In one recruitment area, a community drug team had a tradition of involving former or stable drug users as volunteers, and some of these volunteers had previously helped to administer questionnaire surveys. The researchers invited two of these volunteers to help with the project as peer recruiter/interviewers. In another recruitment area, the researchers found it much harder to identify former or stable drug users who were both able to control their addiction while in contact with more chaotic users, and to work as peer interviewers.

Eventually four former or stable drug users were trained to contribute to the project. They used their own networks to identify parents using illicit drugs, and managed to recruit and interview non-service users as well as service users.

The use of ‘peers’ facilitated access to the views of a relatively ‘hidden population’ with a view to developing services that might help them. However, the researchers highlighted a number of issues relating to the practicalities and ethics of employing peer recruiters and interviewers. In relation to the quality of the insights obtained, they noted that the peer interviewers did not tape record many of the interviews but took detailed notes during and after the interviews. This meant that the researchers were working with ‘second hand’ data. This was of particular concern given that the peer interviewers and respondents shared a language and lifestyle that was relatively alien to the researchers. The peer interviewers had not written notes about some of the issues that they regarded as common knowledge. When the researchers learned about these issues in the context of the lengthy de-briefing sessions that they held with the peer interviewers after every couple of interviews, they did regard them as important (they were only common knowledge among the drug using community). The researchers reflected that in future they would probably try to make more use of peers as ‘finders’ who used their networks to identify people who would be willing to be interviewed by ‘outsiders’ whom the peers could vouch for.


Research ethics and governance requirements usually specify the kinds of information that researchers must provide when inviting people to participate in research. The topics considered important for securing informed consent usually include:

- The aims of the research
- The rationale for conducting the research
- The kinds of contribution that the researchers hope their study will make
- The methods of the research
- How the person being invited to participate was identified and why they are being invited to participate
- Who else (which other people) is (are) being invited to participate
What participation in the study would involve (what participants are asked to do), including for example what kinds of issues participants they will be asked to express their views about and how

Who will have access to research data (e.g. who will see any questionnaires they complete, or hear recordings of what they say in interviews)

How the researchers plan to analyse the data

Where, how and to whom the researchers plan to report their study findings

Which organisation(s) is(are) funding the research

Which organisation(s) is(are) sponsoring or otherwise supporting the research

Which organisation(s) and individual(s) are involved in conducting the research

The relationships between the organisations and individuals that are funding and conducting the research and the health services that service users might be expressing views about in the course of the research

Within the general requirements of information provision, there is usually some flexibility in terms of exactly what information is communicated and how in standardised information materials about the study. There may also be significant variation in what recruiters say more informally.

Depending on what is said, how and by whom, potential participants may form different views about the proposed study, about what exactly researchers would require of them, about what the research aims to achieve and is likely to deliver, and about how important this might be for themselves and/or for others. Invitational information might also influence potential participants’ views about the motivations and trustworthiness of the various organisations and individuals associated with the research, and whether they would feel comfortable engaging with them. All these views and others may influence both whether people agree to participate and what views they express if they do.

Invitations to participate in research may also have important implications for potential participants’ sense of self, particularly in relation to services they use. Information about why they are being asked to participate and how they were identified is often also information about how they are viewed by others. It may sometimes cause surprise or upset, for example if an information sheet suggests to someone that they have a problem they had not previously thought of themselves as having, or that they are in receipt of a service they had not recognised as such.21

Researchers thus need to be very careful about what they communicate in initial invitations and discussions with potential participants. They need to ensure that their communication is clear and non-threatening. They may also seek to use their recruitment information to anticipate and address any misperceptions and concerns that potential participants might have, and to set the tone for any future data collection, for example by emphasising that they want to hear people’s frank and honest opinions, and by stressing that they will not be ‘judging’ service users’ views.

The ability of a research team to optimise their opening communications with potential research participants (in terms of ensuring both that these communications are experienced positively and that they encourage appropriately informed participation in the research) is likely to be enhanced if the team includes or seeks
advice from people who are members of the study population or from people who have experience of listening to and advocating for those people. 'Piloting' and conducting early assessments of recruitment approaches with a view to identifying areas for improvement may also be helpful.27

5.4.2 Collection of data

Researchers have a variety of methods for tapping service users’ views, and there are several possible ways of grouping these. This section makes reference to just a few basic types (structured questionnaires, short structured individual interviews, semi-structured individual interviews, focus groups and diaries) to illustrate the kinds of issues that researchers need to consider.

For some research tasks, one kind of basic data collection method might be more obviously suitable than others. For example, structured questionnaires or short structured interviews are particularly useful if researchers need to examine the views of large numbers of people, to consider the distribution of views on a particular issue, and/or to make standardised comparisons between the views of different groups of people. Structured questionnaires require more literacy on the part of participants than short structured interviews, but they offer participants more privacy as they respond. Semi-structured individual interviews or focus groups are particularly useful when there is a need to examine views in more depth, or to identify the range of views that might be held on a topic that has not been much researched before.11,28 Focus groups are particularly useful if researchers want to see how people are likely to respond to particular suggestions about service development (people usually develop their views on issues in the context of discussion with others). They can also be useful if researchers want to explore a potentially embarrassing topic (people might feel safer discussing among a group of peers than in a one to one situation with a researcher).29,30 Diaries can be particularly useful for examining people’s views through a period of transition, or otherwise when it is important to collect data on a regular basis over a period of time and to avoid problems of recall.31
Box 30

A diary/interview study of experiences during recovery

Howard Griffiths and Sue Jordan sought to better understand the experiences of people who had been hospitalised with a lower limb trauma in order to inform the practice of health care professionals. They set out to explore the stressors that patients experienced, the coping strategies that they adopted, and the kinds of health care practices that might help to alleviate stress and augment coping.

The researchers recognised that diaries could be particularly useful in the study of life transitions. They chose to use health diaries to allow symptoms and health care activities to be recorded as they occurred and to “captur[e] the individuals’ perspectives on their experiences as they evolved over time”.

The researchers only approached people with a good prognosis, normal recovery expectations and no known communication or literacy problems. They gave each participant a structured diary to complete daily for up to 6 weeks post-operatively. The diaries asked structured questions about pain, mobility and sleep, and open questions about how participants had felt, who or what had helped them cope, whether anything had upset them and whether anything had helped them. They also provided space for general comments.

After the participants had handed over their diaries, the researchers interviewed them to check how accurate they felt their diaries had been and to discuss their experiences.

Nine people aged between 19 and 58 participated in the study. The researchers organised their findings into three main themes: dealing with uncertainty and stress; seeking control; and returning to normality. In addition to the insights they obtained into participants’ experiences of suffering and coping, they identified several issues relating to the delivery of care that health care professional might seek to improve on. These included the flexibility of pain control regimes, and the provision of information about a number of issues. They also found that participants had valued the personal qualities of some nurses and some informality in the delivery of care (although in the context of predictable routines) as helpful for their coping.

The people who participated in the study found the diaries helpful as self-monitoring tools.

review of all the techniques that might be used to examine service users’ views is beyond the scope of this resource, but once you have identified a basic method, you are advised to consult relevant text books, methodological reviews (e.g. 32-34) and discussions about emerging techniques to inform the details of your approach.

Thinking activity:

Suppose you were seeking to elicit the views of people with spinal cord injuries who live in remote and rural areas about the health services they use and the extent to which these meet their perceived needs. You are particularly keen to explore their current or potential use of telephone and electronic-based consultations with health service providers.

What kind of data collection approach would you favour?

Discussion:
There is no single right answer to this, but it is worth reflecting on the kinds of assumptions and considerations you made when thinking about the question.

I might be inclined to try telephone focus groups.35 Focus groups allow people to explore their views about issues that they may have limited familiarity with (telephone and electronic based consultations) in the context of a discussion with others. Conference call technology now allows focus groups to be carried out by telephone, which is potentially very useful in this context given that the service users of interest are geographically dispersed and may find it difficult to travel because of their injuries.

Most people in the UK have access a telephone. Some of these service users at least might welcome the opportunity to ‘meet’ and talk with other people in similar situations, and to develop ideas in interaction with each other, about the kinds of services they would find helpful. Some might also find it easier to talk about sensitive topics such as incontinence (which is often a problem for people with spinal cord injuries) in the context of a telephone-based rather than a face to face discussion.

It might be useful to ask people towards the end of the telephone focus group session (or individually afterwards) to comment on how they found it, and whether and how their experiences of the technology in the context of the study might have influenced their views about telephone-based consultations with health service providers.

The remainder of this section highlights just a few key issues relating to the ways in which questions are asked, the language of asking and the use of interpreters, the medium of communication (including the characteristics of interviewers and facilitators), and the setting and timing of data collection.
The ways in which questions are asked

As Chapters 3 and 4 highlighted, there are many ways of asking people questions about their views about particular health service issues, and ways of asking often have important implications for the answers obtained. There are many texts that cover issues to do with the wording of questions (and where appropriate response options) for questionnaires, interview schedules and diary prompts, and more broadly with design issues such as the number and order of questions.

The study summary in Box 28 illustrated some of the modifications that might be made to ‘traditional’ questionnaires to improve their accessibility to people with disabilities. Many other modifications are possible. For example, a questionnaire administered by paper and pen or computer might be made more accessible to people with learning difficulties by the use of simple language and the addition of pictures and symbols. However, if researchers are concerned to reach a broad population, this increase in accessibility to one group might only be achieved at the cost of some loss of the nuances of understanding that might be achieved among other people if more complex language was used. Some people are put off responding to very simple questions if they regard them as patronising.

Researchers need to be as careful to ensure that the transfer of information between researcher and service user – in both directions - preserves the meanings intended by the two parties as faithfully as possible. There are various ways of attending to this. As noted in section 5.4.1 with reference to the development of invitational communications for potential participants, the ability of a research team to optimise data collection among a particular group of service users may be enhanced by the inclusion of, or consultation with, members of that group during the planning of data collection.

For structured questionnaires and short structured interviews, cognitive testing of draft instruments with members of the intended group(s) of respondents can be extremely useful. In semi-structured interviews, there is usually more scope for both parties to check that they have understood what each other are trying to say. Researchers in particular should make the most of opportunities to ensure that they have correctly ascertained service users’ meanings. For example, if a service user mentions that she expects something to happen in a forthcoming conversation, it might be appropriate for an interviewer to check whether she means she thinks it will happen or whether she means she thinks it should happen. If a service user commends a doctor for “really involving me well”, it might be appropriate for an interviewer to probe a bit further and ask him to say a bit more about what kinds of things the doctor did that made him feel that he had been well involved. In focus groups, research participants may sometimes clarify meanings among themselves, thus obviating the need for researchers to interject. In diary studies, researchers might interview participants to review and clarify their entries.

In some situations, researchers may want to introduce prompts and cues to stimulate service users’ thinking – either to remind people about the issues of interest or to introduce new ideas. The introduction of audio and/or visual material may make the research experience more interesting for participants and may help them to provide a more accurate, more reflective and/or fuller account of what they think about particular issues. Audio visual cues may be particularly useful when working for
people with cognitive problems, including memory loss, to help them to remember and focus on topics of interest.21

For studies with broad inclusion criteria, some flexibility in terms of the ways in which questions are asked might be appropriate, although the implications of this for the interpretation of findings need to be carefully considered. Katherine Curtis and her colleagues used a range of methods in their efforts to explore children’s experiences of health services. They sought to elicit the views of children who ranged in age from 4 to 19 and who had a variety of health and social problems and learning disabilities. For the youngest children, they used small discussion groups with picture and photographs as prompts and toys for role play. With older children they used drawing, writing and modelling activities, and with teenagers they used games and group discussions. In a special school for teenagers with learning disabilities, the researchers were able to build on work the teacher had done with the class to identify a range of feelings such as anger, embarrassment, happiness, sadness and fear. When it became apparent that some of the young children, especially those with significant experience of health problems and health care, were skilled in one to one discussion with adults, the researchers used conventional interviews as appropriate.37 However, the diversity of data collection approaches raises issues for data analysis and reporting. If it was important to be able to make standardised comparisons of views across groups, multiple approaches would render this difficult.

Language and interpretation

Researchers’ reliance on majority languages has often presented a barrier to participation in research. Efforts to use plain words and clear communication within the majority language, and to supplement words with symbols and pictures, may increase the range of people who can participate to some extent, but sometimes people can only be included if researchers engage with them in their own languages.

Perhaps ideally, research instruments (questionnaires, interviewers and interview schedules, diary frameworks etc.) would be made available in whatever languages were required. This would not be without its problems, as translations of questions into different languages inevitably introduces some concerns about comparability because the words and concepts of one language do not always readily map onto the words and concepts of another.38 However, researchers are unlikely to consider it feasible to produce all the multiple language versions of research instruments that might be required when research projects seek to elicit the views of members of linguistically diverse populations.

A more usual way of extending the range of people who are able to participate is to encourage or offer the use of interpreters or communication mediators (e.g. skilled sign language users) alongside the ‘standard’ data collection approach. However, interpreters may (helpfully or otherwise) do a lot more (or less) than a straightforward translation of questions and responses, and their presence in the data collection context may influence service users’ experiences of research and the views they express in a variety of ways.
**Communication media (including interpersonal relations)**

As the range of information and communication technologies grows, so does the range of possible variations on basic data collection methods. Researchers need to consider the accessibility and acceptability of any technologies they propose to use for their research participants. Judgements might usefully be informed by studies such as that summarised in Box 31 – although researchers need to be aware that the experiences and preferences of particular groups of service users may change over time.

**Box 31**

**Preferences for touch-screen versus paper-and-pen questionnaires**

Bodil Wilde Larsson compared two different media for collecting responses to a questionnaire about health care quality.

People aged over 18 who could communicate in Swedish and who attended outpatient appointments at either of two hospitals were invited to complete the questionnaire. The questionnaire included questions about 15 aspects of health care quality (the importance service users attached to these aspects and their experiences of them) as well as 3 items about how easy or otherwise the questionnaire was to complete and 1 item about how long the questionnaire took to complete. Half of the people were asked to complete the questionnaire on a touch screen computer and half were asked to complete the questionnaire in paper and pen form. (It is not clear how people were assigned to the two groups). In both cases data collection was completed before service users left the clinic.

75% of people who met the inclusion criteria completed a questionnaire. The demographic characteristics and self-rated health of the people in the two groups were similar. Responses to the questions about health care quality were generally very similar for the two groups (statistically significant differences between the responses for only 2 of the 30 questions). However, there were statistically significant differences between the two groups for all of the questions about ease of completion. People in the touch screen group rated the questionnaire as easier to understand, easier to read and easier to answer than people in the paper-and-pen group. They also estimated that it had taken them less time to complete. These differences in favour of the touch screen group were more marked among older people and people with limited education.


In contexts in which researchers collect data ‘in person’, their personal characteristics, professional backgrounds and known affiliations and may impact on service users’ sense of comfort in the research context, on the views they express, and on which aspects of these views researchers notice and respond to during the interviews. Box 32 summarises the reflections of two health professionals and a university-based researcher on the implications of what they disclosed about their identities to people whom they interviewed.
The nature of the ‘relationship’ between researchers and service-user participants may be particularly important when the service users are relatively disempowered in service use and more broadly in daily life. A number of researchers have suggested that members of minority and disadvantaged groups might feel more comfortable and speak more freely about some sensitive topics if they are interviewed by people who they can identify – people who are somehow like them. As the study in Box 27 illustrated, for example, members of ethnic minority groups may be less likely to discuss issues experiences of racism with researchers from other – particularly majority – ethnic groups. The use of ‘peer’ interviewers is becoming more popular – particularly in the context of efforts to give members of disadvantaged groups opportunities to acquire new skills and experiences of paid employment. However, the implications of the practice may vary quite significantly across different research contexts, and a number of issues require careful consideration. 6,7,39,40

Box 32

Respondents’ views of professional interviewers

(1) Helen Richards and Carol Emslie compared their reflections on interviews they had carried out with service users after disclosing their identities as, respectively, ‘a GP involved in research’ and a ‘researcher’ with no medical qualifications. In interviews conducted by a self-declared GP, working class respondents were noticed to be inclined to be deferential to the interviewer and to speak very positively about members of the medical profession. Middle class respondents tended to align themselves with the interviewer by assuming commonality of opinions and experience. When invited to add comments or ask questions at the end of the interview, interviewees often expanded on their health problems, asked health-related questions, and gave positive opinions of doctors and other aspects of health services.

In interviews conducted by a young, self-declared researcher, some respondents seemed unsure of the professional status of their interviewer, and may have considered her age and gender when making their responses. Interviewees were more likely than in the study conducted by the GP to comment unfavourably on medical professionals, and talked about a broader range of non-health related topics when given an opportunity to add comments and questions at the end of the interview.

(2) Pat Hoddinott reflected on her experiences as a GP researching how women decided how to feed their first baby. In the course of her study she conducted in-depth semi-structured interviews with women from her own practice, women from other practices who were told she was a GP, and women from other practices who did not know that she was a doctor. Pat found it easier to recruit women from her own practice, especially among women who wanted to bottle feed their babies. She presented evidence to suggest this was perhaps due to women’s reluctance to agree to talk about personal or sensitive issues with strangers with whom they had no prior trust relationship. (It is worth noting that if, as a GP, she had not established a good rapport with the women in her practice, or had given women who preferred to bottle feed the impression that she would not respect their choice, her recruitment experiences might have been different). However, she also noted some ethical concerns about people feeling obliged to
participate in research conducted by their own GPs in view of their need to continue in a relationship with them.

Pat also noted the concern that people might tend to give someone they knew to be a GP the answers they thought the GP would want to hear, but her data did include examples of people expressing beliefs that were contrary to medical knowledge, and speaking about engaging in behaviours that had adverse health implications. In such situations Pat had difficult decisions to make about appearing to collude if she did not comment but influencing subsequent data collection if she did comment.

Sources:
(1) Richards H, Emslie C. The ‘doctor’ or the ‘girl from the university”? Considering the influence of professional roles on qualitative interviewing. *Family Practice*, 2000; 17 (1): 71-75.

Particularly when using open ended questions (e.g. in semi-structured interviews, focus group discussions, and some forms of diaries), researchers need to think carefully about how they will record what service users say. Service users vary in terms of how comfortable they will feel with different recording media, but some are particularly uneasy about having what they say audio- or video-recorded.

If service users are not willing for audio-recordings to be made of what they say in the context of research interviews, researchers must rely on the notes they take during and after the interview. This inevitably introduces significant scope for biases associated with researchers’ selective attention and imperfect memory. It may be feasible in some circumstances to compensate for these to some extent by asking service user respondents to check a summary of the resulting notes for accuracy, but this will not always be appropriate to the aims of the research or acceptable to the service users whose views have been sought. As the study summarised in Box 29 suggested, reliance on notes may be particularly problematic if the researchers who are responsible for the final analysis of data did not conduct the interviews and take the notes themselves.

**The setting and timing of data collection**

The setting of data collection may affect service users’ physical, social and emotional comfort. Many researchers express a general preference for interviewing service users in their own homes if possible, particularly if they are keen to ensure the service users are at ease and/or to ‘distance’ the research project from the health services that the service users are being asked to express views about (particularly in order to minimise any constraints service users may feel about commenting negatively on those services). However, when service users are interviewed in their own homes, there is little other than the researchers’ questions to stimulate their recall of their experiences of health service use, and they may feel constrained in what they say by the presence of other family members.

Judgements about the appropriateness of different possible time points for data collection need to take into account the implications of these for service users’ experiences of the research process and their future health service use. For example,
service users who have just emerged from a hospital outpatient consultation might not appreciate an ‘immediate post consultation interview’ if they are tired and emotional as a result of concerns about their health and because they had had to travel a long way to the hospital, struggle to find the building in which their appointment was to be held, wait over an hour before they were seen and experience several other periods of waiting between being seen by a junior doctor, undergoing a test procedure, and being seen by a consultant to discuss the results.

Some service users have days of the week and times of the day at which they may feel more or less well and be more or less alert. If researchers are able to negotiate to elicit their views at better times, this may enhance the quantity and quality of the data they collect as well as service users’ experience of participation.

Service users’ views about health services, particularly their predicted expectations, experiences and evaluations of particular services, are likely to develop over time. Researchers need to decide when (and perhaps how often) they will seek to elicit service users’ views, and whether and how they need to explore possible changes in individual service users’ views over time.

Researchers sometimes need to make trade offs as they choose between data collection points. For example, if researchers try to collect data about service users’ prior expectations of an episode of care prospectively, before the episode commences, they risk the data collection exercise influencing what service users do and experience in the course of that episode. If they try to collect data about service users’ prior expectations of an episode of care by asking them retrospectively after they have been through that episode what expectations they had previously, they risk the reported expectations being ‘contaminated’ by the service users’ experience of the episode of care.

**5.4.3 Communication about findings**

Most discussions about feeding back research findings to study participants focus on the ways in which researchers might report back their (finalised) findings. It is now widely accepted that researchers should usually inform participants (or at least those participants who have indicated that they would like to be informed) about their overall findings and what has been done with these. The way this is done may have important implications for participants’ assessments of their experience of participation as a whole, and for their willingness to participate in future research projects.

Researchers who have collected qualitative data, for example from semi-structured interviews, focus group discussions or extended diary entries, have sometimes contacted participants at an earlier stage in the development of their analyses. Some have sent people transcripts or summaries of their own interviews (or, as in the study example summarised in Box 30, giving them an opportunity to review their diary entries). They have done this for a number of reasons, including as an expression of thanks, to ensure the accuracy of the record of what was said, to offer opportunities to clarify, expand on or amend what was said, to indicate respect for the service user and their ownership of the data, and sometimes to offer an opportunity to revisit the service users’ consent to have their data used. Service users’ experiences of and
responses to such follow up are likely to vary, and the appropriateness of the practice may depend on the context. For example, in an investigation of the understandings and experiences of care of people with bipolar disorders and those with whom they lived in intimate (caring) relationships, participants were asked in a second interview about what it had been like for them to receive transcripts of their first interview. While some apparently found the transcripts useful, and drew on them as a means of thinking more about their experiences, others suggested it had been challenging at times to read their own words. Receipt of a transcript at home could also raise questions of with whom it might (or ought to) be shared.41

Some researchers have presented participants with a summary of their early analyses and offered them opportunities to comment on and shape researchers’ interpretations of the broader body of data. The appropriateness of offering the individuals who originally contributed data an opportunity to critique the researchers’ findings is hotly contested. While it can be interpreted as reflecting openness and a commitment to understanding service users’ perspectives, it may be overburdening or unhelpful to some service users in some contexts, and there are concerns that researchers might be unduly influenced by feedback from a few articulate participants who try to ‘correct’ analyses that researchers have based on the views of a range of people to more closely reflect their own particular views.42

The practice of asking a separate sample of service users to comment on the interpretations emerging from researchers’ preliminary analyses is perhaps less problematic. In this case, rather than asking individual service users to compare the preliminary analyses with (a subset of ) the data (or to reiterate their own views and interpretations), a new group of service users are asked to ‘react’ to a presentation of key points from the analysis/interpretation.43 The study summarised in Box 21 used this approach, which might be regarded as an extension of data collection as well as a means of discussing early findings with service users.6

5.5 Research to inform future research

As the examples reported in this Resource suggest, there have been a number of more or less critical reflections on and methodological studies of some of the wide variety of approaches that might be used to investigate service users’ views of health services. However, there are still many uncertainties about the implications of different approaches and there is thus plenty of scope to improve our understanding of how best to investigate service users’ view of health services.

Box 33

Questionnaire length and response rates

It is often assumed that longer questionnaires will result in fewer people returning questionnaires and more missing data on those questionnaires that are returned. Crispin Jenkinson and his colleagues set out to compare the performance of the 15 item Picker Patient Experience questionnaire (PPE-15) when it was embedded in a short (31 item, 4 page) and a longer (108 item, 12 page) questionnaire.

They identified 1445 adults who had recently been discharged from either of two hospitals and randomly allocated them to be sent either the short or the longer version
of the questionnaire. They then compared the proportions of people in the two groups who returned a questionnaire and who filled in all the items on the PPE-15. They also compared the mean scores and a measure of internal reliability for the PPE-15.

721 people were sent the short version of the questionnaire and 67.7% returned this. 724 people were sent the longer version of the questionnaire and 63.7% returned this. Of the people who returned their questionnaires, 81.2% and 78.5% respectively completed all 15 items on the PPE-15. The mean scores on the PPE-15 were 42.41 for the group that received the short questionnaire and 40.57 for the group that received the long questionnaire. None of these differences were statistically significant.

The authors conclude that length of questionnaire does not necessarily affect response rates or the performance of core sets of questions, although they note that their findings cannot be generalised beyond 12 page questionnaires. They also suggest that the extent to which questions on longer questionnaires appear to repetitive to respondents may also influence overall response rates and data quality.


The relative merits of different approaches to identifying and approaching, collecting data from, and feeding back study findings to potential participants might be assessed in terms of a number of criteria. These include:

- Resource requirements (including equipment, skills and costs – for both researchers and participants)
- Research ‘yield’ in terms of:
  - How many people contribute their views
  - Which people contribute their views
  - Which kinds of views can be collected
  - How ‘good’ (complete, honest etc.) the views data is
  - How well researchers are able to understand service users’ views
- Service users’ experiences of participating (including, for example, whether this was easy or difficult, interesting or boring, enjoyable or distressing, helpful or not helpful to them personally)

Although some methodological research will require dedicated funding and separate personnel, there is scope within many research projects to contribute important insights to the improvement of future research into service users’ views with relatively little additional resource or effort. Researchers who are studying service users’ views might thus add value to their investigations of particular substantive questions, for example, by:

- Documenting reflections on issues faced when using specific methods with different groups of people
- Using ‘questerviews’ (‘think aloud’ or retrospective commentary techniques) to explore how people understand, interpret and respond to structured questions and their fixed-response options
- Comparing the ‘yield’ of different methods (e.g. individual and group interviews, alternative questionnaire scales) within studies
- Examining how much and what kind of variability can be seen in accounts obtained at different times or in different ways from the same service users
- Investigating service users’ views about research processes – including those used in studies in which they have participated

SUMMARY OF KEY POINTS

- Services users’ experiences of research that is intended to investigate their views are important both in their own right and because they affect the views that researchers hear and come to understand service users to hold.
- Service users, broadly defined, vary significantly in a number of ways. Individuals may be very differently affected by particular research processes and differently able and willing to express their views in particular data collection contexts.
- Some groups of people are regularly excluded from research studies that aim to canvas the views of a broad population because these studies are usually conducted in the majority language, take place in social contexts that tend to disable and marginalise people who do not conform to dominant norms, and use methods that require significant cognitive, communication and sometimes literacy skills on the part of participants.
- People who tend to be excluded from mainstream research are also likely to have problems using general health services. Some are the intended beneficiaries of particular health and social care services. It is thus important that their views about services can be investigated.
- Broad-based research studies might be made more inclusive by improving the design of invitations and data collection instruments so they are more broadly accessible and acceptable, and/or by providing assistance or modifying approaches to groups with special needs.
- Efforts to improve service users’ experiences of research might improve participation rates and the quality of data collected. However, they might also sometimes be in tension with efforts to improve the robustness of understandings that can be generated about service users’ views.
- Carers may play a number of roles in relation to research to investigate the views of the people they care for. However, carers have their own agendas in relation to the health and social care services provided to the people they care for, and the extent to which they understand and agree with those people’s views is variable. Researchers are thus encouraged to find ways to enable people to express their views for themselves.
- Service users’ experiences and interpretations of invitations to participate in research, of data collection approaches, and of communication from researchers about study findings may all have implications for the views that researchers come to hear.
- Research teams may be better able to ensure that their approaches are well-tailored to their particular study populations if they include members of those populations and/or consult with them as they consider how to invite people to participate, how and when to collect data, and how to provide feedback relating to study findings.
- There are still a number of methodological questions to be answered in relation to studies of service users’ views of health services. Researchers are encouraged to
make use of and to contribute to critical reflections on and formal comparisons of different approaches to the study of service users’ views.
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This document was published by the National Coordinating Centre for the Service Delivery and Organisation (NCCSDO) research programme, managed by the London School of Hygiene & Tropical Medicine.

The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk.
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