Service user experience in adult mental health

Improving the experience of care for people using adult NHS mental health services

National Clinical Guideline Number X

National Collaborating Centre for Mental Health
Commissioned by the
National Institute for Health and Clinical Excellence

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1. PREFACE

This piece of guidance has been developed to advise on improving the experience of care for people using mental health services. The guidance recommendations have been developed by a multidisciplinary team of healthcare professionals, service users, their carers and guideline methodologists after careful consideration of the best available evidence. It is intended that the guidance will be useful to health and social care professionals and service commissioners in providing and planning a high-quality experience of care for people using mental health services (see Appendix 1 for more details on the scope of the guidance).

Although the evidence base is expanding, there are a number of major gaps, and future revisions of this guidance will incorporate new scientific evidence as it develops. The guidance makes a number of research recommendations specifically to address gaps in the evidence base. In the meantime, it is hoped that the guidance will assist health and social care professionals, and people using mental health services and their carers, by identifying ways to improve the experience of care where the evidence from research and clinical experience exists.

1.1 NATIONAL GUIDANCE

1.1.1 What is guidance?

Guidance is derived from the best available research evidence, using predetermined and systematic methods to identify and evaluate the evidence relating to the improvement of the experience of care. Where evidence is lacking, the guidance incorporate statements and recommendations based upon the consensus statements developed by the Guidance Development Group (GDG).

Guidance is intended to improve the process and outcomes of healthcare in a number of different ways. They can:

- be used as the basis to set standards to assess the practice of healthcare professionals
- form the basis for education and training of healthcare professionals
- assist service users and their carers in making informed decisions about their treatment and care
- improve communication between healthcare professionals, service users and their carers
- help identify priority areas for further research.

1.1.2 Uses and limitation of guidance

Guidance is not a substitute for professional knowledge and clinical judgement. They can be limited in their usefulness and applicability by a number of different factors: the availability of high-quality research evidence, the quality of the methodology used in the development of the guidance, the generalisability of research findings and the uniqueness of individuals.

Although the quality of research in this field is variable, the methodology used here reflects current international understanding on the appropriate practice for guideline development (Appraisal of Guidelines for Research and Evaluation Instrument [AGREE]; AGREE Collaboration, 2003[1]), ensuring the collection and selection of the best research evidence available and the systematic generation of recommendations applicable to the majority of people using mental health services. However, there will always be some people and situations for which clinical guideline recommendations are not readily applicable. The guidance does not, therefore, override the individual responsibility of healthcare professionals to make appropriate decisions in the circumstances of the individual, in consultation with the person or their carer.

1.1.3 Why develop national guidance?

The National Institute for Health and Clinical Excellence (NICE) was established as a Special Health Authority for England and Wales in 1999, with a remit to provide a single source of authoritative and reliable guidance for service users, professionals and the public. NICE guidance aims to improve standards of care, diminish unacceptable variations in the provision and quality of care across the NHS, and ensure that the health service is person-centred. All guidance is developed in a transparent and collaborative manner, using the best available evidence and involving all relevant stakeholders.

In the past, NICE has generated guidance in a number of different ways, three of which are relevant here. First, national guidance is produced by the Technology Appraisal Committee to give robust advice about a particular treatment, intervention, procedure or other health technology. Second, NICE commissions public health intervention guidance focused on types of activity (interventions) that help to reduce people's risk of developing a disease or condition or help to promote or maintain a healthy lifestyle. Third, NICE commissions the production of national clinical guidelines focused upon the overall treatment and management of a specific condition. To enable this latter development, NICE has established four National Collaborating Centres in conjunction with a range of professional organisations involved in healthcare.

In addition to these types of guidance, NICE has now commissioned guidance and associated quality standards to improve the experience of people using

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[1] http://www.agreetrust.org

NHS services. More specifically, two pieces of guidance were commissioned; guidance developed by the National Collaborating Centre for Mental Health (NCCMH) for people using adult NHS mental health services (the topic of this report) and guidance developed by the National Clinical Guideline Centre (NCGC) for people using general adult NHS services.

1.1.4 From national guidance to local protocols

Once national guidance has been published and disseminated, local healthcare groups will be expected to produce a plan and identify resources for implementation, along with appropriate timetables. Subsequently, a multidisciplinary group involving commissioners of healthcare, primary care and specialist mental health professionals, service users and carers should undertake the translation of the implementation plan into local protocols taking into account both the recommendations set out in this guidance and the priorities set in the National Service Framework for Mental Health (Department of Health, 1999) and related documentation. The nature and pace of the local plan will reflect local healthcare needs and the nature of existing services; full implementation may take a considerable time, especially where substantial training needs are identified.

1.1.5 Auditing the implementation of guidance

This guidance identifies key areas of clinical practice and service delivery for local and national audit. Although the generation of audit standards is an important and necessary step in the implementation of this guidance, a more broadly based implementation strategy will be developed. Nevertheless, it should be noted that the Care Quality Commission will monitor the extent to which Primary Care Trusts, trusts responsible for mental health and social care, and Health Authorities have implemented this guidance.

1.2 THE NATIONAL SERVICE USER GUIANCE

1.2.1 Who has developed this guidance?

This guidance has been commissioned by NICE and developed within the NCCMH. The NCCMH is a collaboration of the professional organisations involved in the field of mental health, national service user and carer organisations, a number of academic institutions and NICE. The NCCMH is led by a partnership between the Royal College of Psychiatrists and the British Psychological Society's Centre for Outcomes Research and Effectiveness, based at University College London.

The GDG, convened by the NCCMH, included people with experience of using mental health services and carers, and professionals from psychiatry, clinical psychology, general practice, nursing, occupational therapy, and the private and voluntary sectors.

Staff from the NCCMH provided leadership and support throughout the process of guidance development, undertaking systematic searches, information retrieval, appraisal and systematic review of the evidence. Members of the GDG received training in the process of guidance development from NCCMH staff, and the service users and carers received training and support from the NICE Patient and Public Involvement Programme. The NICE Guidelines Technical Adviser provided advice and assistance regarding aspects of the development process.

All GDG members made formal declarations of interest at the outset, which were updated at every GDG meeting. The GDG met a total of eight times throughout the process of guideline development. The GDG was supported by the NCCMH technical team, with additional expert advice from special advisers where needed. The group oversaw the production and synthesis of research evidence before presentation. All statements and recommendations in this guideline have been generated and agreed by the whole GDG.

1.2.2 For whom is this guidance intended?

This guidance will be relevant for adults using secondary mental health services and covers the care provided by community, secondary, tertiary and other health and social care professionals who have direct contact with, and make decisions concerning the care of adults using those services.

The guidance will also be relevant to the work, but will not cover the practice, of those in:

- occupational health services
- the independent sector.

1.2.3 Specific aims of this guidance

The guidance aims to:

- Develop recommendations and quality standards to provide a framework that describes the key requirements for providing a high quality service user experience.
- Identify quality measures that set the expected degree of achievement.
- Identify key areas for improvement in current service user experience.
- Identify key areas for further research that are likely to improve understanding of how to measure and improve the experience of care within adult mental health services.

1.2.4 Quality Standards

Quality standards are a set of specific, concise quality statements and measures that act as markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions.

NICE quality standards enable:

- Health and social care professionals to make decisions about care based on the latest evidence and best practice.
- Service users to understand what service they can expect from their health and social care providers.
- NHS Trusts to quickly and easily examine the clinical performance of their organisation and assess the standards of care they provide.
- Commissioners to be confident that the services they are providing are high quality and cost effective.

For this topic, a NICE quality standard will be produced based on the guidance recommendations. The guidance and the quality standard will be published at the same time. Further information about how NICE produces quality standards can be found on the NICE website[2].

1.2.5 The structure of this guidance

The guidance is divided into chapters. The first three provide a general introduction to guidance and to the methods used to develop them. Chapters 4 to 11 provides a review of the key problems associated with service user experience of mental health services. Chapter 12 provides a review of interventions designed to improve the experience of care. Within each chapter, an 'evidence summary' section is used to summarise the evidence presented, and an 'evidence to recommendations' section is used explain how the GDG moved from the evidence to the recommendations. Finally, recommendations related to each topic are presented at the end of each chapter. On the CD-ROM, further details about the methods used and evidence underpinning the recommendations can be found (see Text Box 1).

Text Box 1: Appendices on the CD-ROM

Search strategies for the identification of studies (interventions review)	Appendix 7
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[2] http://www.nice.org.uk/guidance/qualitystandards/qualitystandards.jsp

2. INTRODUCTION TO SERVICE USER EXPERIENCE

2.1 WHY IS SERVICE USER EXPERIENCE IMPORTANT?

Any attempt to judge the quality of health services would be incomplete without considering the experiences of people who use them. By finding out what service users' think, valuable information can be obtained about problems with the way that services are being delivered and used to assess the impact of efforts to improve the quality of healthcare that is provided.

While health services aim to ensure that people have access to treatments which are effective and safe, this is only one part of a service user's experience of the healthcare they receive. The way services are accessed, the way that peoples' problems are assessed, how referrals between different components of health systems are managed, aftercare arrangements, and the process of discharge all play an important part in service user's overall experience of the care they receive.

This is equally true for users of mental health services where the provision of appropriate information and support across the care pathway is as essential part of delivering a high quality service. Misunderstandings and fears about mental health problems and mental health services can act as barriers to people receiving effective treatments. The ability of services to understand and respond to such concerns can improve people's experience of services and help make sure that they make best use of available treatments. Mental health problems can have a major impact on a person's relationships with others and the capacity of staff to form a therapeutic relationship with people who are experiencing emotional distress is the starting point for helping people achieve better mental health.

Some people with mental health problems have high levels of contact with services over long periods of time. The quality of service user experience is more relevant for these groups due to the high level of contact with these services.

2.2 WHY IS SERVICE USER EXPERIENCE ESPECIALLY IMPORTANT IN MENTAL HEALTH?

2.2.1 Mental Health Act

In terms of service user experience, being detained and treated under the Mental Health Act (1983; amended 1995 and 2007; HMSO, 2007) represents a unique experience in health and social care. In no other field can someone be detained and/or treated against their will, with the possible exception of looked after children who are a special case. The English Mental Health Act (HMSO, 2007) is not capacity-based (unlike the Scottish one) which means that service users may be able to make rational decisions but these can be over-ridden usually if risk is perceived to be an issue. Service users subject to the powers of the Mental Health Act (HMSO, 2007) , then, are being forced to be in a place they do not want to be and may be given treatment they do not want. Moreover, most do not change their mind about the appropriateness of the Act's use long after the episode is over. They continue to think it unjustified (Priebe *et al.*, 2009).

2.2.2 Influence of the Mental Health Act on care

In such a situation, it is difficult to deliver care according to the tenets of this guidance simply because many service users subject to the Mental Health Act (HMSO, 2007) will resist efforts to engage them in a therapeutic dialogue as that is not how they perceive the situation. Further, compulsory treatment, such as control, restraint and rapid tranquillisation, can hardly be delivered with 'dignity and respect'. The question must be posed as to what happens when dignity and respect are lost. In this guidance and quality standard some suggestions are made concerning how the most coercive aspects of being subject to the Act may be ameliorated but in effect in many cases what is perceived as 'care' by providers will not be seen that way by service users. Staff must be alert to their perspectives including the possibility that compulsory treatment will be seen as violence.

The use of the Mental Health Act (HMSO, 2007) has implications for everybody on a ward, detained or not. This at least is the case if the ward is locked, as many are, and informal patients need to ask permission to leave. Further, if as is increasingly the case in many places, there is much use of compulsory treatment this affects the atmosphere on the ward and means that informal patients will be witness to distressing events. Care should be taken to de-brief people who have witnessed such events as well as those who have been subject to them and as well as staff.

2.3 WORK THAT HAS BEEN DONE SO FAR

Over the past few years several documents and initiatives have highlighted the importance of the service user's experience and the need to focus on improving these experiences where possible.

Lord Darzi's report 'High quality care for all' (2008) highlighted the importance of the entire service user experience within the NHS, ensuring people are treated with compassion, dignity and respect within a clean, safe and well-managed environment.

The development of the NHS Constitution (2009) was one of several recommendations from Lord Darzi's report. The Constitution describes the purpose, principles and values of the NHS and illustrates what staff, service users and the public can expect from the service. Since the Health Act came into force in January 2010, service providers and commissioners of NHS care have had a legal obligation to take the Constitution into account in all their decisions and actions.

The King's Fund charitable foundation has developed a comprehensive policy resource - 'Seeing the person in the patient: the point of care review paper' (2008). Some of the topics explored in the paper are used in the development of this guidance and quality standard.

National initiatives aimed at improving service users' experience of healthcare include NHS Choices, a comprehensive information service that helps people to manage their healthcare and provides service users and carers with information and choice about their care. Local initiatives, such as patient advice and liaison services (PALS), have also been introduced.

Despite these initiatives, there is evidence to suggest that further work is needed to deliver the best possible experience for users of NHS services.

In 2005 the Department of Health published 'Delivering race equality in mental health care: an action plan for reform inside and outside services and the government's response to the independent inquiry into the death of David Bennett'. The report contained recommendations about the delivery of mental healthcare to service users, in particular those from black and minority ethnic (BME) communities. The recommendations also address wider issues in mental health settings, such as the safe use of physical interventions.

High-quality care should be clinically effective, safe and be provided in a way that ensures the service user has the best possible experience of care. This guidance on service user experience, and the quality standard developed from it, will aim to ensure that users of mental health services have the best possible experience of care from the NHS.

2.4 A FRAMEWORK FOR PERSON-CENTRED CARE

Much has been written about the importance of person-centred care, and for many years, all NICE guidelines have explicitly aimed to promote person-centred care to take into account service users' needs, preferences and strengths. Similar terms include *patient-centred*, *people-centred, consumer-centred, personalised* and *individualised* (Institute of Medicine, 2001). Several organisations (for example, the Institute of

Medicine; World Health Organization) have used frameworks that set out a number of dimensions of person-centred care, largely derived from that developed for the Picker Institute (Gerteis *et al.*, 1993). Most recently, the Picker Institute Europe has set out eight dimensions, divided into two sub-headings.

1. The relationship between individual service users and professionals:

    - Involvement in decisions & respect for preferences.
    - Clear, comprehensible information and support for self-care.
    - Emotional support, empathy and respect.

2. The way that services and systems work:

    - Fast access to reliable health advice.
    - Effective treatment delivered by trusted professionals.
    - Attention to physical and environmental needs.
    - Involvement of, and support for, family and carers.
    - Continuity of care and smooth transitions.

3. METHOD USED TO DEVELOP THIS GUIDANCE

3.1 OVERVIEW

The method used to produce this guidance was developed based on experience gained from the NICE clinical guidelines programme (NICE, 2009c) A team of health professionals, lay representatives and technical experts known as the Guidance Development Group (GDG), with support from the NCCMH staff, undertook the development of person-centred guidance, based on the best evidence available. There were six basic steps in the process of developing this guidance:

1. Define the scope, which sets the parameters of the guidance and provides a focus and steer for the development work.
2. Define review questions covering all aspects of the scope.
3. Develop criteria for evidence searching and search for evidence.
4. Develop protocols for reviewing the evidence.
5. Synthesise evidence retrieved, guided by the review questions, and produce evidence summaries.
6. Answer review questions with evidence-based recommendations for clinical practice.

To ensure a service user and carer focus, the concerns of service users and carers regarding health and social care have been highlighted and addressed by recommendations agreed by the whole GDG.

3.2 THE SCOPE

Topics are selected by the Department of Health and the Welsh Assembly Government, which identify the main areas to be covered by the guidance in a specific remit (see *The Guidelines Manual* [NICE, 2009c] for further information). The NCCMH developed a scope for the guidance based on the remit. The purpose of the scope is to:

- provide an overview of what the guidance will include and exclude
- identify the key aspects of care that must be included
- set the boundaries of the development work and provide a clear framework to enable work to stay within the priorities agreed by NICE and the NCC and the remit from the Department of Health/Welsh Assembly Government
- inform the development of the review questions and search strategy
- inform professionals and the public about expected content of the guidance

- keep the guidance to a reasonable size to ensure that its development can be carried out within the allocated period.

3.3 THE GUIDANCE DEVELOPMENT GROUP

The GDG consisted of: service users and a carer; professionals in psychiatry, clinical psychology, nursing, social work, occupational therapy and general practice; academic experts in psychiatry and psychology; experts in guidance development. The group had two joint chairs – one professional and one service user. The guidance development process was supported by staff from the NCCMH, who acted as full members of the GDG, and undertook the literature searches, reviewed and presented the evidence to the other members of the GDG, managed the process, and contributed to drafting the guidance.

3.3.1 Guidance Development Group meetings

Seven GDG meetings were held between January 2011 and May 2011. During each day-long GDG meeting, in a plenary session, review questions and associated evidence were presented and assessed, and recommendations formulated. At each meeting, all GDG members declared any potential conflicts of interest, and service user and carer concerns were routinely discussed as part of a standing agenda.

3.3.2 Topic groups

At two meetings, the GDG members formed smaller topic groups to review chapter drafts. These groups were designed to efficiently manage the large volume of evidence appraisal prior to presenting it to the GDG as a whole. Each topic group was chaired by one of the two Chairs, who introduced and led the GDG discussion of the evidence review for that topic and assisted drafting the section of the guidance relevant to the work of each topic group.

3.3.3 Service users and carers

Individuals with direct experience of services gave an integral service-user focus to the GDG and the guidance. The GDG included six service users (one being the joint chair) and one carer. They contributed as full GDG members to writing the review questions, helping to ensure that the evidence addressed their views and preferences, highlighting sensitive issues and terminology relevant to the guidance, and bringing service-user research to the attention of the GDG. In drafting the guidance, they contributed to writing the guidance and creating recommendations from the service user and carer perspective.

3.3.4 Special advisors

Special advisors, who had specific expertise in one or more aspects of treatment and management relevant to the guidance, assisted the GDG, commenting on specific aspects of the developing guidance and making presentations to the GDG. Appendix 3 lists those who agreed to act as special advisors.

3.4 MATRIX OF SERVICE USER EXPERIENCE

While scoping the guidance, the technical team developed a matrix of service user experience, designed to aid the guidance development process. The matrix was based on the dimensions of patient-centred care developed by the Picker Institute Europe[3] and the key points on a pathway of care (as specified by the GDG). With regard to terminology, the GDG preferred the term 'person-centred' rather than 'patient-centred', therefore the latter is not used in the matrix. For more information about the dimensions of person-centred care, see Section 2.4.

A separate matrix was developed for non-acute care, acute care – not under the Mental Health Act (HMSO, 2007), and acute care – under the Mental Health Act. Templates for each matrix can be found in Appendix 6. The matrix was primarily used to classify evidence during the data abstraction and synthesis process (see 3.6.3).

3.5 REVIEW PROTOCOL

For each review, the technical team prepared a review protocol that outlined the background, the objectives and the planned methods. Each protocol contained the associated review questions based on the PICO (Population, Intervention, Comparison and Outcome) framework (see Table 1). A summary of the review protocols can be found in Chapters 4 and 11, and the full protocols in Appendix 5.

Table 1: Features of a well-formulated question on effectiveness intervention – the PICO guide

Population	Which population of service users are we interested in? How can they be best described? Are there subgroups that need to be considered?
Intervention	Which intervention, treatment or approach should be used?
Comparison	What is/are the main alternative/s to compare with the intervention?
Outcome	What is really important for the service user? Which outcomes should be considered: intermediate or short-term measures; mortality; morbidity and treatment complications; rates of relapse; late morbidity and readmission; return to work, physical and social functioning and other measures such as quality of life; general health status; costs?

To help facilitate the literature review, a note was made of the best study design type to answer each question. There are four main types of review

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[3] http://www.pickereurope.org/patientcentred

question of relevance to NICE guidance (see Table 2). For each type of question, the best primary study design varies, where 'best' is interpreted as 'least likely to give misleading answers to the question'.

However, in all cases, a well-conducted systematic review (of the appropriate type of study) is likely to always yield a better answer than a single study.

Deciding on the best design type to answer a specific review question does not mean that studies of different design types addressing the same question were discarded.

Table 2: Best study design to answer each type of question

Type of question	Best primary study design
Effectiveness or other impact of an intervention	Randomised controlled trial (RCT); other studies that may be considered in the absence of RCTs are the following: internally/externally controlled before and after trial, interrupted time-series
Accuracy of information (for example, risk factor, test, prediction rule)	Comparing the information against a valid gold standard in a randomised trial or inception cohort study
Rates (of disease, service user experience, rare side effects)	Prospecitve cohort, registry, cross-sectional study
Costs	Naturalistic prospective cost study
Experience of care	Qualitative evidence

3.6 LITERATURE REVIEW

The aim of the literature review was to identify and synthesise relevant evidence from the literature in order to answer the specific review questions developed by the GDG.

3.6.1 Methodology

A stepwise, hierarchical approach was taken to locating and presenting evidence to the GDG. The approach used varied depending on the review question (see the relevant review protocol in Appendix 5).

3.6.2 The search process

A broad preliminary search of the literature was undertaken in June 2010 to obtain an overview of the issues likely to be covered by the scope, and to help define key areas. Searches were restricted to clinical guidelines and systematic reviews, and conducted in the following databases and websites:

- British Medical Journal (BMJ) Clinical Evidence

- Canadian Medical Association (CMA) Infobase (Canadian guidelines)
- Clinical Policy and Practice Program of the New South Wales Department of Health (Australia)
- Clinical Practice Guidelines (Australian Guidelines)
- Cochrane Database of Abstracts of Reviews of Effects (DARE)
- Cochrane Database of Systematic Reviews (CDSR)
- Embase
- Guidelines International Network (G-I-N)
- Health Evidence Bulletin Wales
- Health Management Information Consortium (HMIC)
- Health Technology Assessment (HTA)
- MEDLINE / MEDLINE In-Process
- National Health and Medical Research Council (NHMRC)
- National Library for Health (NLH)
- New Zealand Guidelines Group
- NHS Centre for Reviews and Dissemination (CRD)
- OMNI Medical Search
- Scottish Intercollegiate Guidelines Network (SIGN)
- Turning Research Into Practice (TRIP)
- United States Agency for Healthcare Research and Quality (AHRQ)
- Websites of NICE and the National Institute for Health Research (NIHR)
- Health Technology Assessment (HTA) programme for guidelines and health technology assessments in development.

Systematic literature searches

After the review questions were formulated, a systematic search strategy was developed to locate all the relevant evidence.

Evidence resulting from searches of: (i) existing NICE mental health guidelines for qualitative research and surveys of service user experience; and (ii) survey literature published by the Care Quality Commission informed the evidence base of each review question. Additional searching was undertaken for evidence of interventions as is outlined below.

The search process for the interventions review

Reviews cited by Goodrich and Cornwell (2008) or included in the Cochrane Consumers and Communication Group or the Cochrane Effective Practice and Organisation of Care Group list of reviews were assessed for eligibility. Additionally, the following websites were checked for eligible reviews:

- Health Issues Centre
- The Studer Group
- Planetree
- The Picker Institute
- The Commonwealth Fund
- The Schwartz Center
- Implementation Science
- Canadian Agency for Drugs and Technologies in Health.

The search strategy used by the most general review of service user focused interventions (Coulter & Ellins, 2006), was updated to identify recent evidence of interventions to improve the experience of care.

Update searches were restricted to RCTs and observational studies, and conducted in the following bibliographic databases:

- Allied and Complementary Medicine Database (AMED)
- Cochrane Central Register of Controlled Trials (CENTRAL)
- Cumulative Index to Nursing and Allied Health Literature (CINAHL)
- Embase
- MEDLINE / MEDLINE In-Process
- PsycINFO.

Search strategies were initially developed for Medline and subsequently translated for use in other databases/search interfaces.

Full details of the search strategies used in the systematic identification of evidence for questions on interventions are provided in Appendix 7.

Reference Manager

Citations retrieved from database searches were downloaded into Reference Manager (a software product for managing references and formatting bibliographies) and all duplicates removed. Records were subsequently screened against the inclusion criteria of the reviews before being quality appraised. The unfiltered search results were saved and retained for future potential re-analysis to help keep the process both replicable and transparent.

Search filters

The RCT filter utilised in the searches is an adaptation of a filter designed by the Health Information Research Unit of McMaster University, Ontario. The observational study filter was created in-house. Each filter comprises medical subject headings (MeSH), explosions (exp), subheadings (sh), and text words (ti,ab/tw) based on study design features and characteristics.

Date and language restrictions

For the key problems review

The search of existing NICE mental health guidelines for qualitative research and survey literature published by the Care Quality Commission was conducted in January 2011.

For the interventions review

The search for existing reviews was completed by March 2011. An update search for RCTs and observational studies was conducted in April 2011 up to the most recent searchable date.

Other search methods

Other search methods involved scanning the reference lists of all eligible publications for more published reports and citations of unpublished research. Key papers were also tracked (prospectively) through time for further useful references.

Study selection and quality assessment

Specific eligibility criteria were developed for each review question and are described in Chapters 4 and 12. Eligible systematic reviews and primary-level studies were critically appraised for methodological quality (see Appendix 9 for methodology checklists). The eligibility of each study was confirmed by the GDG.

3.6.3 Data abstraction and synthesis

Study characteristics were extracted from all eligible studies and guidelines using Microsoft Word-based forms (see Appendix 8).

For the key problems review (see Chapter 4), survey results, and where available, benchmark data published by the Care Quality Commission, were entered into Microsoft Excel (see Appendix 11). Key themes from qualitative evidence were abstracted into the matrix of service user experience (see Appendix 12 and 13).

For the review of interventions, a simplified version of the matrix of service user experience was used to classify each study (see Chapter 12). With regard to the evidence from each study, a narrative description of the key findings relating to the experience of care was drafted by a member of the technical team.

Consultation with another reviewer or members of the GDG was used to overcome difficulties with coding. Data from studies was extracted by one reviewer and checked by a second reviewer. Disagreements were resolved through discussion. Where consensus could not be reached, a third reviewer or GDG members resolved the disagreement. Masked assessment (that is, blind to the journal from which the article comes, the authors, the institution and the magnitude of the effect) was not used since it is unclear that doing so reduces bias (Jadad *et al.*, 1996; Berlin, 2001).

3.7 KEY REQUIREMENTS FOR THE PROVISION OF HIGH QUALITY SERVICE USER EXPERIENCE

Before drafting recommendations, the GDG developed a set of qualitative statements, based on their expert opinion, that set out what they thought would be needed to improve service user experience. These statements were based on discussions held during meetings, as well as feedback between meetings.

3.8 FORMING THE RECOMMENDATIONS

To show clearly how the GDG moved from the evidence (key problems/interventions and key requirements) to the recommendations, each chapter has a section called ‘evidence to recommendations’. The strength of each recommendation is reflected in the wording of the recommendation, rather than by using labels or symbols.

Where the GDG identified areas in which there are uncertainties or where robust evidence was lacking, they developed research recommendations. Those that were identified as ‘high-priority’ were included in the NICE version of the guidance, and in Appendix 14.

3.9 STAKEHOLDER CONTRIBUTIONS

Professionals, service users, and companies have contributed to and commented on the guidance at key stages in its development. Stakeholders for this guidance include:

- service user/carer stakeholders: the national service user and carer organisations that represent people using mental health services
- professional stakeholders: the national organisations that represent health care professionals who are providing services to service users
- commercial stakeholders: the companies that manufacture medicines and other products used in the treatment of mental health problems
- Primary Care Trusts
- Department of Health and Welsh Assembly Government.

Stakeholders have been involved in the guidance’s development at the following points:

- commenting on the draft of the guidance
- highlighting factual errors in the pre-publication check.

3.10VALIDATION OF THE GUIDANCE

Registered stakeholders had an opportunity to comment on the draft guidance, which was posted on the NICE website during the consultation period. Following the consultation, all comments from stakeholders and others were responded to, and the guidance updated as appropriate.

Following the consultation period, the GDG finalised the recommendations and the NCCMH produced the final documents. These were then submitted to NICE for the pre-publication check where stakeholders are given the opportunity to highlight factual errors. Any errors are corrected by the NCCMH, then the guidance is formally approved by NICE and issued as guidance to the NHS in England and Wales.

4. KEY PROBLEMS – REVIEW PROTOCOL AND SOURCES OF EVIDENCE

4.1 INTRODUCTION

This chapter provides the review protocol and information about the source of evidence used when reviewing the key problems associated with service users' experience of care. For the purposes of the guidance, qualitative and survey evidence were categorised using a matrix of service user experience (see Chapter 3 for further information). The evidence and associated recommendations relating to each of the key points on the care pathway can be found in subsequent chapters.

4.2 REVIEW PROTOCOL (KEY PROBLEMS)

The review protocol, including the review questions, information about the search strategy, and the eligibility criteria used for this section of the guidance, can be found in Table 3.

Table 3: Review protocol for the review of key problems in current service user experience

Component	Description
Review question	For people who use adult NHS mental health services, what are the key problems associated with their experience of care?
Sub-question	For people who use adult NHS mental health services, what would help improve the experience of care?
Objectives	To identify the key problems in current service user experience of NHS mental health services.
Population	All people who use NHS inpatient and community adult mental health services
Intervention(s)	Inpatient and community adult mental health services.
Comparison	N/A
Critical outcomes	Key problems associated with the experience of care (including examples of poor experience).
Search strategy	Search all existing NICE mental health guidelines for qualitative research and surveys of service user experience (including complaints from service users); search for relevant Care Quality Commission surveys.
Date searched	February 2011.
Study design	Existing analyses and reviews of qualitative evidence and surveys of service user experience.
Review strategy	Narrative synthesis using tabulation and triangulation between sources of evidence.

Note. Problems clearly associated with treatment in primary care were not included, unless they concerned access to treatment in secondary care.

4.3 SOURCE OF EVIDENCE (KEY PROBLEMS)

Eight NICE clinical guidelines (NCCMH, 2006; 2008; 2009a; 2009b; 2010a; 2011; in press; in preparation) met eligibility criteria. Across these guidelines, there were 133 qualitative studies or reviews of qualitative studies (see Table 4, Table 5, Table 6 and Table 7). Also included were qualitative analyses conducted for three guidelines (NCCMH, 2008; 2010a; in press) (see Table 8 and Table 9), and one new qualitative analysis conducted for the present guidance (see Table 10). Finally, three surveys (Community Mental Health Survey[4], Inpatient Service User Survey[5], The People First survey [Rogers, Pilgrim & Lacey, 1993]) were included (see Table 11).

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[4] http://www.nhssurveys.org/surveys/511

[5] http://www.nhssurveys.org/surveys/520

Table 4: Existing guideline reviews of qualitative evidence

Guideline	**Alcohol dependence and harmful alcohol use (NCCMH, 2011)**	**Antisocial personality disorder (NCCMH, 2009a)**
Review search parameters		
Databases and websites searched	Medline, EMBASE, PsycINFO, CINAHL	Medline, EMBASE, PsycINFO, CINAHL, HMIC
Years searched	Database inception to March 2010	Database inception to May 2008
Inclusion criteria	**Population**: People who are alcohol dependent or harmful drinkers, families and carers, staff who work in alcohol services **Outcome**: Any narrative description of service user/carer experience of alcohol misuse. **Study design**: Systematic reviews and narratives of qualitative studies, qualitative studies.	**Population**: People with antisocial personality disorder, psychopathy or personaity disorder. **Outcome**: Qualitiative data on the experience of care. **Study design**: Any quantiative or qualitative primary study.
Included studies		
Number of included studies	N = 33	N = 15
Total number of participants	Not reported	Not reported
Study design	Qualitative primary studies	Quantiative or qualitative primary studies
Country and setting	Not reported	Not reported
Method of analysis		
Brief description of method and process of analysis	Thematic analysis of qualitative studies (not explicitly stated).	Thematic analysis of qualitative studies (not explicitly stated).
Limitations		
Brief description of limitations	Detail of the reviews' method of analysis was limited.	Not clear how many participants were included in the studies and the review overall. Detail of the reviews' method of analysis was limited.

Table 5: Existing guideline reviews of qualitative evidence

Guideline	Bipolar disorder (NCCMH, 2006)	Borderline personality disorder (NCCMH, 2009b)
Review search parameters		
Databases and websites searched	Not reported	HMIC, Medline, EMBASE, PsycINFO, CINAHL
Years searched	Not reported	Database inception to January 2007 for HMIC; other databases till Aug 2007. Update searches: March 2008/May 2008.
Inclusion criteria	Not reported	**Population**: People with a diagnosis of personality disorder. **Outcome**: qualitiative data on the experience of care. **Study design**: qualitative studies, surverys or observational studies.
Included studies		
Number of included studies	N=2	N=10
Total number of participants	Not reported	N=341
Study design	Qualitative primary studies	Qualitative primary studies.
Country and setting	UK	Not reported
Method of analysis		
Brief description of method and process of analysis	Thematic analysis of qualitative studies (not explicitly stated).	Thematic analysis of qualitative studies (not explicitly stated).
Limitations		
Brief description of limitations	The guideline does not specificy the methods used for qualiative searching of the literature. It is not certain whether the two studies identified were from a systematic search. The details such as the number of participants and method of qualitative data analysis of the studies was not provided.	The authors noted that the qualitative evidence was limited with regards to the treatments reviewed, with an emphasis on dialectical behaviour therapy (DBT), and very little on therapeutic communities to support the positive statements made in the personal accounts above. The literature on self-harm was not reviewed for this guideline. Detail of the reviews' method of analysis was limited.

Table 6: Existing guideline reviews of qualitative evidence

Guideline	**Depression update (NCCMH, 2010a)**	**Drug misuse: psychosocial interventions (NCCMH, 2008)**
Review search parameters		
Databases and websites searched	CINAHL, EMBASE, Medline, PsychInfo, HMIC, PsycEXTRA, PsycBOOKS.	Not reported
Years searched	Database inception to February 2009.	Not reported
Inclusion criteria	**Population**: people with depression and families/carers. **Outcome**: qualitiative data on the experience of care. **Study design**: systematic reviews of qualitative studies, surverys or observational studies.	Not reported
Included studies		
Number of included studies	Total: N = 3 Systematic review: N = 1 Primary qualitative studies (not included in the systematic review): N = 2	N=11
Total number of participants	Not reported	Not reported
Study design	Qualitative primary studies and systematic reviews.	Qualitative and quantitative studies.
Country and setting	Not reported	Not reported
Method of analysis		
Brief description of method and process of analysis	Thematic analysis of qualitative studies (not explicitly stated).	Thematic analysis of studies (not explicitly stated).
Limitations		
Brief description of limitations	The review included primary qualitative sudies but only searched for systematic reviews. This limits the confidence that all relevant primary qualitiative studies were identidied. Detail of the reviews' method of analysis was limited.	The methods used in the review were not reported including how the studies were identified and the method of analysis.

Table 7: Existing guideline reviews of qualitative evidence

Guideline	**Psychosis with substance misuse (NCCMH, in press)**	**Self-harm – longer term management (NCCMH, in preparation)**
Review search parameters		
Databases and websites searched	CINAHL, EMBASE, Medline, PsycINFO, HMIC, PsychEXTRA, PsycBOOKS.	CINAHL, EMBASE, Medline, PsycINFO, HMIC, PsychEXTRA, PsycBOOKS.
Years searched	Database inception to 2010	From 2006
Inclusion criteria	**Population**: People with psychosis and co-existing substance misuse. **Outcome**: Qualitiative data on the experience of psychosis and co-existing substance misuse. **Study design**: Systematic reviews of qualitative studies, qualitative studies.	**Population**: People Individuals who self harm by any method in longer term management. **Outcome**: any narrative description service user experience with self harm. **Study design**: Systematic reviews of qualitative studies, qualitative studies, observational studies and quantitative studies.
Included studies		
Number of included studies	N=21	Systematic review: N=1 Primary studies: N=33
Total number of participants	Not reported	Not reported
Study design	Qualitative studies.	Qualitative and quantitative studies.
Country and setting	Not reported	Not reported
Method of analysis		
Brief description of method and process of analysis	Thematic analysis of qualitative studies (not explicitly stated).	Thematic analysis of qualitative studies (not explicitly stated).
Limitations		
Brief description of limitations	The author of the review noted several of the included studies had limited description of the methodlogy and data analysis procedures. In addition, a variety of approaches were used and the population varied across studies. This limited the synthesis of the studies due to the heterogeniety among the included studies. It was not always clear which populaion the extracted themes was relevant to, making it difficult to assess the generalisability of the finding.	Detail of the reviews' method of analysis was limited.

Table 8: Existing guideline qualitative analyses

Guideline	Depression update (NCCMH, 2010a)	Drug misuse: psychosocial interventions (NCCMH, 2008)
Source of personal accounts		
Websites searched	Healthtalkonline (http://www.healthtalkonline.org)	WIRED website (http://www.wiredinitiative.com/research-addiction.htm)
Year conducted	2008	2006
Inclusion criteria	Personal accounts from people with depression	Not reported
Participants		
Total number of participants	38	Not reported
Country (setting)	UK (any setting)	UK (any setting)
Method of analysis		
Brief description of method and process of analysis	The review team for this guideline used a thematic analysis of interview transcripts to identify emergent themes relevant to the experience of people with depression. From the interviews, the review team identified emergent themes relevant to the experience of people with depression that could inform the guideline. Each transcript was read and re-read, and sections of the text were collected under different headings using a qualitative software program (NVivo). Two reviewers independently coded the data and all themes were discussed to generate a list of the main themes. The anticipated headings included: 'the experience of depression, 'psychosocial interventions', 'pharmacological interventions' and 'healthcare professionals'. The headings that emerged from the data were: 'coping mechanisms', 'accessing help and getting a diagnosis of depression', 'stigma and telling people about depression' and 'electroconvulsive therapy'. The methods adopted by Healthtalkonline to collect interviews were two-fold. First,	The guideline review team took extracts from peronal stories on the WIRED website.

	the participants were asked to describe everything that had happened to them since they first suspected a problem. The researchers tried not to interrupt the interviewees in order to have a relatively unstructured, narrative dataset. The second part was a semi-structured interview in which the researcher asked about particular issues that were not mentioned in the unstructured narrative but were of interest to the research team.	
Limitations		
Brief description of limitations	The guideline review team reported that as they relied on transcripts collected by other researchers with their own aims and purposes, information on issues that are particularly pertinent for people with depression that could be used to inform recommendations may not have been collected. Moreover, the review team did not have access to the full interview transcripts and therefore had a selective snapshot of people's experience.	Little information about the method used to extract themes and the number of personal stories used.

Table 9: Existing guideline qualitative analyses

Guideline	**Psychosis with substance misuse (NCCMH, in press)**
Source of personal accounts	
Websites searched	Healthtalkonline (http://www.healthtalkonline.org/), Dual Recovery Anonymous (http://draonline.org/), Meriden Family Programme (http://www.meridenfamilyprogramme.com/), Talktofrank (http://www.healthtalkonline.org/), Foundations Associates (http://dualdiagnosis.org/), Bipolarworld (http://www.bipolarworld.net/), and Rethink (http://www.rethink.org/)
Year conducted	2009
Inclusion criteria	Personal accounts from people with bipolar disorder, schizophrenia, schizoaffective disorder, or psychotic disorder with coexisting problematic or dependent substance use.
Participants	
Total number of participants	48
Country and setting	Majority from UK, but some from US (any setting)
Method of analysis	
Brief description of method and process of analysis	The guideline review team undertook their own thematic analysis of the narrative accounts to explore emergent themes. Each transcript was read and re-read and sections of the text were collected under different headings using a qualitative software programme (NVivo). Initially, the text from the transcripts was divided by a member of the guideline review team into six broad headings emerging from the data: impact and experience of psychosis and coexisting substance misuse; access and engagement; experience of treatment; carers' perspectives; and support and services. Under these broad headings, specific emergent themes that were identified separately and coded by two researchers. Three GDG members also individually coded the testimonies into emergent themes. Overlapping themes and themes with the highest frequency count across all testimonies were extracted and regrouped under the subsections below.
Limitations	
Brief description of limitations	The guideline review team reported that some of the accounts were written in retrospect, whereas others were written more recently, or in the present. This may have had an impact on the way in which the experiences were recalled; moreover, the accounts cover different time periods which may affect factors such as attitudes, and information and services available.

Table 10: Qualitative analysis conducted for service user experience guidance

Guidance	Service user experience
Source of personal accounts	
Website	Healthtalkonline (Healthtalkonline, 2011) (http://www.healthtalkonline.org/mental_health/experiences_of_psychosis)
Year conducted	2010
Inclusion criteria	Personal accounts from people with psychosis (many had received a diagnosis of schizophrenia)
Participants	
Total number of participants	31
Country and setting	UK (any setting)
Method of analysis	
Brief description of method and process of analysis	
Limitations/ notes about the analysis	
Brief description	• Qualitative researchers are usually reluctant to use numbers in the analysis because the sampling strategies typically aim to represent a wide range of perspectives and experiences, rather than to replicate their frequency in the wider population. Thus, even if an experience is relatively rare, we would seek to include it. If we take this approach to collecting the sample it is important that the analysis reflects the diversity of experiences, not just those that are most frequent. This explains why, although some qualitative researchers may use terms such as 'few', 'many' or 'some' in describing their data, they tend to avoid relative frequencies (for example, 54% of our sample liked their doctor, or had a particular side-effect) that would be misleading if they were assumed to apply to the wider population. • Participants in the sample often disagree with each other – and for important reasons – so the key points section at the end of each brief document often contains necessarily contradictory information. This is appropriate and evidence of a diverse sample. • The stories that people told were not organised into discrete events along an easily identifiable 'care pathway'; instead relevant parts have been extracted from the data set as a whole. Whilst this provides relevant information about the experiences of services, a deeper understanding of the data can be gained if they are understood in context.

	• Related to the above point: this data has been somewhat artificially separated; that is, sometimes access, assessment, referral to inpatient care, and experience of an inpatient unit could happen in a matter of hours and be counted as one event in the context of the stories that people told. • Participants were not always aware of who they were being treated by (primary or secondary care/different professionals) and whether this intervention was voluntary or compulsory. • Participants were asked about their life histories, and accordingly some data on their experiences of services may not be contemporary, but where this happens it is noted.

Table 11: Surveys of mental health service user experience

Guidance	**Service user experience**
Source of personal accounts	
Website/publication	The People First survey, conducted by MIND (Rogers A, Pilgrim D, Lacey R (1993) *Experiencing Psychiatry: User Views of Services*. Macmillan/ Mind Publications, London.) Care Quality Commission Surveys: • National Centre for Social Research (2010) Community Mental Health survey: http://www.nhssurveys.org/surveys/511 • Care Quality Commission (2009) Inpatient Service User Survey: http://www.nhssurveys.org/surveys/520
Year conducted	The People First survey: 1990 Community Mental Health survey: 2010 Inpatient Service User Survey: 2009
Inclusion criteria	The People First survey: People who had received at least one period of inpatient treatment in a psychiatric hospital in England and Wales. Community Mental Health survey: Service users aged 16 and over, who had been seen at a NHS Trust between 1 July 2009 and 30 September 2009 and had received specialist care or treatment for a mental health condition. Inpatient Service User Survey: People aged 16-64, who had stayed on an acute ward or a psychiatric intensive care unit (PICU)* for at least 48 hours between 1 July 2008 and 31 December 2008 and were not current inpatients at the time of the survey.
Participants	
Total number of participants	The People First survey: 516 Community Mental Health survey: 17,000 + Inpatient Service User Survey: 7,500 +
Country and setting	UK (any setting)
Method of analysis	
Brief description of method and process of analysis	
Limitations	
Brief description of limitations	
* "Other types of wards were not included in the scope of the survey. This included rehabilitation, secure and specialist units, for example, for people requiring treatments for substance misuse or wards which primarily served people with a learning disability. This is because service provision varies between trusts, and the services received would be very different." (CQC, 2009)	

5. ACCESS TO COMMUNITY CARE

5.1 INTRODUCTION

This chapter provides evidence about the key problems relating to access to community care services, and the key requirements for high quality service user experience. Recommendations for best practice and recommendations for research can be found at the end of the chapter.

People with mental health problems may seek help, avoid help or, in some cases, not realise that they either could benefit from help or that treatment and help that could be of benefit to them is available. There are probably many other orientations or attitudes towards treatment and help in mental health, or indeed towards physical health. These different attitudes are commonly collapsed into 'treatment seeking' and 'treatment avoidant'. In mental health, people may be treatment avoidant and treatment rejecting, as a result of a lack of insight into their condition, or because the treatments are associated with sometimes severe side effects or because treatment has been regarded as ineffective (NCCMH, 2010b).

When people seek help, access to effective help will depend upon availability, speed and ease of access, and the direct experience of making contact with a service provider. Moreover, when people are seeking help with their mental health for the first time, the way in which they encounter services will influence the degree to which they engage with services and sustain their engagement in the future. There are many reasons why people experience obstacles to access, including lack of locally effective treatments and long waiting lists (NCCMH, 2011). In addition, many services pay little regard to communication skills, information provision and staff attitudes, all of which will influence the experience at first point of contact and impair the extent and degree of engagement with services and treatment. For people who are 'treatment avoidant', these factors become even more important as to whether they will even consider help when relatives or friends encourage potential service users to seek help. For this group, particular efforts on behalf of mental health and social care professionals are required.

While it is important to ensure services reach out and adapt to all those who are treatment avoidant, as well as ensuring a good experience for those who are treatment seeking, there are particular groups who seek help much less than others. For example, African-Caribbean and some other minority ethnic groups are suspicious of services, and their first direct contact is often experienced as alienating. This is at least partly a result of services not being tailored to the specific needs and orientations of ethnic subgroups, including those who have been shown to have a higher incidence of some serious mental health problems (NCCMH, 2010b, see 5.3). Sadly, experiences of racism, discrimination or simply cultural ignorance or insensitivity, also occur within the health service, including in mental health. The result is that people from African-Caribbean backgrounds, for example, access services much later than many other ethnic groups, and are, therefore, over-represented within crisis services and subject to compulsion more often than others (NCCMH, 2010b, 5.3.6).

Current practice

Following the closure of the old asylums, the development of community psychiatry was an unplanned reaction to the absence of services for significant numbers in the population, except in-patient units within general hospitals. With high rates of re-admission, often reaching 70% or more, community mental health teams were developed to help maintain people in the community. Mental health services have since tried to improve access to most groups with varying degrees of success. New teams have been developed as a result of the National Service Framework (DH, 1999). For example, to provide more assertive community-based care for people who are often treatment avoidant, the NSF led to the widespread development of teams, such as Assertive Community Treatment (also known as Assertive Outreach) Teams. Other teams aimed to provide treatment at home, to promote engagement and to avoid admission to hospital (Crisis Resolution and Home Treatment Teams; CRHT). And still others were designed to improve those early and formative experiences of services for people with psychosis, experiences that can prefigure entrenched negative attitudes to service. In addition, these Early Intervention Services (EISs), it was hoped, would be particularly engaging for ethnic subgroups (NCCMH, 2010b).

There is evidence now, that CRHTs do reduce dependence on in patient units and probably improve access to services in a crisis. There is also evidence that EISs are effective and preferred to other services, which may improve engagement and readiness to access services (NCCMH, 2010b). However, evidence for any of these community services specifically improving access or engagement for people from minority ethnic groups is equivocal, lacking or negative (NCCMH, 2010b). Nevertheless, wherever comparisons with inpatient units have been made, most of these services, as well as day hospitals and crisis houses, are preferred (Johnson, *et al.* 2010) and are likely to improve access for some groups.

5.2 KEY PROBLEMS REGARDING ACCESS

Evidence from qualitative reviews/analyses and surveys addressed the following domains of person-centred care:

- involvement in decisions and respect for preferences
- clear, comprehensible information and support for self-care
- emotional support, empathy and respect

- fast access to reliable health advice
- effective treatment delivered by trusted professionals.

No evidence was identified that directly addressed:

- attention to physical and environmental needs.
- involvement of, and support for, family and carers
- continuity of care and smooth transitions.

For the purposes of the review, themes from the qualitative evidence are summarised only briefly here, with further details provided in Appendix 12. Domains and sources of evidence without themes are not listed below.

5.2.1 Involvement in decisions and respect for preferences

Evidence from qualitative reviews

Barrier: information

One study found that a barrier to accessing services was due to the mismatch between how information was offered and how people with depression prefer to seek information:

> *I would never sit down and read something about medicine. It has never interested me. I learned more from watching that commercial on television.* (Depression update guideline [NCCMH, 2010a])

Evidence from qualitative analyses

Facilitator: longer time to speak about problems

Service users expressed wanting to have more time to speak about their problems which were often complex, and not be given pills and 'sent home':

> *He [the GP] asked me what was going on in my head, and I said, "I had thoughts in the third person, like voices in my head telling me stuff." And he said, "Had I been taking drugs and stuff?" I said, "Just smoking weed." And he said, I hadn't been… I can't remember what he said now. He said something else as well. And then he prescribed me some anti-psychotic medications, as well as a sleeping pill, and anti-anxiety pills as well.[***]*
>
> *I: So what was this first doctor like?*
>
> *R: He was all right, but I don't think he actually had that much time. Compared to doctor I've got now, because the surgery I went to before, obviously had like more people to cover. And they seemed like in a rush, they weren't, like, as bothered in my opinion as the ones that I see now.*
> (Experiences of psychosis [Healthtalkonline, 2011])

5.2.2 Clear, comprehensible information and support for self-care

Evidence from qualitative analyses

Barrier: information

The qualitative analysis found that a key problem regarding access to services was due to the provision of information. Service users described that it was not uncommon that there was a lack of information being offered on treatment facilities available to them (Drug misuse guideline [NCCMH, 2008]).

5.2.3 Emotional support, empathy and respect

Evidence from qualitative reviews

Barrier: professionals

Across three guidelines professionals were viewed as a barrier to accessing services (Alcohol guideline [NCCMH, 2011]; Depression Update guideline [NCCMH, 2010a]; Self-harm guideline [NCCMH, in preparation]). In the Alcohol guideline, two studies described the experience of women when accessing services and found that when they sought help from professionals they were denied access, treated poorly or silenced (Alcohol guideline [NCCMH, 2011]); and found in another guideline that healthcare professionals were unresponsive (Depression Update guideline [NCCMH, 2010a]). In order to access services, service users' described how confidence and trust were important in order to seek help but how they would not ask strangers for help or support including professionals:

> *If there would be someone with whom I have no trusting relation I would of course not allow a touch, I would not say a word, I would not show a feeling. Nothing! Only someone I trust.* (Self-harm guideline [NCCMH, in preparation])

Evidence from qualitative analyses

Facilitator: professional

Many service users in one quantitative analysis described how difficult it was to access help when they were very distressed and the role of the healthcare professional to facilitate and improve experience of care. For example, one service users described the 'courage' it took to see his GP when he had cut his wrists. He was spotted by reception staff who took him straight to the doctor who was 'very warm' when he couldn't manage to speak (Experiences of psychosis [Healthtalkonline, 2011]).

5.2.4 Fast access to reliable health advice

Evidence from qualitative reviews

The qualitative reviews in four guidelines highlighted service users' preferences to accessing fast and reliable health advice, for example by using a telephone service. The ability to self-refer was seen positively (Alcohol guideline [NCCMH, 2011]; ASPD guideline [NCCMH, 2009a]; BPD guideline [NCCMH, 2009b]; Self-harm guideline [NCCMH, in preparation]).

Barrier:

Long waiting lists and being passed from one service to another before getting the right intervention were seen as barriers to accessing care (BPD guideline, [NCCMH, 2009b]).

Preference: GPs

Preferences to fast access to reliable health advice included access to services via a GP to discus alcohol-related problems (and to deliver brief interventions) but a referral to a specialist when the problem could not be treated in primary care (Alcohol guideline [NCCMH, 2011])

Preference: psychiatric emergency services

Another preference included access to services via A&E that had a separate psychiatric emergency service (ASPD guideline [NCCMH, 2009a]).

Preference: phone or crisis team

Service users also expressed wanting fast immediate support through the use of telephone services or (ideally) 24-hour crisis intervention teams with specific training and expertise in personality disorders, with a range of service options to choose from and access at different times such as one-to-one sessions, out-of-hours phone support, crisis beds and an open clinic. The ability to self-refer was seen as beneficial (BPD guideline [NCCMH, 2009b]).

Preference: greater accessibility

A similar theme was found in the self-harm guideline where across two studies service users described their preference for more accessible services by including 24-hour staff, walk-in services, minimal waiting times, central location and telephone access (Self-harm guideline [NCCMH, in preparation]).

Facilitator: crisis care

One study suggested that prompt and improved access to crisis care in early phases of acute relapse is needed in the community to avoid admission to hospital:

> *...everything should be done to avoid hospital: the staff there are generally not interested and offer virtually no psychological support. The experience is traumatic and one's stay tends to be prolonged.* (Bipolar disorder guideline [NCCMH, 2006])

One service user benefited from intensive community psychiatric nurse (CPN) home support and a relapse prevention plan (Bipolar disorder guideline [NCCMH, 2006]).

Facilitator: alternatives

Other improvements to community care suggested by service users were an out-of-hours service and a safe house and an advocate service and helpline (BPD guideline [NCCMH, 2009b]).

Evidence from qualitative analyses

Barriers: service (waiting list)

Two qualitative analyses found that a barrier to accessing services was due to the prolonged waiting times when being referred to services and the limited resources available (Depression Update guideline [NCCMH, 2010a]; Drug misuse guideline [NCCMH, 2008]).

Service users with depression raised issues regarding referral, waiting lists and accessing NHS services. Some people said that that they waited too long to be referred to a psychiatrist or receive psychotherapy. One person said that while she was on a waiting list she was unable to cope with her depression:

> *I was referred to the psychiatric hospital for assessment. Although I think it probably took about two months I believe between the initial sort of GP's referring letter and getting an appointment. Which again in retrospect was, was way, way too long, way too long. I was really, really ill and barely coping.* (Depression Update guideline [NCCMH, 2010a])

This was also expressed in the Drug misuse qualitative review where service users expressed concern over the delay in accessing treatment and how this can lead to criminal behaviour, return to drug misuse and can have a negative impact on seeking further treatment (Drug misuse guideline [NCCMH, 2008]). The use of violence to access services was described by a service user with depression as her only resort in order to be referred to NHS services:

> *It's very difficult to get a hospital bed for quite severe mental illness. You've got to be suicidal . . . I was feeling suicidal. I was also quite violent at times. I mean in my own doctor's surgery, I swept all the things off his desk you know . . . there was a part of me, kind of watching what I was doing . . . saying, 'Right, well make it really dramatic.' I wasn't pretending exactly, but I knew I had to make a song and dance to get heard.* (Depression Update Guideline [NCCMH, 2010a])

Due to the strain on resources and limited spaces available in different treatment settings, some service users with drug misuse problems experienced being turned away from services:

> *I really thought I was going to get off it, but I was told that I was going to have to wait a month for an appointment. When I went for that appointment they said I wasn't on it too badly so there wasn't a rush for me to be seen; it was going to take over 6 months.* (Drug misuse guideline [NCCMH, 2008])

Barrier: medication

Prescriptions not being available at the right time were a barrier to accessing medication (Experiences of psychosis [Healthtalkonline, 2011]).

Barrier: Professional

One person was discouraged by primary care staff from seeing a mental health professional (Experiences of psychosis [Healthtalkonline, 2011]).

Evidence from surveys

The Community Mental Health Survey (National Centre for Social Research, 2010) (see Chapter 4 for further information about the survey) had four questions relevant to the domain of 'fast access to reliable health advice' (see Appendix 11 for full results). On a national level, of those survey respondents who knew who their care co-ordinator (or lead professional) was, most (74%) could always contact their care co-ordinator if they had a problem, but 22% answered 'sometimes' and 4% answered 'no'. The benchmark data indicate that there was a relatively small variation in performance between trusts. However, across all service users, 44% did not have the number of someone from their local NHS Mental Health Service that they could phone out of hours, and the benchmark data indicate wide variation in performance between trusts. Of those who had called the out of office number, the majority (66%) got through immediately, but half only got help to some extent (32%) or not at all (18%). The benchmarking data suggested relatively wide variation between trusts.

5.2.5 Effective treatment delivered by trusted professionals

Evidence from qualitative reviews

Barrier: lack of support as caregiver

One study found that female service users with mental health and coexisting substance misuse problems described reduced access to services when there was no available child care (PSM guideline [NCCMH, in press]).

Facilitator: lack of access to psychologists

Many service users in one study reported that they had little access to psychologists:

> *...pushed for some counselling but was made to feel like I was asking for a pot of gold by the hospital psychiatrist.* (Bipolar disorder [NCCMH, 2006])

Evidence from qualitative analyses

Barrier: professionals

Some service users reported that they did not receive adequate help when trying to access services:

> *I went to every doctor's . . . everywhere. But we're smack heads, "See the door, close it on the way out, fuck off". That's all we got . . . them days . . . I was asking for methadone, that was all. I wasn't asking for valies [valium] or temazies [temazepam] or anything. . . You get sick of asking for help and not getting any.* (Drug misuse guideline [NCCMH, 2008])

Service users described not being given help when it was needed during the first stages of being assessed for severe mental illness:

> *I was about 27, [um] I realised something was going drastically wrong and I picked up the phone to my then GP and said, "I think I need to be in hospital. A psychiatric hospital." It's quite a renowned psychiatric hospital in this area. And her response to that was, "Well what do you want to go there for?" And that was the limit of the help I got from the GP at that time.* (Experiences of psychosis [Healthtalkonline, 2011])

5.2.6 Other themes (including stigma)

Evidence from qualitative reviews

Barrier: stigma

Service users in one study described stigma as another barrier to seeking help due to the concern of disclosing to others about self-harm because of fear that others would not understand them and fear of being labelled (Self-harm guideline [NCCMH, in preparation]).

Barrier: stigma of diagnosis

Two barriers to accessing effective treatment delivered by trusted professionals was due to the stigma associated with their diagnosis as seeking help may *'threaten an already weakened sense of self'* (Depression Update [NCCMH, 2010a]).

Barrier: stigma of diagnosis

Service users in three guidelines found that the stigma associated with their diagnosis was a barrier to accessing help (Bipolar guideline [NCCMH, 2006];

BPD guideline [NCCMH, 2009b]; PSM guideline [NCCMH, in press]) however a minority in two qualitative reviews viewed the opposite (BPD guideline[NCCMH, 2009b]; PSM guideline [NCCMH, in press]). For example, in one qualitative review, service users described how the stigma associated with mental illness was a barrier to them accessing services and ultimately receiving a diagnosis and treatment for their condition:

> *'I was 42 before I was diagnosed. I first became aware I was suffering severe mood swings as a young child. I can only ever remember being either very happy or very sad. When low I wished I'd never been born. My dad had also always suffered severe mood swings throughout my childhood and spent long spells in hospital, but I was told it was for treatment for a 'heart attack'. My parents felt such shame about his mental illness they never told me about it, and they never told me their suspicions about my illness. It was only when I broke the news about my diagnosis more than 20 years later that they said they 'had always known'. I felt quite angry really that they'd never said something earlier. If I had been diagnosed earlier I would have got the right treatment earlier.'* (Bipolar guideline [NCCMH, 2009b]*)*

Another service user described how the stigma associated with their diagnosis hindered their recovery:

> *'It makes you feel bad... it makes you feel even worse… when people don't trust you and think you're going to do something to someone.'* (PSM guideline [NCCMH, in press])

However, a minority expressed the positive aspects of their diagnosis and how it accurately described their experience:

> *'I feel that if I survive it I've been through a very privileged experience and that I can actually make something of it...'* (PSM guideline [NCCMH, in press])

Barrier: stigma of services

Service users in two guidelines found that the stigma associated with seeking help and receiving treatment was a barrier to accessing help (Alcohol guideline [NCCMH, 2011]; Self-harm guideline [NCCMH, in preparation]) including the stigma associated with receiving treatment by specialists as it was perceived that you had a severe alcohol problem (Alcohol guideline [NCCMH, 2011]).

Barrier: attitudes

Another barrier to accessing services was the stigma and attitudes towards seeking help. A minority in one study included in the qualitative review on self-harm, viewed seeking help as unacceptable. These views were echoed in other study where service users viewed themselves as strong enough to handle the problem on their own; or that the problem would resolve itself; or that no one could help (Self-harm guideline [NCCMH, in preparation]).

Barrier: lack of motivation

Another barrier to accessing help was the lack of motivation characteristic of the depression itself (Depression Update [NCCMH, 2010a]).This barrier was also found in the Drug Misuse guideline (NCCMH, 2008):

> *'You have to actually seek treatment. It's up to them if they want to start…If a person's not ready, they're not ready.'*

Improvement: education

Service users in one study felt that a way to reduce the stigma of their diagnosis and seeking help which acted as barriers to accessing services was to provide more education about mental health difficulties in schools, to educate about vulnerability and to teach students how to seek appropriate help if they are experiencing difficulties themselves (BPD guideline [NCCMH, 2009b]).

Evidence from qualitative analyses

Barrier: fear of involving social services

For some service users the obstacle to accessing treatment was fear of involving social services with regard to their children:

> *'I used to work around the children so that I could pick them up from school and make dinner and things like that . . . I was worried what would happen to the children if I went to get help . . . so I just stayed on it, so I could get up in the morning and get the kids to school.'* (Drug misuse guideline [NCCMH, 2008])

Barrier: stigma of diagnosis

As found in the qualitative review, many online accounts, from both service users and carers, highlighted the experience of interacting with others in the community and the stigma that their dual diagnoses carried. The experience of stigma often elicited feelings of shame, embarrassment, and frustration:

> *'When we go out there in the community people might know you have got a mental health problem, you might not look different to the, but they know you have got that. There is a stigma against it and a discrimination taboo..because of the label, and because of what it stands for. Which is people don't understand.'* (PSM guideline [NCCMH, in press])

Barrier: stigma of diagnosis/cultural issues

One theme that emerged in several testimonies was that access to care was more difficult for those coming from a black or minority ethnic (BME) group or a different cultural background. Factors that affected access to care for BME groups were a fear of accessing treatment due to the conceptualisation of mental illness in their home country or native culture, or fear of stigma.

> *'Well people look at you differently if you say you've got a mental health problem back home. They don't treat you the same. I think now it's changed but that, when I was there it was different…'* (PSM guideline [NCCMH, in press])

Barrier: fear of contacting services

A significant number of factors affected accessing services, including fear of contacting a healthcare professional about substance misuse, and uncertainty about how to begin accessing treatment or who to contact.

> *'And I did ask somebody from my mental health team if it was possible to have like a social worker and she said no, she didn't know how I would access that. I asked my doctor the same thing she didn't know how I would access anything like that so it just leaves you vulnerable.'* (PSM guideline [NCCMH, in press])

Barrier/facilitator: social networks

Many participants described how their social networks facilitated or impinged on accessing care or treatment (PSM guideline [NCCMH, in press]).

Barrier/facilitator: initial contact

The first time people accessed mental health services, or spoke about their mental health, often had an influence on their engagement with services after that (Experiences of psychosis [Healthtalkonline, 2011]).

5.2.7 Evidence summary

Below is a summary of the evidence found for the key problems associated with access to care, categorised according to the dimensions of person-centred care.

Involvement in decisions and respect for preferences

The qualitative evidence suggested that service users' preference for types of information may not match how information is offered, which can act as a barrier to accessing services. Furthermore, limited time and healthcare professional understanding in primary care act as a barrier.

Clear, comprehensible information and support for self-care

The qualitative evidence suggested that a lack of information acts as a barrier to accessing services.

Emotional support, empathy and respect

The qualitative evidence suggested that a key problem regarding access was professionals who did not display emotional support, empathy and respect which acted as a barrier to accessing services. Healthcare professionals who demonstrated support and qualities of empathy and respect could facilitate access.

Fast access to reliable health advice

The qualitative evidence suggested that long waiting lists for mental healthcare and being passed from one service to another were barriers to accessing services. A preference was shown for self-referral and fast access to health advice through, for example, a telephone service. In addition, improved access to crisis care in early phases of acute relapse is needed in the community to avoid admission to hospital.

The survey results suggest that many service users do not have the phone number of someone from their local NHS Mental Health Service that they can contact out of hours. In addition, more could be done to help those that do contact services out of hours.

Effective treatment delivered by trusted professionals

The qualitative evidence suggests that getting access to secondary care healthcare professionals can be difficult, and no child care services can stop service users accessing mental healthcare.

5.3 KEY REQUIREMENTS FOR THE PROVISION OF HIGH QUALITY SERVICE USER EXPERIENCE

The key requirements (qualitative statements based on the GDG's expert opinion) for the provision of high quality service user experience for access to care are shown in Table 12.

Table 12. Key requirements for the provision of high quality service user experience (access to care).

Dimensions of person-centred care	**Statement**
Involvement in decisions and respect for preferences	• Service user preferences should be considered when offering appointments, including requirements under the Equality Act 2010.
Clear, comprehensible information and support for self-care	• Service users will be able to understand and use information which will support them. The range and type of information produced will vary according to the range of service users' needs

	and capacities. (This includes educational, developmental and language needs). Professionals will be trained to assess and match service users to information and support which will have meaning and be relevant for the individual service user. Professionals will need to review their assessments regularly and respond to service users' changing needs. • Secondary care mental health services should give information to primary care services (GPs) so they are able to pass it onto the service users. This should include information on the mental health service, what will happen at the appointment etc. This should include who the person will be seen by, and their role, when they go to the mental health service. • Various formats should be used to contact services users such as emails, texts, phone calls etc. not just letters. Services should establish/agree how the service user would prefer to be contacted. • Service users should be sent a copy of the referral letter. • Healthcare professionals should be easily recognisable.
Emotional support, empathy and respect	• Service users will be treated in a respectful way at all times. It is the duty of the professional to make the effort and to employ other resources where necessary (trained Mental Health Interpreters for example) in order to understand Service users' world views, life experiences and immediate needs for safety.
Fast access to reliable health advice	• Service users should be able to have fast/24 hour access to reliable health advice and interventions which they understand and which meet their perceived needs for safety. A range of containing interventions should be available if there is any waiting period for an appointment, including trained and supervised reception staff (face to face or by telephone) help lines, texting services etc. • Support and health and social care professionals, trusted by the Service user, should be able to refer directly into secondary care.
Effective treatment delivered by trusted professionals	• Treatment offered should be appropriate for the individual service user and delivered by a professional the service user trusts. If the service user does not trust the allocated professional, the professional should cease working with the service user and a professional whom the service user trusts needs to be found within a reasonable time period. • Service users should be contacted by secondary care services within a week of being referred by primary care. • People in crisis should be seen within 4 hours.
Attention to physical and environmental needs	• Access should be available from settings which are appropriate for service users. These may include community settings such as community centres and libraries.
Involvement of, and support for, family and carers	• Families and carers' support needs should be identified at the earliest opportunity and appropriate services should be involved where requested. • Fully qualified and trained mental health interpreters should always be used. • Family and carers should not normally be used for interpreting purposes as this could compromise their relationship with the service user and the service user's right to confidentiality. •
Continuity of care and smooth transitions	• Service users should be involved in and kept informed at every point of a transition or referral to another service. The referring

	professional is wholly responsible for the service user's care until the referral has been acknowledged and a first session with the referrer has been delivered.

5.4 EVIDENCE TO RECOMMENDATIONS

The key problems outlined in the qualitative reviews, analyses and surveys highlighted a wide range of issues. These included the following: limited time with healthcare professionals to discuss problems, incorrect or inadequate information about treatment options and facilities, a lack of rapport with professionals, long waiting lists, lack of continuity of care and limited NHS resources, including childcare and access to secondary healthcare professionals. Another barrier to accessing community care highlighted by service users was the stigma and negative attitudes associated with their diagnosis and treatment. In particular, access to community care was found more difficult for BME groups due to stigma and cultural issues. Finally, the evidence highlighted the requirement for improved access to crisis care.

The GDG articulated a number of goals for improving the access to community care in mental health services. Some of the more fundamental targets for improvement included the following: the provision of comprehensive information about how mental health services can be accessed matched to the needs, preferences, language and understanding of the individual; communication and involvement amongst professionals and service users at all steps of the care pathway; treating service users with respect; and finally the provision of treatment that is person-centred and delivered by a trusted professional. Some other key requirements were aspirational in nature, such as access to 24 hour health advice and interventions, secondary care services contacting service users within a week of referral from primary care, and finally the provision of fully qualified and trained mental health interpreters.

On reviewing the key problems and requirements the guidance group identified a number of broad issues that relate to all points on the care pathway, but were of particular importance to access to community care. The recommendations for these aspects of the experience of care included the following: building supportive, empathic and non-judgemental relationships with service users; ensuring the provision of comprehensible verbal and written information in the appropriate language or format about the nature, treatments, and services for their mental health problems including relevant 'Understanding NICE Guidance', and finally, acknowledging stigma and respecting service users' diverse cultural, ethnic and religious backgrounds. Finally, trust boards should develop a strategy with all other local organisations to combat the stigma associated with mental health problems and using mental health services, both within the community and in the NHS.

All these issues were placed in care across all points on the care pathway in the NICE guidance.

Areas identified by the guidance group of particular importance for improving the access to community care included the following: receiving a copy of the referral letter when it is sent to mental health services, being offered an appointment within 2 weeks of the date of referral, providing comprehensive information about the assessment such as the name of the professional who will assess them, information about the mental health service and the process of assessment amongst other things. Finally, mental health services should establish close working relationships with primary care services and voluntary organisations to enhance accessibility of mental health services.

5.5 RECOMMENDATIONS

5.5.1 Practice recommendations relating specifically to access

5.5.1.1 When people are referred to mental health services, ensure that:

- they are given or sent a copy of the referral letter when this is sent to mental health services
- they are offered an appointment with mental health services within 2 weeks of referral and are informed that they can change the date and time of the appointment if they wish
- any change in appointment does not result in a delay of more than 2 weeks. [QS6]

5.5.1.2 When people are sent an appointment letter for mental health services it should:

- give the name and professional designation of the person who will assess them
- include information about the service including a website address, and different options about how to get to there
- explain the process of assessment using plain language
- specify all the information needed for the assessment, including about current medication
- address the likely anxiety and concern often experienced by people attending mental health services for assessment
- explain that although they can be accompanied by a family member, carer or advocate if they wish for all or part of the time, it is preferable to see the person alone for some of the assessment
- ask if they will need an interpreter, or have any hearing, sight or speech problems, a learning disability or any disability access requirements
- give a number to ring if they have problems getting to the appointment or wish to change it.

5.5.1.3 Mental health services should establish close working relationships with primary care services to ensure:

- agreed processes for referral, consistent with 1.2.1, are in place, and
- primary care professionals can provide information about local mental health and social care services to the people they refer. [QS6]

5.5.1.4 Local mental health services should work with primary care and local voluntary organisations to ensure that:

- people with mental health problems from black and minority ethnic groups have the same access to services as other service users based on clinical need
- services are culturally appropriate. [QS2]

5.5.1.5 Take into account the requirements of the Equality Act 2010 and make sure services are equally accessible to, and supportive of, all people using mental health services.

5.5.2 Practice recommendations relating to access and all points on the pathway

5.5.2.1 Avoiding stigma and promoting social inclusion Trust boards should work with all other local organisations with an interest in mental health (including social services, other hospitals, voluntary organisations, local press and media) to develop a strategy to combat the stigma in the community and in the NHS associated with mental health problems and using mental health services,.

5.5.3 Research recommendations

What is the impact of training local minority ethnic organisations/associations in the recognition of mental health problems in their own communities and what basic interventions would enhance engagement with mental health services? This should include training the local mental health service (CMHT) in cultural competence appropriate to the local ethnic groups.

5.5.3.1 For people using adult mental health services, what are the personal and demographic factors associated with late access to services and an increased likelihood of compulsory and intensive treatment, and what are the key themes that are associated with poor engagement?

6. ASSESSMENT (NON-ACUTE)

6.1 INTRODUCTION

This chapter provides evidence about the key problems relating to assessment, and the key requirements for high quality service user experience. Recommendations for best practice and recommendations for research can be found at the end of the chapter.

Timely, comprehensive assessments conducted by appropriately trained health and social care professionals are vital to ensure that the right care and treatment can be planned for individual service users. It has been acknowledged in other guidance that mental health assessments should be more than a simple symptom count (for further information, see the updated edition of the Depression guideline, [NCCMH 2010a]). Consideration should also be given to the need for a formal Community Care Assessment under the NHS and Community Care Act (HMSO, 1990). Moreover, the Department of Health (DH, 2011) has emphasised the need for more stream-lined mental health assessments.

Mental health assessments can vary; this might be an appointment with a GP, an assessment at ones home or local service by a recognised mental health professional or an assessment in Accident and Emergency department. It may be necessary for an appointment with a specialist at a hospital.

Good practice dictates that health and social care professionals should have the knowledge, skills and attitudes to assess service users in a sensitive and professional manner. It is essential that the professional makes every effort to build a trusting, respectful and empowering therapeutic relationship with the service user. It is important that anyone conducting an assessment tries to make sure that the service user's experience of their assessment is positive and that they feel valued and listened to during the process.

Mental health assessments are conducted for different reasons depending on the service user, this may be to provide a diagnosis, to develop a psychological formulation and identify aspirations, strengths and needs, for screening purposes (including risk assessments) and to evaluate treatment outcomes (NICE, 2009b). Assessments should be culturally sensitive (NICE, 2009b) and reflect the context of the service user's life; and their physical, family, social and environmental needs. Assessments will focus on the service user's mental health and also take into consideration any family, social or work related responsibilities. During the assessment, professionals should try to instil the principles of hope and recovery. Other guidance has emphasised the need for service users to be partners in the assessment process and outcomes of the assessment should reflect both the assessor's and service user's concerns (NICE, 2009b).

Assessments should, wherever possible take place in a safe and suitable location and at a time chosen by the service user. If this is not possible, the privacy, dignity and confidentiality must be considered in relation to the service user.

Other NICE guidance suggests that relevant standardised assessment tools should be used (NICE, 2009a). Such tools aid diagnosis and treatment planning, monitoring and evaluation. A careful clinical judgement by the assessor decides which is the most appropriate and whether the time is right to conduct such assessments.

New guidance endorses the need for a whole family assessment and necessary support plans (Department of Health, 2011). This includes an assessment of the family or carer's own mental, physical and caring responsibilities (NICE, 2009b, NICE, 2006).

There are a number of potential problems that may arise during mental health assessments. Service users may find it difficult to participate and provide accurate self-report at the time of the assessment due to their levels of distress or symptoms. It is possible that information will need to be gained from the service user's family or carer, other professionals involved in their care or documentation reports by others.

6.2 KEY PROBLEMS REGARDING ASSESSMENT

Evidence from qualitative reviews/analyses and surveys addressed the following domains of person-centred care:

- involvement in decisions and respect for preferences
- clear, comprehensible information and support for self-care
- emotional support, empathy and respect
- fast access to reliable health advice
- effective treatment delivered by trusted professionals

No evidence was identified that directly addressed:

- attention to physical and environmental needs.
- involvement of, and support for, family and carers
- continuity of care and smooth transitions.

For the purposes of the review, themes from the qualitative evidence are summarised only briefly here, with further details provided in Appendix 12. Domains and sources of evidence without themes are not listed below.

6.2.1 Involvement in decisions and respect for preferences

Evidence from qualitative reviews

Barrier: lack of transparency

One guideline found that there was a lack of transparency in the assessment process as 16% of services users found out about their diagnosis from their records (half found out from a psychiatrist) which increased their feelings of stigma associated with their diagnosis (ASPD guideline [NCCMH, 2009a]).

Barrier: lack of time and involvement

Service users also expressed their disappointment when the assessor did not give them sufficient time to talk during the assessment and involve them in the process:

> *O.K. The first interview was just "so tell us what happened" and he wrote it up and said "um hm, um hm" and wrote notes and he didn't look at me but he was nodding and looking at the other guy. And they looked at each other and exchanged nods. It was very factual like "So what did you take?" and "What happened at the house?" Um, you know I felt like saying "I can understand English, doctor". It was just very factual. They filled out their little form and that was it.* (Self-harm guideline [NCCMH, in preparation])

Evidence from surveys

The Community Mental Health Survey (National Centre for Social Research, 2010) (see Chapter 4 for further information about the survey) had four questions relevant to the domain of 'involvement in decisions and respect for preferences' (see Appendix 11 for full results). Taken together, the survey results suggest that during assessment, many service users are not being involved in decisions and having their preferences respected. For instance, nearly half thought their views were not (13%) or only to some extent (34%) taken into account when deciding what was in their care plan. Furthermore, 26% were not given a chance to talk to their care coordinator before the review meeting about what would happen during the meeting. At the review meeting, 4% were not given a chance to express their views, and 25% answered 'yes, to some extent'. Finally, many were not (18%) or only to some extent (21%) given the chance to discuss whether they needed to continue using mental health services. The benchmark data indicate that there was considerable variation in performance between trusts on some questions, and all trusts have room to improve.

6.2.2 Clear, comprehensible information and support for self-care

Evidence from qualitative reviews

In two guidelines, information was perceived as an important component in the assessment process (BPD guideline [NCCMH, 2009b]; Self-harm guideline [NCCMH, in preparation]). Some service users felt that a barrier to assessment was the lack of information provided about their diagnosis. Service users stated that they had little information, negative information, unclear information or in some instances, were not even disclosed about their diagnosis, or did not know what the term BPD meant (BPD guideline [NCCMH, 2009b]). Many service users expressed that an improvement to services would be the provision of information in the assessment process (Self-harm guideline [NCCMH, in preparation]).

Evidence from qualitative analyses

Service users described an improvement to their experience of care would be the provision with a clear explanation of what they were going through, especially on first contact with mental health services (Experiences of psychosis [Healthtalkonline, 2011]).

Evidence from surveys

The Community Mental Health Survey (National Centre for Social Research, 2010) (see Chapter 4 for further information about the survey) had three questions relevant to the domain of 'clear, comprehensible information and support for self-care' (see Appendix 11 for full results). Taken together, the survey results suggest that during assessment, many service users are not being given sufficient information and support for self-care. For instance, 44% were not given (or offered) a written or printed copy of their care plan. In those with a care plan, 30% answered that their care plan does not cover what to do if they have a crisis. Furthermore, 9% did not understand what was in their care plan, and 29% were only to some extent sure. The benchmark data indicate that there was large variation in performance between trusts with regard to giving written or printed copies of care plans to service users, and all trusts have room to improve.

6.2.3 Emotional support, empathy and respect

Evidence from qualitative reviews

Facilitator: professional

Four guidelines found that the role of the professional could act as a facilitator to the assessment process (Alcohol guideline [NCCMH, 2011]; Bipolar disorder guideline [NCCMH, 2006]; BPD guideline [NCCMH, 2009b]) or as a barrier (Self-harm guideline [NCCMH, in preparation]). A quarter of service users in one study expressed the therapeutic relationship to be the most important factor in assessment. These factors included the professional to 'genuinely care' and have an understanding of the individual (Alcohol guideline [NCCMH, 2011]). This was echoed in the Self-Harm: Longer Term Management guideline [NCCMH, in preparation] where service users described assessment to be a positive experience when there was engagement with the professional and when it involved restoration of hope (Self-harm guideline [NCCMH, in preparation]). Assessment was often considered difficult because of the focus on painful past experiences but support and information from professionals made the process easier and was a facilitator to assessment (BPD guideline [NCCMH, 2009b]).

Barrier: professional

The ways in which the professional may act as a barrier to the assessment process was when participants felt devalued by the assessor, were treated in a judgemental manner, or felt they were not understood or not involved in the process (Self-harm guideline [NCCMH, in preparation]).

Barrier: lack of time

Other barriers in the assessment process included not having enough feedback from the professional and having the time to talk (Alcohol guideline [NCCMH, 2011]).

Evidence from qualitative analyses

Facilitator: professional

Some people described how the experience of having someone try to make sense of their problems was helpful and aided their recovery:

> *...my psychiatric nurse told me that I was [um] once I was diagnosed with schizophrenia...*
>
> *I: And how did you react to being told….?*
>
> *R: [um] I was sort of shocked. I was sort of relieved that I could put a name to what I was going through. [um] When I sort of researched schizophrenia I could simply recognise all the symptoms, all the symptoms, and so I sort of, you know, I could recognise this was schizophrenia, so I was sort of relieved to have a diagnosis, it felt I had something to work with.* (Experiences of psychosis [Healthtalkonline, 2011])

6.2.4 Fast access to reliable health advice

Evidence from qualitative reviews

Barrier: diagnostic delay

Service users described their experience of severe diagnostic and treatment delay for their bipolar disorder.

> *Over the next 27 years, they all treated me for depression, prescribing me more than a dozen different antidepressants. As far as I can tell they did nothing to stabilise my mood swings. None of the GPs ever recognised that my high*

> *moods in between the lows were symptomatic of bipolar disorder.* (Bipolar disorder guideline [NCCMH, 2006])

Barrier: time

Some service users in one qualitative review (BPD guideline [NCCMH, 2009b]) found that a barrier to the assessment process was the length of time that is involved in the assessment process, (often several weeks).

6.2.5 Effective treatment delivered by trusted professionals

Evidence from qualitative reviews

Barrier: validity of diagnosis

Across the two guidelines on personality disorder, service users questioned the validity of their diagnosis (ASPD guideline [NCCMH, 2009a]; BPD guideline [NCCMH, 2009b]). One study found that service users questioned the legitimacy of the diagnosis of personality disorder as they suffered from other primary, co-morbid problems. However, one participant in another study found it to accurately describe his condition (ASPD guideline [NCCMH, 2009a]). In the BPD guideline (NCCMH, 2009b), the validity of their diagnosis was questioned because some service users received many diagnoses in the past and were therefore sceptical about the diagnosis and others were unsure whether they were ill or just a troublemaker (BPD guideline [NCCMH, 2009b]).

Barrier: lack of, or inconsistent assessment

In one guideline, four included studies found that not all service users received a psychosocial assessment while in hospital, and for those who did, they had varied experiences (Self-harm guideline [NCCMH, in preparation]).

Facilitator: professional

If the healthcare professional handled the situation in a positive informed way, then service users could make better use of the diagnosis (BPD guideline [NCCMH, 2009b]).

Evidence from qualitative analyses

Barrier: professional

A negative experience of the assessment process was being told by professionals that they were not mentally ill when they felt distressed: (

> *I went to the doctor, and then I got my Mum involved, and she said, "Oh he wants to see a psychiatrist." And, and, you know, I was told all these things. "Do you want to be viewed as mad?" And all that. "Do you want to go to the mental hospital?" And you know, it was all like real negative. And the GP*

> *really, he just gave me some pills to take, and said, "You know, you don't want to see psychiatrist. It's meant for people that are mentally ill."* (Experiences of psychosis [Healthtalkonline, 2011])

6.2.6 Other themes (including stigma)

Evidence from qualitative reviews

Barrier: stigma of diagnosis

Many service users felt stigma was attached to the diagnosis in the form of stereotyping and negative judgment by services and society wanting the terminology 'borderline personality disorder' changed (BPD guideline [NCCMH, 2009b]).

Evidence from qualitative analyses

Barrier: symptoms hidden from others

Participants described how they would hide their symptoms from people.

> *'You can't lump everybody in together, you know, to say oh this is, these people are manic depressives, so their behaviour would be blah, blah, blah. Everybody is different…I might act different to the next manic depressive or whatever and, you know, perhaps I might not show my symptoms because there's one thing about manic depression, depressives you really are clever at hiding your symptoms and very good at manipulating people* (PSM guideline [NCCMH, in press]).'

6.2.7 Evidence summary

Below is a summary of the evidence found for the key problems associated with assessment, organised by the dimensions of person-centred care.

Involvement in decisions and respect for preferences

There was evidence from both the qualitative reviews and the survey that many service users are not being fully involved and informed throughout the assessment process.

Clear, comprehensible information and support for self-care

The qualitative evidence and survey both suggest that many service users are not getting sufficient information about the assessment process, about their diagnosis, and about their care plan.

Emotional support, empathy and respect

The qualitative evidence suggests that healthcare professionals can act as both a barrier and a facilitator of a good experience of care; a poor therapeutic relationship with insufficient time for the service user to talk impacts negatively on the experience of the assessment process.

Fast access to reliable health advice

The qualitative evidence suggests that a long drawn out assessment process and delays in receiving a diagnosis lead to poor experience of care.

Effective treatment delivered by trusted professionals

The qualitative evidence suggested that inconsistency of the diagnosis and healthcare professionals downplaying the seriousness of the problem can seriously impact on the experience of the assessment process.

6.3 KEY REQUIREMENTS FOR THE PROVISION OF HIGH QUALITY SERVICE USER EXPERIENCE

For assessment, the key requirements (qualitative statements based on the GDG's expert opinion) for the provision of high quality service user experience for each dimension of person-centred care are shown in Table 13.

Table 13. Key requirements for the provision of high quality service user experience (assessment).

Dimensions of person-centred care	**Statement**
Involvement in decisions and respect for preferences	• Individual needs of service user are considered: 1. prior to the assessment (language, communication) 2. at the assessment (second opinion for diagnosis) 3. following the assessment (communication, including to the carer)
Clear, comprehensible information and support for self-care	• Assessment process are clearly explained • Information is provided about how services could be contacted • Permission is sought for anyone else to be present, e.g. student • Full information if a diagnosis is given.
Emotional support, empathy and respect	• Assessments are person and culturally centred • Service user is treated with respect and empathy
Fast access to reliable health advice	• Service users are contacted about a new assessment appointment within two weeks of the date of the referral • If a diagnosis is made, this is shared with the service user and sufficient time and information provided to help the service user understand the meaning of this label and its implications for future treatment and health.
Effective treatment delivered by trusted professionals	• Treatment options are provided and discussed and service users are involved in a discussion about an agreed treatment plan. • Options for a second opinion are provided when requested
Attention to physical and environmental needs	• Assessments consider all relevant areas of a person's life, including their physical, financial and environmental needs
Involvement of, and support for, family and carers	• Service users' wishes about the involvement of their family and carers in the assessment process is respected • There is regard to the possibility of safeguarding issues and the need to see the service user alone • Family/carers are offered an assessment of their needs as a carer

	• Family/carers are also provided with information about the outcome of the assessment and plans for future treatment./ contact with services when the service user supports this
Continuity of care and smooth transitions	• Service users' permission is sought to share information between health professionals • Service user receives copies of all communications unless declined • Management plan is shared with service user • Service users should be involved in and kept informed at every point of a transition or referral to another service. The referring professional is wholly responsible for the service user's care until the referral has been acknowledged and a first session with the referrer has been delivered.

6.4 EVIDENCE TO RECOMMENDATIONS

The key problems outlined in the qualitative reviews, analyses and surveys addressed a number of fundamental issues. These included, but were not limited to, the following: delayed or inconsistent diagnosis, insufficient time to discuss complex issues and gain feedback during assessment, poor involvement of service users, a lack of or insufficient information about their diagnosis and care plan, and finally a lack of understanding, support or empathy on part of the professional.

The GDG expressed a range of targets for improving the quality of assessment in non-acute mental health services including the following: the full consideration of the biopsychosocial needs of the service user, providing a clear outline of the assessment process, treating services users with respect and empathy, allowing sufficient time during the assessment process, providing comprehensive information about any diagnosis made, and involving service users in the discussion of their care plan. Furthermore, professionals should respect service user's requests about the involvement of their family and carers in the assessment process. Finally, service users should be kept as informed as possible at every point of the care pathway.

After reviewing the key problems and requirements, the GDG outlined a number of broad issues that relate to all points on the care pathway, but were of particular importance to assessment. The recommendations for these aspects of the experience of care included the following: building supportive, empathic and non-judgemental relationships with service users; ensuring the provision of comprehensible verbal and written information in the appropriate language or format about the nature, treatments, and services for their mental health problems including relevant 'Understanding NICE Guidance'; and fostering autonomy in the service user. When working with people using mental health services be respectful and sensitive to diverse cultural, ethnic and religious backgrounds and take into account stigma and discrimination that are often associated with using mental health services. Ensure that all healthcare professionals are competent in assessing people from diverse ethnic and cultural backgrounds using explanatory models of

illness if necessary and explain the causes of different mental health problems, treatment options, expectations and adherence.
All these issues were placed in care across all points on the care pathway in the NICE guidance.

Areas identified by the GDG that were of particular importance for improving the assessment in non-acute mental health settings included the following: greeting services in a warm, empathetic and professional manner on arrival; ensuring that the service user is provided with information about the process of assessment; and allowing sufficient time to discuss problems, questions and provide feedback. Moreover, a shared decision making approach should be facilitated by providing adequate information about the different treatment options available and allowing time for discussion of any concerns or issues that the service user may have. Waiting time should be kept to a minimum and waiting facilities should be made comfortable. Finally, if the service user is not satisfied with their assessment they should be offered an opportunity for a second opinion.

6.5 RECOMMENDATIONS

6.5.1 Practice recommendations relating specifically to assessment

6.5.1.1 On arrival at mental health services for assessment, service users should be greeted and engaged by reception and other staff in a warm, friendly, empathic, respectful and professional manner, anticipating possible distress.

6.5.1.2 Before the assessment begins, the health or social care professional undertaking the assessment should ensure that the service user understands:

- the process of assessment and how long the appointment will last
- that the assessment will cover all aspects of their experiences and life
- confidentiality and data protection as this applies to them
- the basic approach of shared decision-making
- that although they can be accompanied by a family member, carer or advocate for all or part of the time, it is preferable to see the person alone for some of the assessment
- that they can refuse permission for any other member of staff, such as a student, to be present.

6.5.1.3 When carrying out an assessment:

- ensure there is enough time for the service user to describe and discuss their problems

- allow enough time towards the end of the appointment for summarising the conclusions of the assessment and for discussion, with questions and answers.
- explain the use and meaning of any clinical terms used
- explain and give written material about any diagnosis given
- outline different treatment options and give information about these to promote discussion and shared understanding
- offer support after the assessment, particularly if sensitive issues, such as childhood trauma, have been discussed. [QS7]

6.5.1.4 If a service user is unhappy about the assessment and diagnosis, give them time to discuss this and offer them the opportunity for a second opinion.

6.5.1.5 Copy all written communications with other health or social care professionals to the service user at the address of their choice, unless the service user declines this.

6.5.1.6 Ensure that if a service user needs to wait before an assessment, this is for no longer than 10 minutes after the agreed appointment time. [QS6]

6.5.1.7 Ensure that waiting rooms are comfortable, clean and warm, and have areas of privacy, especially for those who are distressed or who request this, or are accompanied by children.

6.5.1.8 Inform service users of their right to a formal community care assessment, and how to access this.

6.5.2 Practice recommendations relating to assessment and all points on the pathway

Avoiding stigma and promoting social inclusion

6.5.2.1 When working with people using mental health services:

- take into account that stigma and discrimination are often associated with using mental health services
- make sure that discussions take place in settings in which confidentiality, privacy and dignity are respected.
- be clear with service users about limits of confidentiality. [QS2 & QS22]

6.5.2.2 When working with people using mental health services

- be respectful of, and sensitive to, diverse cultural, ethnic and religious backgrounds

- be aware of possible variations in the presentation of mental health problems according to cultural, ethnic or religious background. [QS2 & QS22]

6.5.2.3 Health and social care professionals working with people using mental health services should have competence in:

- assessment skills and using explanatory models of illness for people from diverse cultural, ethnic and religious backgrounds
- explaining the causes of different mental health problems, if possible, and treatment options
- addressing cultural and ethnic differences in treatment expectations and adherence
- addressing cultural and ethnic beliefs about biological, social and familial influences on the causes of mental health problems
- negotiating skills for working with service users' families and carers
- conflict management and conflict resolution. [QS2 & QS22]

6.5.3 Research recommendations

What is the extent to which people using adult mental health services know their diagnosis and what they understand by it? A survey and purposively sampled selection of in-depth interviews should be used, including asking if service users wish to know their diagnosis, and if so, what do they want to know. In addition, the research should aim to identify any inter-diagnostic differences in preferences and needs for knowledge.

7. COMMUNITY CARE

7.1 INTRODUCTION

This chapter provides evidence about the key problems relating to community care, and the key requirements for high quality service user experience. Recommendations for best practice and recommendations for research can be found at the end of the chapter.

The term "Community Care" is used to describe services and support for people that enable them to live as independently as possible either in their own homes or in other residential homes within the local community. The concept has become increasingly significant in care provision not least due to its ongoing difficulties with development and financial support.

Background

For readers interested in the history of mental health and community care, a MIND factsheet[6] sets out the key dates and important reports and policy documents.

In the past ten years, mental health policy has determined that service users and carers should have greater influence in both the strategic and frontline decisions about care and support. This culminated in the 2007 *Putting People First* English government adult health and social care policy directive (Department of Health, 2007) which outlined the personalisation agenda and implementation plans, such as self directed support, personal budgets and an increase in user-led organisations as part of the adult health and social care support infrastructure. These reforms were prefigured the *White Paper Our Health, Our Care, Our Say: a new direction for community services* (Department of Health, 2006a) and by the activities of the Government's Social Exclusion Unit, which had a programme to tackle the social exclusion of people with mental health problems. Eligible people with mental health problems are entitled to direct payments to choose and control their own social care and support since and can now use different personal budget options:

"*For adult mental health services, the duty on councils to make direct payments to meet social care needs can be incorporated into the CPA, the joint health and social care assessment framework for 'all adults of working age in contact with the secondary mental health system (health and social care)', which should provide 'access, through a single process, to the support and resources of both health and social care''* (Department of Health, 2006b).

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[6] http://www.mind.org.uk/help/research_and_policy/the_history_of_mental_health_and_community_care-key_dates

The aims of these reforms were to change attitudes towards mental health and illness, to support people with mental health problems to lead more independent and fulfilling lives, to work towards a more preventative and collaborative model of health and social care, to design mental health service provision alongside universal community provision such as education, employment, leisure and transport and in doing so, to challenge the stigma of mental illness and promote social inclusion and self-determination.

Current Practice

Community care presently refers to methods of locality based services provided by both specialist and general multi-disciplinary teams operating the 'care program approach' (CPA). It is intended to enable a 'seamless service' between hospital and community.

The term CPA currently describes the approach used to assess, plan, review and co-ordinate the range of treatment, care and support needs for people in contact with secondary mental health services who may have complex characteristics or support requirements.

Fundamental to CPA is the role of the care co-ordinator, but historically the role has not been clearly defined and has been subject to diverse local interpretations and criteria. The role has two critical functions:
Building a respectful relationship based upon trust, empathy and shared expertise with the service user.

Supporting the individual to assess, plan, identify and choose their care and support along with the agreed outcomes they want from that support. The standard approach to care and support planning should be person-centred, and directed by the service user with support as needed. As part of this the service user should be offered the option to have a personal budget, including a direct payment so they can control what social care and support is in their plan. This social care support can be purchased through single or multiple providers from any of the local authority, voluntary and community or independent sectors.

7.2 KEY PROBLEMS REGARDING COMMUNITY CARE

Evidence from qualitative reviews/analyses and surveys addressed the following domains of person-centred care:

- involvement in decisions and respect for preferences
- clear, comprehensible information and support for self-care
- emotional support, empathy and respect
- fast access to reliable health advice
- effective treatment delivered by trusted professionals

- attention to physical and environmental needs
- involvement of, and support for, family and carers
- continuity of care and smooth transitions.

For the purposes of the review, themes from the qualitative evidence are summarised only briefly here, with further details provided in Appendix 12. Domains and sources of evidence without themes are not listed below.

7.2.1 Involvement in decisions and respect for preferences

Evidence from qualitative reviews

Facilitator: service user involvement

Service users across four guidelines expressed wanting to be involved in decisions regarding their care with respect shown for their preferences in treatment (ASPD guideline [NCCMH, 2009a]; Bipolar disorder guideline [NCCMH, 2006]; BPD guideline [NCCMH, 2009b]; Self-harm guideline [NCCMH, in preparation]).

Service users also described wanting involvement in decisions in community care. In one study service users emphasised that they had important views on treatment on what was worked or not worked for them in the past which professionals should listen to when deciding on treatment options (ASPD guideline [NCCMH, 2009a]).

This was further expressed in the Bipolar Disorder guideline [NCCMH, 2006] where service users stated that they want their preferences to be taken into account in treatment in community care and to be treated as equal partners to their professionals:

> *my psychiatrist and other professionals tend to decide what is best for me, rather than listening to my thoughts and feelings.* (Bipolar disorder guideline [NCCMH, 2006])

Service users stated that they would benefit from information on treatment options and deciding for themselves what would best meet their need (BPD guideline [NCCMH, 2009b]).

Service users said they were not able to play an active role in treatment. Some felt treatments were forced upon them and were not listened to when they expressed that certain treatments were not helpful for them. Service users want more responsibility to manage their care:

> *...I wanted to go to a meeting that's discussing my future or what possibly could happen in my future. And they said no, clients are not allowed. I think that's badly wrong...* (Self-harm guideline [NCCMH, in preparation])

Facilitator: more treatment options

Service users across six guidelines identified that they wanted more treatment options including more options for psychological therapy and less reliance on pharmacological treatment (ASPD guideline [NCCMH, 2009a]; PSM guideline [NCCMH, in press]; Bipolar disorder guideline [NCCMH, 2006]; BPD guideline [NCCMH, 2009b]; Depression Update guideline [NCCMH, 2010a], Self-harm guideline [NCCMH, in preparation]).

Two studies in one qualitative review found that service users with personality disorder wanted more choice in treatment with less reliance on pharmacological medication and more 'talking therapies' (ASPD guideline [NCCMH, 2009a]).

Service users described a lack of treatment options whereby mainly medication was offered (Bipolar Disorder guideline [NCCMH, 2006]). Service users described the lack of individual talking therapies in treatment to deal with their multiple problems (PSM guideline [NCCMH, in press]).

In addition to wanting more choice between pharmacological and psychological treatment, service users in one study expressed wanting more choice among psychological therapies, as the only treatment offered to them was DBT (BPD guideline [NCCMH, 2009b]).

Service users' involvement in community care was not only about their treatment but about services. In one study, service users described wanting to make their own choices regarding services to increase engagement and to be involved in clinicians' training (BPD guideline [NCCMH, 2009b]).

One systematic review found that the majority of service users did not receive information about psychological interventions and different treatment options. One participant commented that the only option given was pharmacology and wanted more psychological interventions:

> *They just handed me a drug and said go on it right now . . . I felt rushed along, given a prescription, told this will fix it.* (Depression Update [NCCMH, 2010a])

Evidence from qualitative analyses

Barrier: concealing information to comply with the professional

There was a feeling among service users of having to conceal certain issues or disclose specific aspects of their illness in order to comply with the expectations and views of their mental health practitioner:

> *...make it clear that you believe what they say, very clearly that you believe what they say because if you show or hint that you don't believe what they say*

> *then that's, then you've undermined your own authority in their eyes and therefore that makes the repair process a lot, a lot more difficult and a lot more long term.* (PSM guideline [NCCMH, in press])

Evidence from surveys

The Community Mental Health Survey (National Centre for Social Research, 2010) (see Chapter 4 for further information about the survey) had four questions relevant to the domain of 'involvement in decisions and respect for preferences' (see Appendix 11 for full results). Taken together, the survey results suggest that a significant number of people are not being fully involved in decisions about their care. For instance, 3% of service users did not feel their healthcare professional listened carefully to them, and a further 17% thought they were listened to only to some extent. Similarly, 4% thought their views were not taken into account by the professional caring for them, and 21% answered, 'Yes, to some extent'. Some (7%) service users do not think they are given enough time to discuss their condition and treatment, and 19% think they are, but only to 'some extent'. Importantly, 12% of service users do not think their views are taken into account when deciding which medicines to take, and 31% answered 'Yes, to some extent' on this question. The benchmark data indicate that there was relatively small variation in performance between trusts, although all trusts have room to improve.

7.2.2 Clear, comprehensible information and support for self-care

Evidence from qualitative reviews

Barrier: information

Two qualitative reviews found that a key problem in community care was the lack of information provided to service users about their treatment (Alcohol guideline [NCCMH, 2011]; Self-harm guideline [NCCMH, in preparation]).

The majority of service users in one study expressed that they had inadequate information about the medication they were taking and the potential side effects:

> *I didn't know what they were, what they were going to do to me … they didn't tell me why I was taking them.* (Alcohol guideline [NCCMH, 2011])

Service users in two studies expressed a lack of information of services for people who self-harm and wished they knew about types of support services before they had self-harmed. Service users recommend that information should be made available on self-harm (Self-harm guideline [NCCMH, in preparation]).

Facilitator: information

Service users also stated that there is a need for full discussion about dose and side effects of treatment which is not being provided. They also want information about their condition and preferred this to be provided in booklets, newsletters, videos that are sensitive to social, cultural and educational backgrounds (Bipolar Disorder guideline [NCCMH, 2006]). Information was also wanted in other areas including information about specialist community care and how it differed from mainstream services (BPD guideline [NCCMH, 2009b]).

Facilitator: Information

When information was provided in community care, this was perceived favourably. Coping with rules and boundaries in a community-based service for people with personality disorder was easier when they were made explicit and transparent, and were able to be negotiated (BPD guideline [NCCMH, 2009b]).

Evidence from surveys

The Community Mental Health Survey (National Centre for Social Research, 2010) (see Chapter 4 for further information about the survey) had six questions relevant to the domain 'clear, comprehensible information and support for self-care (see Appendix 11 for full results). Taken together, the survey results suggest that many service users are not having adequate information about the medication they are prescribed and about how their care is coordinated. For instance, a third of people did not have the purposes of their medications fully explained to them, and 29% were not told about possible side effects of their medication and a further 28% are only told to 'some extent' about side effects. In response to the question "Do you think your views were taken into account in deciding which medicines to take", 12% answered 'no', and 31% answered 'yes, to some extent'. Worryingly, 28% are not sure or don't know who their care coordinator is. Of those who have a care plan, 48% do not believe their care plan fully sets out their goals. Of those that had a care review, 9% thought it was not helpful, and 39% thought it was only helpful to 'some extent'. The benchmark data indicate that there was substantial variation in performance between trusts on some questions, and all trusts have room to improve.

7.2.3 Emotional support, empathy and respect

Evidence from qualitative reviews

Facilitator: professional

Across four guidelines, service users described the characteristics of professionals that were facilitators to community care (Alcohol guideline [NCCMH, 2011]; BPD guideline [NCCMH, 2009b]; PSM guideline [NCCMH, in press]; Self-harm guideline [NCCMH, in preparation]).

Service users wanted professionals treating their alcohol problem to be supportive and to treat them with dignity, respect and genuine concern. Helpful professionals were viewed by one service user as those who:

> *…view you as a person and a woman, not just an addict. They see you have a lot of needs and they try to come up with some kind of a plan.* (Alcohol guideline [NCCMH, 2011])

Service users expressed that the most productive relationship with professionals was when it was collaborative, when staff were non-judgmental, caring, and respectful, amongst other characteristics (BPD guideline [NCCMH, 2009b]).

Female service users with coexisting mental health problems and substance misuse described the traits of empathy, honesty, encouraging and direct as important aspects for effective treatment (PSM guideline [NCCMH, in press]).

Service users in eight studies reported on characteristics that they valued in professionals which were a caring attitude; recognition of service users' individuality; were direct, proactive, and genuine; were non-judgemental; and did not focus on the physical disfigurements as a result of the self-harm:

> *Look at the individual, not the harm. Look at the person beyond the scars. Scars aren't important. It's the person that did them that's important.* (Self-harm guideline [NCCMH, in preparation])

Barrier: professional

Service users in three studies reported on barriers that hindered their relationship with the professional including: when professionals appeared not to care about their distress; were slow to respond; and were dismissive of personal problems (Self-harm guideline [NCCMH, in preparation]).

Barrier: stigma by professionals

Other barriers included stigma by professionals. Mental health services were characterised by one study as judgmental and lacking in understanding of service users' problems (Self-harm guideline [NCCMH, in preparation]).

Barrier: support

A barrier to self-care was that service users did not have the support needed in times of crisis and felt instead that they were pushed towards self-care (BPD guideline [NCCMH, 2009b]).

Evidence from qualitative analyses

Barrier: professionals

A number of service users suggested that mental health practitioners did not always show respect, which ranged from the way that staff spoke to the service users to the amount of power a doctor had over the service user.

Evidence from surveys

The Community Mental Health Survey (National Centre for Social Research, 2010) (see Chapter 4 for further information about the survey) had one relevant question (see Appendix 11 for full results). The question asks whether the service user's healthcare professional treated them with respect and dignity. In response, 2% answered 'no', and 10% answered 'yes, to some extent'. The benchmark data indicate that there was relatively little variation in performance between trusts.

7.2.4 Fast access to reliable health advice

Themes relating to access can be found in Chapter 5.

7.2.5 Effective treatment delivered by trusted professionals

Evidence from qualitative reviews

Facilitator: professional

The ways in which professionals facilitate effective treatment were described in two guidelines (BPD guideline [NCCMH, 2009b]; Self-harm guideline [NCCMH, in preparation]). Therapists who were non-judgmental, who considered service users as an equal and where the therapist pushed and challenged them were viewed favourably by service users (BPD guideline [NCCMH, 2009b]). This was also expressed in the Self-Harm: Longer Term Management guideline (NCCMH, in preparation), that professionals who were respectful, listened and were understanding were perceived favourably. These positive factors were considered present in specialist services as they built a sense of belonging due to sharing experiences with other users and building relationships with professionals and allowed more discussions with service users around recovery (BPD guideline [NCCMH, 2009b]).

Other facilitators to effective treatment were key workers. Service users in two guidelines found key workers to be facilitators to effective treatment in community care (PSM guideline [NCCMH, in press]; Self-harm guideline [NCCMH, in preparation]). Service users in one study described their key worker as an important part of effective treatment as they allowed access to local counselling services or alternative treatment options (PSM guideline [NCCMH, in press]). This was also expressed in the Self-Harm: Longer Term Management guideline (NCCMH, in preparation) that having a long-term relationship with one key worker was seen as a facilitator for effective treatment.

In one review it was found that people needed to understand a language and framework of longer-term recovery to tell their own story of improvement; that getting better meant different things to different people; and that people needed to have control over their recovery (Depression Update guideline [NCCMH, 2010a]).

Facilitator: support

For those undergoing DBT therapy, 24-hour telephone skills coaching was perceived as valuable (BPD guideline [NCCMH, 2009b]).

Facilitator: peer support

Service users in two studies described the importance of peer support in effective treatment; to have someone who can understand them:

> *most of the counsellors there were ex-addicts themselves and I could relate to them, and the things they said because they've been through it.* (PSM guideline [NCCMH, in press])

Barrier: professional

Professionals were also viewed as barriers to effective treatment when they did not demonstrate understanding for the service user's experience and when they forced uninvited ideas upon an individual (Self-harm guideline [NCCMH, in preparation]).

Barrier: stigma by professionals

Service users in one study (which was reported in both the ASPD [NCCMH, 2009a] and BPD guideline [NCCMH, 2009b]) found that when a diagnosis of personality disorder was viewed by professionals as being untreatable this was a barrier to effective treatment.

Barrier: medication

Other key problems regarding community care were related to service users' views on specific treatments that they experienced including medication and specific psychosocial therapy. One systematic review found that service users had mixed feelings about taking medication which included a sense of relief because it helped them cope better but they also felt a lack of control and that there was stigma associated with taking medication (Depression Update guideline [NCCMH, 2010a]).

Mixed views regarding medication were found in another guideline where service users in four studies found medication to be helpful to cope with their underlying problems; however, not all participants had a positive attitude.

Barrier: undue focus on stopping self-harm

No-harm contracts and the rigid focus of some therapies on stopping self harm were viewed by service users as ineffective. Rather than focusing on immediately stopping harm, they valued treatment that targeted underlying issues. One service user's view on no-harm contracts:

> *I won't make a promise unless I can keep it. Or, I try not to. I need to feel a deep sense of obligation to that person and that particular cause to make that promise. So that wouldn't have worked for me.* (Self-harm guideline [NCCMH, in preparation])

Facilitator: choice of modality

For those users undergoing group psychotherapy, the treatment was considered a good opportunity to share experiences and they valued the peer support. This sentiment was not shared by those who preferred individual therapy (BPD guideline [NCCMH, 2009b]).

Evidence from qualitative analyses

Barrier: professional/treatment

There were many reports within the online accounts of interactions with mental health practitioners. Some service users lacked confidence and trust in their mental health practitioner:

> *I would get very frustrated with what I felt was incompetence and ineptitude by my doctors. I did not feel that they were listening to me nor were they willing to make medication changes when my current mix of medications did not seem to be stopping my cycling. I had three doctors within that year, until I found my current doctor, who I am finally comfortable with.* (PSM guideline [NCCMH, in press])

> *I've seen different psychiatrists but to me they always feel, they, it's always felt like they're sitting on a pedestal… and I'm just there as part of their job really.* (PSM guideline [NCCMH, in press])

Service users said that they did not feel that nurses understood the sensitive nature of their depression, that nurses in the NHS were too busy to talk to their patients and that their attitudes may be because of inadequate training:

> *There's an awful lot there who . . . you felt as though it was people saying to you, 'Oh, for goodness sake pull yourself out of it', and, 'Get yourself together', which you don't want, it's the last thing at the end of the day. I just don't think that there is enough, in regards to, against private and NHS, there is just not enough funding to be able to . . . I don't know, train the nurses in a certain way.* (Depression Update guideline [NCCMH, 2010a])

Service users had mixed experience of psychiatrists. Some did not like how psychiatrists tried to illicit information about their childhood experiences, describing the method as a 'text book' approach that instantly created a barrier. Others did not like to discuss feelings in general:

> *I felt my psychiatrist was a very . . . . oh . . . wet individual. Again, I think because I'd been quite a numerate, factual, organised person, to have someone to talking about feelings and what about this and what about that? And it was . . . nothing could ever be pin-pointed or . . . I just found it annoying.* (Depression Update guideline [NCCMH, 2010a])

Service users also had mixed opinions about how their psychiatrist dealt with their medication. The majority had positive experiences, however some service users were concerned about taking tablets; they did not think pills solved the problem or they had a cynical view of drug companies. Others who tried medication who did not have positive experiences said they felt that it 'robbed' them of feelings:

> *I've been prescribed antidepressants in the past but I've always felt reluctant and apprehensive about taking it, largely because a) I feel that the effects are probably short-term, they're not going to actually resolve the depression, b) because they do have side-effects and, c) I didn't feel comfortable, myself, with taking some tablets.* (Depression Update guideline [NCCMH, 2010a])

Many people with depression reported side effects from taking medication, notably dry mouth, hair loss, increased sweating, weight gain and problems with sexual dysfunction. A minority also reported experiencing suicidal thoughts as a consequence of their medication. However, some service users with depression said that the benefits of medication outweighed the potential side effects. One service users with side effects explained:

> *For many years I hadn't had any suicide thoughts at all, and I had certainly never thought of cutting myself, but while I was on Seroxat, I did start to get sudden images in my head of you know, cutting long gashes in myself.* (Depression Update guideline [NCCMH, 2010a])

One of the most prominent themes that emerged from all the online accounts was a strong opinion about medication regimes for psychosis. Feelings towards medication were typically ambivalent, and side effects often outweighed the positive aspects of medication in managing symptoms. In some cases, medication had a debilitating effect and was not allowing the service user to engage in other activities in their daily life, for example, holding down a job, staying awake (PSM guideline [NCCMH, in press]).

Some online accounts highlighted the problematic nature of increasing and changing doses, and how this resulted in them stopping their medication altogether, or relapsing:

> *I was seeing a psychiatrist once a week and slowly I felt like my life was getting better. However the medication did not continue to work. So my doctors just put the dose up each time they saw me. I was incredibly frustrated with this and decided that I would take myself off all the medication and do it my own way.* (PSM guideline [NCCMH, in press])

Others were concerned about the side effects of their medication:

> *Well, lithium turned me into an emotionless zombie. I think they just had me on too high of a dose, but I wasn't about to live my life that way, so I stopped taking it. Of course, I went back on a manic high right away.* (PSM guideline [NCCMH, in press])

Four service users recounted their experience of ECT; the majority had negative experiences because of the frightening nature of the intervention and loss of memory post-treatment (Depression Update guideline [NCCMH, 2010a]).

Some service users felt that they were not listened to when they discussed the side-effects of medication, or were misinformed about what the likely side-effects would be (Experiences of psychosis [Healthtalkonline, 2011]).

One service user felt that they were allowed to get too unwell before mental health practitioners intervened, while on the other hand, another service user felt that professionals were reluctant to reduce the service user's medication (Experiences of psychosis [Healthtalkonline, 2011]).

Evidence from surveys

The Community Mental Health Survey (National Centre for Social Research, 2010) (see Chapter 4 for further information about the survey) had five relevant questions (see Appendix 11 for full results). Taken together, the survey results suggest that many service users are not getting effective treatment from trusted professionals. For example, in response to the question about trust and confidence in the service user's healthcare professional, 7% answered 'no' and 21% answered 'yes, to some extent'. With regard to how well their care coordinator (or lead professional) organised care and services, only 62% answered 'very well'. Furthermore, 19% of service users had not been asked how they were getting on with their medication, and 15% did not find talking therapy helpful. Worse still, 38% did not get enough support with their care responsibilities. The benchmark data indicate that there was substantial variation in performance between trusts on some questions, and all trusts have room to improve.

7.2.6 Attention to physical and environmental needs

Evidence from qualitative reviews

Barrier: lack of privacy

Some service users felt that the lack of privacy in treatment rooms, particularly in waiting rooms, was a barrier to treatment (Self-harm guideline [NCCMH, in preparation]).

Facilitator: childcare services

Women service users with alcohol problems expressed in two studies that they want outpatient services to be flexible to their needs by providing childcare and be available in the evening or weekends for treatment (Alcohol guideline [NCCMH, 2011]).

Evidence from qualitative analyses

Barrier: day centre/depressing/boring

A few people found going to day centres helpful, but one woman said that her day centre was depressing and boring for her son (Experiences of psychosis [Healthtalkonline, 2011]).

Evidence from surveys

The Community Mental Health Survey (National Centre for Social Research, 2010) (see Chapter 4 for further information about the survey) had five questions relevant to physical and environmental needs (see Appendix 11 for full results). Taken together, the survey results suggest that physical and environmental needs are poorly catered for. For example, 37% of service users were not asked about their physical health needs, and many were not given enough help from anyone in mental health services to find or keep work (48%), find or keep accommodation (43%) and get financial advice or benefits (43%), even though the service user would have liked help. The benchmark data indicate that there was substantial variation in performance between trusts on most questions, and all trusts have room to improve.

7.2.7 Involvement of, and support for, family and carers

Evidence from qualitative reviews

Facilitator: involvement of family, carers and peer support

Service users in one study noted the influence of family and friends in helping promoting change in alcohol consumption. In particular, the support from peers in facilitated treatment programmes using peer support approaches:

> *Here was a bunch of people who really understood where I was coming from.* (Alcohol guideline [NCCMH, 2011])

A quarter of service users felt that professionals did not offer families and carers enough support (Drug misuse guideline [NCCMH, 2008]).

Evidence from surveys

The Community Mental Health Survey (National Centre for Social Research, 2010) (see Chapter 4 for further information about the survey) had two questions relevant to involving family and carers (see Appendix 11 for full results). Taken together, the survey results suggest that many people are not getting the involvement of, and support for, their families and carers. For instance, 20% of service users were not told they could bring a friend, relative or advocate to their care review meetings, and 20% felt that mental health services had not involved a member of their family (or someone else close to them) as much as they would like. The benchmark data indicate that there was some variation in performance between trusts, and all trusts have room to improve.

7.2.8 Continuity of care and smooth transitions

Evidence from qualitative reviews

Barrier: service organisation

Staff turnover and a lack of co-ordination between services, was also judged to be a barrier to effective treatment (PSM guideline [NCCMH, in press]).

Evidence from qualitative analyses

Barrier: coordination between the police and mental health services

A theme which emerged from the online accounts was the link between mental health services and the criminal justice system and the police. Several accounts compared how, in the UK, there needs to be more co-ordination between the police and mental health services in order to make the most effective referrals for people with psychosis and co-existing substance misuse. In addition, information regarding mental illness was mentioned as necessary to circulate to the police.

> *…if you're struggling with a substance misuse problem you'd be better off in, in the criminal justice system. People say that their lives have been saved by being put in the criminal justice system being forced to come off the drugs and then given help to stay off. And I have to tell you that at the moment there's no, no plan to, to give that kind of care to, to people in my [NHS] trust.* (PSM guideline [NCCMH, in press])

Barrier: poor continuity

Poor continuity of care was a theme that emerged, with one service user explaining that they had to see different psychologists every time, while another person said they were made to repeat their story numerous times, while another said they had been seen by different services and received different diagnoses (Experiences of psychosis [Healthtalkonline, 2011]).

Barrier: service design

One service user explained that they were seen by different services and given different diagnoses (Experiences of psychosis [Healthtalkonline, 2011]).

Evidence from surveys

The Community Mental Health Survey (National Centre for Social Research, 2010) (see Chapter 4 for further information about the survey) had one question relevant to the domain 'continuity of care and smooth transitions' (see Appendix 11 for full results). The results show that 43% of service users did not have a care review meeting during the previous 12 months to discuss their care plan. The benchmark data indicate that there was variation in performance between trusts, and all trusts have room to improve.

7.2.9 Other themes

Evidence from qualitative reviews

Barrier: process issues

Service users described methadone scripts to be time-consuming (must be collected daily). This restricted their job opportunities (Drug misuse guideline [NCCMH, 2008]).

Barrier: stigma of medication

Three studies in one qualitative review described reasons for service-users' non-adherence to medication which included service users expressing that they did not need medication in the first place or that they did not have a mental illness, the side effects of medication, the stigma associated with medication and the concern that the medication would not allow them to have control over their symptoms (PSM guideline [NCCMH, in press]).

Barrier: stigma of psychological therapy

Stigma associated with psychological therapy caused some service users to miss appointments:

> *I hated it. Couldn't stand the psychiatrist... Just thought "I must be crazy" that's all that came into my head. That's what I thought "if you see one of them, you're crazy"* (Self-harm guideline [NCCMH, in preparation]).

Preference: community care

Service users expressed a preference for specialist community-based intervention that had immediate aftercare and acknowledged that self-harm may not necessarily involve its prevention (Self-harm guideline [NCCMH, in preparation]).

Evidence from qualitative analyses

Barrier: stigma

Service users described the stigma around receiving treatment for depression for both psychological and pharmacological interventions:

> *It took a hell of a lot for me to go to therapy. You know A: nutters go to therapy, B: therapy makes you a nutter. These were the kind of things that I grew up with. And it doesn't help. You know, so hostile kind of lower middle class sort of feeling about that sort of thing* (Depression Update guideline [NCCMH, 2010a]).

Service users described a number of other issues that they did not like, including always being considered a mental health 'patient', being encouraged to take a 'dead end' job, and the relative lack of black and minority ethnic doctors (Experiences of psychosis [Healthtalkonline, 2011]).

7.2.10 Evidence summary

Below is a summary of the evidence found for the key problems associated with community care, categorised according to the dimensions of person-centred care.

Involvement in decisions and respect for preferences

There is considerable evidence from both qualitative reviews and survey data suggesting that some service users are not being fully involved in decisions about their care and their preferences respected.

Clear, comprehensible information and support for self-care

The qualitative evidence and survey data both suggest that a key problem in community care is a lack of information provided to service users about treatment. One qualitative review described that when information was provided, it facilitated treatment and enabled informed choice for support.

Emotional support, empathy and respect

The qualitative evidence suggested that service users do experience problems to do with poor emotional support, empathy and respect from mental health practitioners. The survey data suggest that at least 12% of service users are not all ways being treated with respect and dignity.

Effective treatment delivered by trusted professionals

The qualitative evidence suggested considerable problems regarding treatment, ranging from medication side effects and lack of psychological therapies to problems associated with non-flexible services. In particular, when professionals give service users the impression that a particular disorder is untreatable, the experience of care will be poor. The survey data supports the qualitative evidence, and suggests much more can be done to improve experience.

Attention to physical and environmental needs

The qualitative evidence suggested barriers regarding the physical and environmental needs of service users in community care. These included a lack of privacy currently available in waiting rooms and a lack of services available to the needs of service users including child care. The survey data also suggests that much more can be done to the experience of care through focusing on physical and environmental needs.

Involvement of, and support for, family and carers

The qualitative reviews identified that the experience of care could be improved by involving family, carers and peers in community care. The survey data supports this finding, with many service users not being enabled to receive the support of their families.

Continuity of care and smooth transitions

Qualitative evidence suggested the lack of co-ordination between the police and mental health services, service configuration problems and staff turnover lead to poor experience. The survey data suggest that many service users are not receiving regular care review meetings.

Other themes (including stigma)

Other themes which did not relate to a specific dimension of person-centred care were barrier including process issues relating to community treatment (qualitative review; Drug misuse guideline [NCCMH, 2008]) and a preference for community care (qualitative review, Self-harm guideline [NCCMH, in preparation]).

Other themes were related to stigma associated with medication (qualitative review, PSM guideline [NCCMH, in press]) and receiving treatment for severe mental illness including psychological interventions found in one qualitative review (Self-harm guideline [NCCMH, in preparation]) and one qualitative analysis (Depression Update guideline [NCCMH, 2010a]).

7.3 KEY REQUIREMENTS FOR THE PROVISION OF HIGH QUALITY SERVICE USER EXPERIENCE

The key requirements (qualitative statements based on the GDG’s expert opinion) for the provision of high quality service user experience for community care are shown in Table 14.

Table 14. Key requirements for the provision of high quality service user experience (community care).

Dimensions of person-centred care	Statement
Involvement in decisions and respect for preferences	• A standard letter and form sent to service user in advance of appointment. • Service user to be fully involved and active in the design and delivery of the care plan, and health and social care professional and service user to sign the document and a copy kept by service user. • All available treatment options should be offered to service users verbally and in writing on the day of consultation. • Care plan to include meaningful actives/volunteering /education, re-training, part full time employment. • Refusal of a treatment should not automatically be seen as the service user being difficult to engage • People at risk of hospitalisation should have joint crisis plans which should be respected and implemented
Clear, comprehensible information and support for self-care	• The language in care and support plan should be in a language determined and understood by the service user. • SMART[7] objectives should be used. • Service user should have the option of keeping their record in their in a suitable format. • A team leader should be put in place to oversee the service user mental and practical issues • Inform service users of appropriate local user led support organisations or options for peer-support
Emotional support, empathy and respect	• All staff should have empathy and hope and show respect and believe that all service users can recover (as defined by the service user) and progress. • The service user should have the choice of who they think would give the best emotional support and support for decisions.
Fast access to reliable health advice	• A system should be put in place that service users can get advice on the services in local area. • Reception staff should to be trained in interpersonal skills, and where necessary, other languages.
Effective treatment delivered by trusted professionals	• All health and social care professionals should provide a holistic, person-centred approach to their work and service user. • All health and social care professionals should be able to sign post and refer to other services. • All health and social care professionals should provide interdependent coping skills training • All health and social care professionals should have core skills training and option to specialise in any relevant areas deem fit to carry out their role. • All trusts to have service user on their Board, monitoring and audit committees. • Service user to have the option of talking to advocate or have a 3 way to discuss issue before any change are made.
Attention to physical	• The consultation at first should be in a secure venue.

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[7] Specific, Measurable, Attainable, Relevant, Timely.

and environmental needs	• For health and social care professionals and service user after the first meeting the next can be agreed to meeting in a more suitable place if required
Involvement of, and support for, family and carers	• All families and carers should be offered the option of joining a support group or having one to one supervision with health and social care professionals. • A training programme to be developed to help them in their role. • All health and social care professionals must keep confidentiality and share information only with consent of the service user in advance of contact with others.
Continuity of care and smooth transitions	• If all staff have core training the continuity of care should be same when staff moves. • To help sort the problems with communications between agencies and services the service user should keep their information in any format they like and share it as their see fit or a team leader can be appointed to correlate the services.

7.4 EVIDENCE TO RECOMMENDATIONS

The problems identified by the qualitative reviews and analyses and the surveys revealed a broad range of problems which resonated with the experience of the guidance group. For example, the lack of good information about treatments, poor involvement in decision making, few treatment options, especially psychological treatments, and a low level of optimism, especially for service users with more severe mental health problems. Practical support to attend treatment was highlighted especially for mothers, and when people attended mental health facilities the waiting areas were poorly designed with a lack of privacy for some. Families were also recognised as feeling left out of treatment planning and service users often felt stigmatised, especially around the use of medication such as antipsychotics. Nevertheless, the evidence, and the GDG, clearly wanted to see community services improve rather than a return to more institutional care of the past.

The guidance group voiced a wide range of aspirations, not always in agreement. However, the guidance group were most in agreement about the more prosaic aspects of care, such as better waiting areas, the inclusion of meaningful activity and occupation into care plans, service users holding their own care plans and being given information about where to get good advice in the community. Other more far reaching suggestions included service users being represented on trust board and being involved in the design and shaping the delivery of services.

On reviewing the aspirations and the key problems, the GDG focused attention on some broad issues that apply across all points on the care pathway, but were of particular importance to community care. The recommendations for these aspects of the experience of care included the need for health and social care professionals to engage service users and carers in an atmosphere of optimism and hope, with empathy and without judgement; to foster autonomy in the service user; to offer an advocate to support the service user, especially at times of difficulty; to ensure continuity of care; and to provide information about treatments, services, side effects, national and local resources, including websites that may be helpful. Involving families was also a key issue to 'get right': the guidance group wanted one approach for service users who wanted the family involved and another for when they did not, a clear difference is in tactfully negotiating and balancing confidentiality and information sharing differently in each situation. All these issues were placed in care across all points on the care pathway in the NICE guidance.

Areas specifically of importance to improve the experience of care in the community included the use of different media to support communication; jointly developing care and treatment plans to include activities that support social inclusion; promoting and maintaining independence; increased emphasis on personal budgets and direct payments; easy access to care plans, including electronic versions, with a place for service users to contribute directly to their own care records. Helping service users at risk of hospitalisation to plan ahead by developing crisis plans was also seen as a priority, particularly for those with more severe problems, those who have been admitted in the past and/or treated under the Mental Health Act (HMSO, 2007). Service problems to be addressed included continuity of care and the need to stay in touch with known individuals; access to NICE recommended psychological therapies, which are often lacking; supporting people from minority groups to get access to the full range of treatments and making sure that mental health and social care professionals not familiar with working with different ethnic groups should get training and supervision to do this. Although these were by no means exhaustive, and the guidance group could have suggested more, these were the main suggestions for recommendations that mainly apply to community care.

7.5 RECOMMENDATIONS

7.5.1 Practice recommendations relating specifically to community care

7.5.1.1 When communicating with service users use diverse media, including letters, phone calls, emails or text messages, according to the service user's preference.

7.5.1.2 Develop care plans jointly with the service user, and include activities that promote social inclusion such as education, employment, volunteering and other occupations such as leisure activities and caring for dependants. Give the service user an up-to-date written copy of the care plan. [QS9]

7.5.1.3 Support service users to develop strategies, including risk- and self-management plans, to promote and maintain independence and self-efficacy, wherever possible. Incorporate these strategies into the care plan.

7.5.1.4 If they are eligible, give service users the option to have a personal budget or direct payment so they can choose and control their social care and support, with appropriate professional and peer support as needed.

7.5.1.5 For people at risk of hospitalisation, a crisis plan should be developed by the service user and their care coordinator, which should be respected and implemented, and incorporated into the care plan. The crisis plan should include:

- where the person would like to be admitted
- possible early warning signs of a crisis,
- the practical needs of the service user if they are admitted to hospital (childcare or the care of other dependants, including pets). [QS10]

7.5.1.6 Ensure that service users routinely have access to their care plan and care record, including electronic versions. Care records should contain a section in which the service user can document their views and preferences, and any differences of opinion with health and social care professionals.

7.5.1.7 Trusts should ensure that service users:

- can routinely receive care and treatment from a single multidisciplinary community team
- are not passed from one team to another
- do not undergo multiple assessments. [QS4]

7.5.1.8 Ensure that service users have access to the psychological, psychosocial and pharmacological interventions recommended for their mental health problem in NICE guidance.

7.5.1.9 Mental health services should work with local voluntary black and minority ethnic and other minority groups to jointly ensure that culturally appropriate psychological and psychosocial treatments, consistent with NICE guidance and delivered by competent practitioners, are provided to service users from all ethnic and cultural backgrounds.

7.5.1.10 Mental health and social care professionals inexperienced in working with service users from diverse ethnic and cultural backgrounds should seek advice, training and supervision from health and social care professionals who are experienced in working with people from different cultures.

7.5.2 Practice recommendations relating to community care and all points on the pathway

7.5.2.1 Work in partnership with people using mental health services and their families or carers. Offer help, treatment and care in an atmosphere of hope and optimism. Take time to build supportive, empathic and non-judgemental relationships as an essential part of care. [QS1]

7.5.2.2 When working with people using mental health services:

- aim to foster their autonomy, promote active participation in treatment decisions and support self-management [QS3]
- maintain continuity of individual therapeutic relationships wherever possible
- ensure that comprehensive written information about the nature of, and treatments and services for, their mental health problems is available in an appropriate language or format including any relevant 'Understanding NICE guidance' booklets
- offer access to an advocate.

7.5.2.3 Ensure that you are:

- familiar with local and national sources (organisations and websites) of information and/or support for people using mental health services
- able to discuss and advise how to access these resources.

Consent, capacity and treatment decisions

7.5.2.4 Develop advance statements and advance decisions with the person using mental health services, especially if their illness is severe and they have been previously treated under the Mental Health Act (1983; amended 1995 and 2007). Document these in their care plans and ensure copies are held by the service user and in primary and secondary care records. [QS10]

Involving families and carers

7.5.2.5 Discuss with the person using mental health services if and how they want their family or carers to be involved in their care. [QS21]

7.5.2.6 If the person using mental health services wants their family or carers to be involved, encourage this involvement and:

- negotiate between the service user and their family or carers about confidentiality and sharing of information on an ongoing basis
- explain how families or carers can help support the service user and help with treatment plans
- make sure that no services are withdrawn because of the family’s or carers’ involvement, unless this has been clearly agreed with the service user and their family or carers.

7.5.2.7 If the person using mental health services wants their family or carers to be involved, give the family or carers verbal and written information about:

- the mental health problem(s) experienced by the service user and its treatment, including relevant 'Understanding NICE guidance' booklets
- statutory and voluntary local support groups and services specifically for families and carers, and about how to access these
- their right to a formal carer's assessment of their own physical and mental health needs, and how to access this.

7.5.2.8 If the service user does not want their family or carers to be involved in their care:

- seek consent from the service user and if they agree give the family or carers verbal and written information on the mental health problem(s) experienced by the service user and its treatments, including relevant 'Understanding NICE guidance'
- give the family or carers information about statutory and voluntary local support groups and services specifically for families or carers, and how to access these

- tell the family or carers about their right to a formal carer's assessment of their own physical and mental health needs, and how to access this

7.5.3 Research recommendations

7.5.3.1 How can providers of mental health services help to reduce stigma experienced by people with mental health problems?

8. ASSESSMENT AND REFERRAL IN CRISIS (NOT UNDER THE MENTAL HEALTH ACT)

8.1 INTRODUCTION

This chapter provides evidence about the key problems relating to assessment and referral in crisis (when not under a section of the Mental Health Act [HMSO, 1983; amended 1995 and 2007; HMSO, 2007]), and the key requirements for high quality service user experience. Recommendations for best practice and recommendations for research can be found at the end of the chapter.

Current practice

Barriers to accessing services discussed in Chapter 5, mean that in some instances attempts are not made to access mental health services until a person is already in crisis. Existing NICE guidelines recommend that at such times services need to make a timely response to assess a person's mental health and social needs and any risk of harm to self or others (for example, see the update of the schizophrenia guideline; NICE, 2009b).

Services for assessing people in crisis vary among different mental health Trusts, but they generally involve psychiatric liaison services who assess people in acute medical setting such as Emergency Departments and crisis or home treatment teams who aim to assess, support and treat people in the community who may otherwise need to be treated in hospital. This threshold of 'working only with people who may otherwise need to be treated in hospital' means that some people who are experiencing a crisis may not be considered to have mental health needs which are sufficiently great to be treated by such teams. The issue of how people whose mental health is deteriorating can access assessment and support services is therefore an important one.

8.2 KEY PROBLEMS REGARDING ASSESSMENT AND REFERRAL IN CRISIS

Evidence from qualitative reviews/analyses addressed the following domains of person-centred care:

- fast access to reliable health advice
- effective treatment delivered by trusted professionals.

No evidence was identified that directly addressed:

- involvement in decisions and respect for preferences
- clear, comprehensible information and support for self-care
- emotional support, empathy and respect
- attention to physical and environmental needs
- involvement of, and support for, family and carers
- continuity of care and smooth transitions.

For the purposes of the review, themes from the qualitative evidence are summarised only briefly here, with further details provided in Appendix 12. Domains and sources of evidence without themes are not listed below.

8.2.1 Fast access to reliable health advice

Evidence from qualitative reviews

Facilitator: waiting times

Two guidelines found a key problem to assessment and referral to services in crisis was the waiting times (Alcohol guideline [NCCMH, 2011]; Drug misuse guideline [NCCMH, 2008]). Over one third of service users with alcohol problems reported that they wanted quicker referral to treatment in order to maintain treatment motivation and to receive medical care:

> *When you make that decision to ask for help, you need it straight away. If you have to wait a long time to get in you just lose your motivation and you might just give up.* (Alcohol guideline [NCCMH, 2011])

Service users in one study reported that the long waiting time to receive inpatient treatment was a barrier to accessing treatment because their motivation to change decreased over time:

> *I'd go with all the intentions to get off it…but the longer you have to wait, the more and more trouble you get in. Eight months is a long time; you don't know what is going to happen to you.* (Drug misuse guideline [NCCMH, 2008])

However, in some cases, users were aware of the high demand in services and were satisfied with the waiting times (Drug misuse guideline [NCCMH, 2008]).

In a crisis, lack of instant help in A&E was mentioned by the service users as a problem:

I actually thought my heart was going to stop when.. I was just so terrified. So I flee to A & E and I was getting a commentary and they were telling me all about psychiatric drugs. […] And nobody came to help me in A & E. They just put me in a *room and left me there and I was so distressed that I thought, right I've got to get up to [name of place]. (*Experiences of psychosis [Healthtalkonline, 2011])

8.2.2 Effective treatment delivered by trusted professionals

Evidence from qualitative reviews

Barrier: validity of diagnosis

Across the two guidelines on personality disorder, service users questioned the validity of their diagnosis (ASPD guideline [NCCMH, 2009a]; BPD guideline [NCCMH, 2009b]). One study found that service users questioned the legitimacy of the diagnosis of personality disorder as they suffered from other primary, co-morbid problems. However, one participant in another study found it to accurately describe his condition (ASPD guideline [NCCMH, 2009a]). In the BPD guideline, the validity of their diagnosis was questioned because some service users received many diagnoses in the past and were therefore sceptical about the diagnosis and others were unsure whether they were ill or just a troublemaker (BPD guideline [NCCMH, 2009b]). Diagnosis was an important but sometimes controversial outcome of contact with services according to some service users. Many people said they had received different diagnoses over time, had more than one diagnosis at a particular time or felt that schizophrenia was not a valid diagnosis and preferred other descriptions such as 'voice hearers'. (Experiences of psychosis [Healthtalkonline, 2011]).

8.2.3 Evidence summary (not under the Mental Health Act)

Below is a summary of the evidence found for the key problems associated with assessment and referral in crisis (not under the Mental Health Act [HMSO, 2007]), categorised according to the dimensions of person-centred care.

Fast access to reliable health advice

The qualitative evidence suggests that for some service users, waiting for assessment when in crisis can cause problems.

Effective treatment delivered by trusted professionals

The qualitative evidence suggests that for some service users, the legitimacy of their diagnosis can be a problem, especially if different diagnoses had been given in the past. When people changed psychiatrist, their diagnosis sometimes changed too; one person moved around a lot and received many diagnoses. Some people felt angry that they were 'misdiagnosed' and that they had received the wrong treatment because of this.

8.3 KEY REQUIREMENTS FOR THE PROVISION OF HIGH QUALITY SERVICE USER EXPERIENCE

For assessment and referral in crisis, the key requirements (qualitative statements based on the GDG's expert opinion) for the provision of high quality service user experience for each dimension of person-centred care are shown in Table 15.

Table 15: Key points on the pathway of care (acute care, not under MHA)

Dimensions of person-centred care	Statement
Involvement in decisions and respect for preferences	• Service users can expect a health and social care professional to attend to them, respecting their views and exploring other options where possible apart from hospital admission. The inequality of power in the relationship is respected, giving the service user access to an advocate where requested. • It should be recognised that service users often have experience of being in crisis and can recognise when they are heading into a crisis. Health and social care professionals should respect this knowledge and work with the service user to access the appropriate service rather than waiting for a full crisis to occur.
Clear, comprehensible information and support for self-care	• Service users can expect all reasonable support with managing factors which have contributed to the crisis, keeping their options open for return to work or study and protection of their dependents and next of kin.
Emotional support, empathy and respect	• Service users can expect support preventing a crisis becoming a disaster by helpful staff. Because this is difficult to judge, there should be routine recording of telephone conversations according to NHS best practice, and support in managing complaints. The power differential between staff and the service user must be respected.
Fast access to reliable health advice	• Service users can expect to speak in a timely way to an informed professional who will help them make the right decision about their next steps, whether referral, community support, and/or medication. For those who may need inpatient treatment this assessment should take place within four hours of referral. For other referrals in crisis an assessment should take place within 24 hours of referral. • People who have had previous contact with mental health services should be able to self refer to secondary care. • Trusts should ensure that service users have easy access to 24-hour staffed help lines and that all GPs in the area know the number. • Services should recognise that service users often have knowledge and experience of their distress and can recognise when they are heading for crisis even if they are not currently in a crisis. This should be recognised and supported and access to the appropriate service be given to prevent a crisis instead of waiting for a crisis to occur.

Effective treatment delivered by trusted professionals	• Service users can expect to meet a trained healthcare professional who will explore the context of their problems, be experienced in crisis working and able to treat holistically, by appropriate referral, involvement of a multi-agency team, community resources and/or medication. • Provision of crisis assessment should not be focussed solely on the Emergency Department of a general hospital. Some direct access to secondary care mental health services should also be available.
Attention to physical and environmental needs	• The service user can expect a convenient and comfortable location, protected from harassment from those who might wish him/her harm or other service user, and where all staff are kind, welcoming and helpful without exception.
Involvement of, and support for, family and carers	• Service users can request help for family and carers in coming to terms with their difficulties, and someone to be able to contact reliably when more help is needed. • Family and carers should also be informed of how urgent access to assessment services can be arranged.
Continuity of care and smooth transitions	• Access to crisis services should not be restricted to people with certain diagnoses (such as only people with a psychosis). • Service users can expect all staff to work together well; those best known to him/her to have a "buddy" who will cover for the healthcare professional when they are absent; for medication to be prescribed accurately, for appointments to run according to time and delays to be communicated.

8.4 EVIDENCE TO RECOMMENDATIONS

Key problems that were identified by qualitative reviews and analysis relating to assessment and referral in crisis revealed the following issues. In regards to receiving fast access to reliable health advice, service users reported a problem with waiting times for inpatient treatment and referral to treatment, although some service users understood the high demands of services and did not consider waiting times a problem. Long waiting times become a particular problem for service users because of the difficulty in maintaining motivation for treatment and motivation to change. With regard to treatment delivered by trusted professionals, service users reported problems in the validity of their diagnosis. For example, if a service user has received many diagnoses in the past or has had more than one diagnosis at a particular time, he/she can become sceptical about their current diagnosis.

The key requirements voiced by service users for assessment and referral in crisis included the need for health care professionals to acknowledge the inequality of power between professionals and service users and the need for an advocate in some cases if requested. The GDG felt that health and social care professionals should recognise and support the fact that service users have the experience to realise when they are heading into or are in a crisis, and so necessary action should be taken to prevent a crisis rather than waiting for one to occur. One such requirement that could address this issue is to ensure service users have easy access to 24-hour help lines. There should be a holistic approach to the support provided which should manage potential factors that may contribute to a crisis and prevent a crisis from escalating further. Family and carers of service users should be offered help if requested and informed of urgent access to assessment services. There should be an informed decision for next steps regarding referral, community support, medication and/or the involvement of a multi-agency teams. Suggestions for better access to secondary care mental health services include self referral and some direct access.

Areas specifically of importance to improve the experience of assessment in crisis included the following: a service users previous experiences of mental health services, engaging service users in a supportive and respectful way, providing information about processes and outcomes, addressing individual needs, assessment by experienced health and social care professionals and taking account of a service user's preference of place of assessment. The speed of referral to secondary care was seen as a central issue; specifically, when a person is referred in crisis they should be seen by specialist mental health services within 4 hours. Also, ensure access to 24-hour help lines; access to crisis resolution and home treatment teams; assessment and treatment regardless of diagnosis; support in the service users own home; home treatment depending on service users preferences and direct self-referral to mental health services.

8.5 RECOMMENDATIONS

8.5.1 Practice recommendations related specifically to assessment and referral in crisis

8.5.1.1 Immediately before assessing a service user who has been referred in crisis, find out if they have had experience of acute or non-acute mental health services, and consult their crisis plan if they have one.

8.5.1.2 When undertaking a crisis assessment:

- address and engage service users in a supportive and respectful way
- provide clear information about the process and its possible outcomes, addressing the individual needs of the service user, as set out in **Error! Reference source not found.**
- take extra care to understand and emotionally support the service user in crisis, considering their level of distress and associated fear, especially if they have never been in contact with services before, or if their prior experience of services has been difficult and/or they have had compulsory treatment under the Mental Health Act (1983; amended 1995 and 2007).

8.5.1.3 Assessment in crisis should be undertaken by experienced health and social care professionals competent in crisis working, and should include an assessment of the service user's relationships, social and living circumstances and level of functioning, as well as their symptoms, behaviour, diagnosis and current treatment. [QS11]

8.5.1.4 If assessment in the service user's home environment is not possible, or if they do not want an assessment at home, take full consideration of their preferences when selecting a place for assessment.

8.5.1.5 When a person is referred in crisis they should be seen by specialist mental health secondary care services within 4 hours of referral. [QS6]

8.5.1.6 Trusts should ensure that service users have access to 24-hour helplines, staffed by trained health and social care professionals, and that all GPs in the area know the telephone number. [QS6]

8.5.1.7 Trusts should ensure that crisis resolution and home treatment teams are accessible 24 hours a day, 7 days a week, and that they are the first service to assess and provide treatment for service users in crisis regardless of their diagnosis. [QS6]

8.5.1.8 To avoid admission, aim to:

- support a service user in crisis in their home environment

- make early plans to help the service user maintain their day-to-day activities, including work, education, voluntary work, and other occupations such as caring for dependants and leisure activities, wherever possible.

8.5.1.9 At the end of a crisis assessment, ensure that the decision to start home treatment depends not on the diagnosis but on:

- the level of distress
- the severity of the problems
- the vulnerability of the service user
- issues of safety and support at home
- the reliability of access to, and the person's cooperation with, treatment.

8.5.1.10 Consider the support and care needs of families or carers of service users in crisis. Where needs are identified, ensure they are met when it is safe and practicable to do so.

8.5.1.11 Trusts should support direct self-referral to mental health services as an alternative to accessing urgent assessment via the emergency department.

9. HOSPITAL CARE

9.1 INTRODUCTION

This chapter provides evidence about the key problems relating to hospital care (Section 9.2), and the key requirements for high quality service user experience (Section 9.3). Further information about the source of evidence can for the key problems review can be found in Chapter 4. Recommendations for best practice and recommendations for research can be found at the end of the chapter.

Psychiatric hospital beds reached their maximum number in England and Wales in 1955 at approximately 150,000. Enoch Powell made his famous 'Water Tower' speech, calling for the closure of the old asylums, in 1961. Thereafter bed numbers went into decline, although it was not until the late 1980s that the first large hospital was closed.

With the advent of the policy of community care, acute provision was available in psychiatric wards in District General Hospitals and on small purpose-built units. However, bed numbers have continued to fall in recent times. In the period 2002-2003 to 2007-2008, total numbers of mental health beds fell from 32,753 to 26,928, a reduction of 17% (Keown, 2008). This decrease has not affected all client groups in the same way. People with depression or anxiety are much less likely to be admitted today than even ten years ago and, in some parts of the country, acute hospital care is available only to those with a diagnosis of psychosis.

A reduction in beds and an increase in people being detained can lead to a volatile climate on wards. The shift has been accompanied by increased use of the Mental Health Act (HMSO, 1983; amended 1995 and 2007; HMSO, 2007) (see Chapter 11). Further, the number of admissions has not declined as fast as the decline in bed numbers leading to some wards having bed occupancy rates of more than 100%, such that people are put on leave or even 'sleep out' on other wards or spend the night in Bed and Breakfast. However, although acute provision has declined in terms of bed numbers and people treated, this is still the greater part of resources committed to mental health.

Current practice

The grey literature is replete with references to the untherapeutic and unsafe nature of acute care. MIND's 'Wardwatch' campaign (MIND, 2004) invited people who had spent time in inpatient wards to write with an account of their experience. Overwhelmingly, ex-service users had found that staff were unwilling to interact, they were not involved in their care and that people felt unsafe (MIND, 2004). Quirk and Lelliot (2000) also found a lack of interaction between staff and patients and a volatile atmosphere characterising the results of the literature they reviewed and their own ethnographic findings (see also Walsh & Boyle, 2009). Another feature of acute inpatient wards is the lack of activity and the crushing boredom that service users experience (MIND, 2004, Rose, 2001).

It is frequently argued, indeed it is the conclusion of Quirk and Lelliot (2000), that these features of acute wards are a consequence of the policy shift away from hospital care so that only the most unwell and complex service users are admitted to hospital in the first place. However, Sharac and colleagues (2010) reviewed the literature over 40 years, and found these same features, especially lack of interaction between service users and staff, even in the old hospitals. They also uncovered a steady finding over the years of service users spending time in isolation, the corollary of lack of staff/service user interaction.

The state of affairs on acute mental health wards makes it an urgent clinical, social and economic problem. It is well recognised by frontline staff who say that administrative duties take them away from patient care. It is also well recognised by managers, who have to manage the economic resources as well as deal with high levels of staff turnover, sickness and burnout leading to the use of agency staff who do not know the ward or the patient. However, most of all it is recognised by service users, many of whom find acute wards untherapeutic and unsafe. It is not the case for all wards, there are pockets of good practice where staff and service users have worked together collaboratively to redesign services.

9.2 KEY PROBLEMS REGARDING HOSPITAL CARE

Evidence from qualitative reviews/analyses and surveys addressed the following domains of person-centred care:

- involvement in decisions and respect for preferences
- clear, comprehensible information and support for self-care
- emotional support, empathy and respect
- effective treatment delivered by trusted professionals
- attention to physical and environmental needs
- involvement of, and support for, family and carers
- continuity of care and smooth transitions.

No evidence was identified that directly addressed:

- fast access to reliable health advice.

For the purposes of the review, themes from the qualitative evidence are summarised only briefly here, with further details provided in Appendix 12. Domains and sources of evidence without themes are not listed below.

9.2.1 Involvement in decisions and respect for preferences

Evidence from qualitative analyses

Whilst service users recognised that the situation on wards was sometimes chaotic and difficult, they still wanted as many rights as they could realistically expect to have in a hospital context:

> *I think the ones, the nurses I've had the most problem with have been the ones that are ultra controlling, and I think it's because, when I get ill, my head is not in my control. Then if I end up in a situation, say on a section in hospital, and somebody tries to take away all the other controls I've got, then it can be really difficult.* (Experiences of psychosis [Healthtalkonline, 2011])

> *You see the doctor once a week, for like five minutes, when the doctor does the rounds. But there's like ten of them in a room. You go in. You're like Whoa, who are these people, and then they start talking to you. They, [smacks table] they make a decision about you. They obviously are quite knowledgeable, but to you, it seems like what the hell? And they make a decision right you're staying. Stay on the same drugs. Go and that's it.* (Experiences of psychosis [Healthtalkonline, 2011])

Evidence from surveys

The mental health acute inpatient services survey (Care Quality Commission, 2009) (see Chapter 4 for further information about the survey) had four questions relevant to the domain of 'involvement in decisions and respect for preferences' (see Appendix 11 for full results). Taken together, the survey results suggest that many service users are not being fully involved in decisions about their care. For example, 27% were not involved as much as they wanted, and 19% were not given enough time to discuss their condition and treatment with the psychiatrist(s). In addition, 13% did not believe their psychiatrist listened carefully to them, and a further 30% said 'Yes, sometimes'. The situation was similar with regard to nurses listening carefully, with 12% of service users answering 'no' and 40% 'Yes, sometimes'. The benchmark data indicate that there was relatively wide variation in performance between trusts, and all trusts have room to improve.

9.2.2 Clear, comprehensible information and support for self-care

Evidence from qualitative analyses

Several service users mentioned how difficult it was to research their condition or the services that were available in hospital:

> *And like, when I was in the hospital I was like, "Can you give me some literature about what's going on?" and stuff like that. But there was nothing. Yeah. That was horrible too.*

> [***]
> *No one sits down and says right this is what's happened. You're experiencing this, and blah, blah, blah. No one was there to reassure you.*
> [***]
> *And later on I found out there's a gym. You're entitled to benefits. You can get a freedom pass, and no one told me any of that. Do you know what I mean. No one sat me down and helped me? I was just living, I was just living there.*
> (Experiences of psychosis [Healthtalkonline, 2011])

Evidence from surveys

The mental health acute inpatient services survey (Care Quality Commission, 2009) (see Chapter 4 for further information about the survey) had four questions relevant to the domain of 'clear, comprehensible information and support for self-care' (see Appendix 11 for full results). Taken together, the survey results suggest that many service users were not given adequate information about the daily routine of the ward and about the medication they were prescribed. For example, 30% were not told by a member of staff about things such as meal times and visitors when, or soon after, they arrived on the ward. A further 30% felt they were only told about these things to 'some extent'. Nearly a quarter of service users felt that the purpose of their medication was not explained in way they could understand, and 48% felt that possible side-effects were not explained properly. Furthermore, 52% of service users were not made aware of how they could make a complaint if they had one. The benchmark data indicate that there was relatively wide variation in performance between trusts, and all trusts have much room to improve.

9.2.3 Emotional support, empathy and respect

Evidence from qualitative reviews

Barrier: professionals

A key problem noted in hospital care was the characteristics of the professional. Service users felt that there was a lack of rapport with some professionals and felt in some cases that they needed to act in exaggerated ways to get the attention of professionals (Self-harm guideline [NCCMH, in preparation]).

Facilitators: professionals

The importance of professional characteristics in hospital care was found in two other guidelines (Alcohol guideline [NCCMH, 2011]; Drug misuse guideline [NCCMH, 2008]). The most important aspect of inpatient treatment noted by service users was the therapeutic relations in particular staff attitude (non-judgemental and empathetic) and support (Alcohol guideline [NCCMH, 2011]). Service users in inpatient treatment also reported the positive impact that professionals can have in hospital care where building a rapport with key workers motivated them to remain abstinent (Drug misuse guideline [NCCMH, 2008]).

Evidence from qualitative analyses

Barrier: professionals

Many people found that they received greater support from other inpatients than professionals:

> *...the only kind of really support I have to say I got was from the other patients. So you know, there was many a time I was crying on the ward and no nurse came to comfort me. It was you know, for the patient. And there was one lady, I'll never forget this, she went, she saw that I was crying, she went out, to the kind of drinks machine and she bought me back a can of Cola to cheer me up.* (Experiences of psychosis [Healthtalkonline, 2011])

Facilitators: professionals

Even under difficult situation, such as being on constant observation, kindness could be shown by professionals which helped:

> *And there was one nurse, there was one nurse I remember very clearly. She had a polka dot dress on and she was just so warm. She was always there in this empathetic close way, where you felt she wanted to look after me and she was going to be nice.* (Experiences of psychosis [Healthtalkonline, 2011])

Evidence from surveys

The mental health acute inpatient services survey (Care Quality Commission, 2009) (see Chapter 4 for further information about the survey) had five questions relevant to the domain of 'emotional support, empathy and respect' (see Appendix 11 for full results). The results suggest that most service users (85%) are made to feel welcome when they arrive on the ward, but some are not being treated with respect and getting enough privacy. For example, 9% thought the psychiatrist did not treat them with respect and dignity, while 10% thought the same about the nurses. In addition, a further 22% felt the psychiatrists and 34% felt the nurses treated them with respect and dignity 'sometimes'. When discussing their condition or treatment, 13% of service users thought they were not given enough privacy and 29% thought they were only sometimes. Importantly, 30% thought that they were treated unfairly during their most recent stay. The benchmark data indicate that there was relatively wide variation in performance between trusts, and all trusts have room to improve.

9.2.4 Effective treatment delivered by trusted professionals

Evidence from qualitative reviews

Facilitator: reduced waiting time and improved support

In a small survey of inpatients (a highly specialist personality disorder hospital treatment unit), the majority thought psychoeducation to be 'helpful,' but thought it could be improved by reducing the waiting time between assessment and feedback and by receiving support after the intervention (ASPD guideline [NCCMH, 2009a]).

Facilitator: more frequent reviews

In a small survey of inpatients (a highly specialist personality disorder hospital treatment unit), the majority thought social problem solving 'generally useful,' but wanted more frequent reviews on how well the treatment is going and more consistency in how it is delivered (ASPD guideline [NCCMH, 2009a]).

Facilitator: access to specialists

Service users found access to specialist services improved their perceptions of service provision, and built a sense of belonging due to sharing experiences with other users and stronger relationships with professionals (BPD guideline [NCCMH, 2009b]). A few people had access to group therapy in hospital which they found useful:

> *I was getting to actually talk about some stuff, you know, which was good and it was group therapy as well so it was kind of quite helpful to be with other people and kind of be like sort of in a way helping each other like you know, yes so that was good. (*Experiences of psychosis [Healthtalkonline, 2011])

Barrier: access to healthcare professionals

Service users in one qualitative review found inpatient services intentionally limiting with little access to mental health professionals. In some circumstances this is caused by healthcare professionals not viewing borderline personality disorder as a mental illness, therefore not believing the hospital environment is the right environment for treatment, even though the service user may have thought an inpatient ward would be a helpful environment to provide safety, particularly where other options such as crisis houses and so on are not available:

> *'I have also been one of the lucky few who was in the first instant referred to my local hospital, which has very good specialist services such as dual diagnosis, an eating disorders unit, a crisis unit and specialist psychotherapy services for borderline personality disorder. But I was plagued by long waiting lists and being passed from one health professional to another until I was given the right treatment'* (BPD guideline [NCCMH, 2009b]).

Many service users felt that there was little to do in hospital, there was hardly any contact with staff and they were too medicated to be able to interact with anyone properly. Others felt that they could not recuperate in hospital:

> *...well I used to always think it was a bit strange because when you're being detained the last person you see is the Social Worker who normally - [the] rationale for you going into the hospital is you need to go in to have a rest. There's no way you can rest on an acute unit in Britain, that, that is a sort of silly idea.* (Experiences of psychosis [Healthtalkonline, 2011])

Barrier: constant observation

Service users in two studies described the constant observation that occurred, which was experienced as distressing and intolerable (while others felt safe and a reduction of risk). Some service users felt they were merely being watched while in care rather than receiving any therapy for self-harm (Self-harm guideline [NCCMH, in preparation]).

Evidence from qualitative analyses

Barriers: professional

Service users described a mixture of positive and negative experiences. One person said that a psychiatric intensive care unit was 'a place of safety'. Others described a mental health service as a place where they had no responsibilities, where they could 'hand yourself over' to the care of the service.

Accompanying this, however, was the feeling of being institutionalised:

> *In eight weeks, I very quickly became institutionalised myself. I was scared to come out because I was in this enclosed world where I knew what was going to happen. There were routines, mealtimes, getting up times, medication times, OT [occupational therapy] times. There were routines and I had no responsibilities . . . I was in a place where I didn't have to think about anything, and nobody could touch me.* (Depression Update guideline [NCCMH, 2010a])

People also had negative experiences of mental health services provided by the NHS, including not feeling cared for (Depression Update guideline [NCCMH, 2010a]).

One woman wasn't told any detail about her diagnosis of schizophrenia whilst in hospital. Another man felt that he wasn't told in sufficient depth about the possible side effects of his medication (Experiences of psychosis [Healthtalkonline, 2011]).

Barrier: constant observation

The few people who had experienced constant observation found it humiliating. A service user describes his experience:

> *Horrible. You can imagine somebody following you about constantly. It's, it really isn't nice to be on. it's … I don't like it at all. [...]Can you imagine your partner constantly watching you? 24 hours a day. Going to toilet and watching you do a toilet. Going to a shower and watching you do a shower. Eating. it's not nice. (*Experiences of psychosis [Healthtalkonline, 2011])

Evidence from surveys

The mental health acute inpatient services survey (Care Quality Commission, 2009) (see Chapter 4 for further information about the survey) had four questions relevant to the domain of 'effective treatment delivered by trusted professionals' (see Appendix 11 for full results). Taken together, the survey results suggest that trust in healthcare professionals could be improved. For example, 21% of service users answered that they did not have confidence and trust in the psychiatrist, and a further 32% answered, 'Yes, to some extent'. Furthermore, 17% did not have confidence and trust in the nurses, and 39% answered 'Yes, sometimes'. When arriving on the ward, only 28% felt the staff 'definitely' knew about them and about any previous care they had received. Under a third (29%) of service users had talking therapy during their stay in hospital, and of those that did, only 50% thought it definitely helped. The benchmark data indicate that there was some variation in performance between trusts, and considerable room for all trusts to improve.

9.2.5 Attention to physical and environmental needs

Evidence from qualitative reviews

Barrier: physical environment

Some female service users in one study feared being on a mixed ward and some older, adolescent service users in another study had negative experiences of being placed on adult wards (Self-harm guideline [NCCMH, in preparation]).

Evidence from qualitative analyses

Barrier: physical environment

Many service users were shocked by the physical environment on the wards.

> *And* [my dad] *took me to the local Psychiatric Unit and it was a real eye-opening experience. It was absolutely filthy there was people laid on the corridors, there was double mattresses on single beds, it was really, really frightening as well.* (Experiences of psychosis [Healthtalkonline, 2011])

Evidence from surveys

The mental health acute inpatient services survey (see Chapter 4 for further information about the survey) had 10 questions relevant to the domain of 'attention to physical and environmental needs' (see Appendix 11 for full results). The survey suggests mixed results with regard to physical and environmental needs. For example, although it should not happen, 8% had to at some stage share a sleeping area with service users of the opposite sex. Most (91%) thought the hospital ward was fairly or very clean, and 92% thought the bathroom and toilets were fairly or very clean. However, 35% thought there were not enough activities available during the day on week days, and 54% thought there was not enough during the evenings and weekends. Furthermore, 22% of service users felt that not enough care was taken of their physical health problems. The benchmark data indicate that there was quite a lot of variation in performance between trusts on some questions, and most trusts have room to improve.

9.2.6 Involvement of, and support for, family and carers

Evidence from qualitative reviews

Barrier: lack of support

Service users with drug misuse problems expressed wanting more support and visits from family, especially for those drug users who were parents. However, in some cases there was an acknowledgement that the inpatient environment was not appropriate for young children (Drug misuse guideline [NCCMH, 2008]).

Evidence from qualitative analyses

Barrier: lack of support

Some service users felt that their family were told little about what had happened to them or the support that was available:

> *So when I got on ward round me parents and me wife were there and they said, you know, "What's wrong with [name]?." And they said, "It's confidential, ask him." Well I couldn't explain anything because nobody had said anything to me. (*Experiences of psychosis [Healthtalkonline, 2011])

Evidence from surveys

The mental health acute inpatient services survey (see Chapter 4 for further information about the survey) had one question relevant to the domain of 'involvement of, and support for, family and carers' (see Appendix 11 for full results). The results suggest that more could be done to help service users keep in touch with family or friends, with 15% answering 'no, but I would have liked help' and 39% answering 'yes, to some extent'. The benchmark data indicate that there was some variation in performance between trusts, and all trusts have considerable room to improve.

9.2.7 Continuity of care and smooth transitions

Evidence from qualitative reviews

Facilitator: information on continued care

In general service users in inpatient care were positive about the arrangements received about their aftercare treatment; however, patients wanted more information about the next phase in their continuity of care (Alcohol guideline [NCCMH, 2011]).

9.2.8 Other themes

Evidence from qualitative reviews

Facilitator: support for peers

Befriending and supporting other service users was viewed by service users who misuse drugs to be conducive to achieving and maintaining abstinence and increased self-esteem (Drug misuse guideline [NCCMH, 2008]).

9.2.9 Evidence summary

Below is a summary of the evidence found for the key problems associated with hospital care for service users being treated not under the Mental Health Act (HMSO, 2007), categorised according to the dimensions of person-centred care.

Involvement in decisions and respect for preferences

No qualitative evidence was related to this domain, but the survey results suggest that many service users are not being fully involved in decisions about their care.

Clear, comprehensible information and support for self-care

No qualitative evidence was related to this domain, but the survey results suggest that many service users are not receiving adequate information about their care.

Emotional support, empathy and respect

The qualitative evidence suggests that healthcare professionals can act as both a barrier and a facilitator in terms of giving emotional support, empathy and respect. The survey results support this view, with a significant proportion not being treated with respect and dignity.

Effective treatment delivered by trusted professionals

The qualitative evidence suggests that in hospital many service users experience of care is poor, and more could be done to improve support and review progress. The survey results support these findings, demonstrating that much can done to improve service users trust in healthcare professionals, and to provide effective psychological interventions.

Attention to physical and environmental needs

The qualitative evidence found that a problem with hospital care was the physical environment on wards, including females being placed on mixed wards and adolescents being placed on adult wards. The survey results showed that 8% of service users have had to share a sleeping area with members of the opposite sex. In addition, many service users find that there are insufficient activities available on the ward, especially during the weekends.

Involvement of, and support for, family and carers

The physical environment of hospital care was acknowledged by service users in one qualitative review to be a barrier to involving family and carers in their care as it may not be appropriate for young children. The survey results suggest that much more can be done to help service users stay in touch with family and friends.

Continuity of care and smooth transitions

The qualitative evidence did not reveal major problems relating to continuity of care, but an improvement would be the provision of information on continued care when discharged from hospital care.

9.3 KEY REQUIREMENTS FOR THE PROVISION OF HIGH QUALITY SERVICE USER EXPERIENCE

The key requirements (qualitative statements based on the GDG’s expert opinion) for the provision of high quality service user experience for hospital care are shown in Table 16.

Table 16: Key requirements for the provision of high quality service user experience (hospital care).

Dimensions of person-centred care	Statement
Involvement in decisions and respect for preferences	• Service users should be involved in all decisions related to their care and treatment both on admission, during their stay in hospital and on discharge. This could include admission to a hospital ward/unit of their choice. • Services users should be encouraged to engage in activities of their preference or need. • Service users should be involved in developing, and have their own copies of their assessment, treatment and discharge plans. These should be written in a clear format and if necessary in the appropriate language. • Have effective mechanisms for complaints and feedback, which are reported at board level. • All complaints should be handled in a timely and efficient

	manner. Service users should be kept fully informed of the progress and outcome of any complaint made.
Clear, comprehensible information and support for self-care	• On admission, service users should be orientated to the hospital ward environment; this should include where and how to access facilities related to self-care. This should also include introductions to the other service users. • Accessible and clear information should be provided to service users and, if appropriate their carers regarding their stay in hospital. • Clear information regarding how to make a complaint or comment must be provided to service users at the time of their admission. Related information should be displayed in hospital ward/unit. • Welcome packs should be given to service users being admitted to wards.
Emotional support, empathy and respect	• Timely care and treatment should be provided by appropriately trained and empowering staff. • Service users should receive care from staff who recognise and appreciate their cultural and spiritual needs. • Staff should not coerce service users.
Fast access to reliable health advice	• Service users should have timely access to and support from appropriately trained staff throughout their stay in hospital, this includes 24 hours per day. • There should be a range of appropriate assessment and treatments for service users. • There should be a comprehensive assessment of service users physical healthcare needs. • Access to pharmacy staff re medicine side effects.
Effective treatment delivered by trusted professionals	• Staff should undergo appropriate mandatory and supplementary training to provide the best, evidenced-based assessment, care and treatment to service users during their hospital stay. • There should be effective and positive risk assessment and management plans: Service users should be involved in this process.
Attention to physical and environmental needs	• All hospital units/wards should be clean, welcoming and comfortable. • Attention should be paid to the safety and security of service users; this will include single-sex accommodation. • Assessment and treatment of physical healthcare needs.
Involvement of, and support for, family and carers	• Hospital wards/units should have facilities appropriate for family, carers or children's visits. • Visits should be negotiated between service users, staff and visitor. • Support should be given to families, carers and children during a service users' stay in hospital.
Continuity of care and smooth transitions	• Service users should be involved in all planning related to any discharges or transfers of care. • Any transfers or discharges should be to the most appropriate service. • Families and/or carers should be involved and notified of any plans to discharge or transfer a service user, if this has been agreed by the service user in advance.

9.4 EVIDENCE TO RECOMMENDATIONS

The problems identified by the qualitative reviews and analyses and the surveys revealed a broad range of problems which resonated with the experience of the guidance group. For example, poor involvement in decision making, lack of time given to discuss treatment, lack of support to keep in touch with family, not being listened to and lack of information about conditions, treatments, side-effects, ward operations and complaints procedures. Service users found it difficult to build a therapeutic relationship with some professionals and felt that they were not always given emotional support, empathy, respect and privacy. Access to mental health professionals and interaction with others was thought to be limited and insufficient activities were provided. Some service users felt they had no confidence and trust in psychiatrists and nurses. Service users often felt that staff on the ward did not know who they were or about any previous care they had received. Finally, there were problems reported of service users being placed on mixed wards and adolescents placed on adult wards.

The GDG expressed a wide range of service user requirements, such as service users being involved in decisions relating to their care and treatment, including admission into a hospital ward of their choice; having copies of their assessment, treatment and discharge plans; having an effective and positive risk assessment management plan, having facilities and support for family or carer visits; having complaints handled efficiently; procedures explained clearly and an effort to have service users orientated to the hospital ward environment.

The GDG discussed the following issues that apply across all points on the care pathway, but were of particular importance to community care. The recommendations for these aspects of the experience of care included the need for health and social care professionals to engage service users and carers in an atmosphere of optimism and hope, with empathy and without judgement; to have discussions in a confidential environment where privacy and dignity are respected; to foster autonomy in the service user and to provide information about treatments, services, side effects. Health and social care professionals should discuss if and how the service user would like to have the support and involvement of their family or carer. When working with people using mental health services and their family and carers ensure that health care professionals are easily identifiable and approachable and that they refer to service users using their preferred name and title. Also health care professionals should use clear and comprehendible language that service users can understand. Ensure that service users who are parents are provided with information regarding childcare support if applicable.

Areas specifically of importance to improve the experience of hospital care included providing an atmosphere of hope and optimism; focusing on the emotional and psychological needs of service users; providing information to service users and their family or carers about treatment plans, activities and services available; an orientation of the hospital ward and procedures should be offered and more activities at evenings and weekends should be made available. Service users should be involved in decisions for their care and a formal assessment should occur within two hours of admission, followed by daily sessions with a healthcare professional and an option of weekly sessions with a consultant. Regular multidisciplinary meetings to discuss the management of care should take place and the trust should ensure that inpatient care includes access to all treatments recommended in NICE guidance.

9.5 RECOMMENDATIONS

9.5.1 Practice recommendations relating specifically to hospital care

9.5.1.1 When a service user enters hospital, greet them using the name and title they prefer, in an atmosphere of hope and optimism, with a clear focus on their emotional and psychological needs, and their preferences. [QS12]

9.5.1.2 Give verbal and written information to service users, and their families or carers where agreed by the service user, about:

- the hospital and the ward in which the service user will stay
- treatments, activities and services available
- expected contact from health and social care professionals
- rules of the ward (including substance misuse policy)
- service users' rights, responsibilities and freedom to move around the ward and outside
- meal times
- visiting arrangements.

Make sure there is enough time for the service user to ask questions.

9.5.1.3 Undertake shared decision-making routinely with service users in hospital, including, whenever possible, service users who are subject to the Mental Health Act (1983; amended 1995 and 2007). [QS15]

9.5.1.4 Undertake formal assessment and admission processes within 2 hours of arrival. [QS13]

9.5.1.5 Shortly after service users arrive in hospital, show them around the ward and introduce them to the health and social care team as soon as possible and within the first 12 hours if the admission is at night. This should include the named healthcare professional who will be involved throughout the person's stay. [QS14]

9.5.1.6 Offer service users in hospital:

- daily one-to-one sessions lasting at least 1 hour with their named healthcare professional
- regular (at least weekly) one-to-one sessions lasting at least 20 minutes with their consultant. [QS16]

9.5.1.7 Ensure that the overall coordination and management of care takes place at a regular multidisciplinary meeting led by the consultant and team manager with full access to the service user's electronic record. These meetings should not be used to see service users or carers, unless the service user specifically requests this in addition to their daily meeting with their named healthcare professional and their weekly one-to-one meeting with their consultant. [QS16]

9.5.1.8 Trusts should ensure that service users in hospital have access to the pharmacological, psychological and psychosocial treatments recommended in NICE guidance provided by competent health or social care professionals. Psychological and psychosocial treatments may be provided by health and social care professionals who work with the service user in the community.

9.5.1.9 Ensure that service users in hospital have access to a wide range of meaningful and culturally-appropriate occupations and activities 7 days per week, and not restricted to 9am to 5pm. These should include creative and leisure activities, exercise, self-care and community access activities (where appropriate). Activities should be facilitated by appropriately trained health or social care professionals. [QS17]

9.5.1.10 Ensure that service users have access to the internet during their stay in hospital.

9.5.1.11 All health and social care professionals who work in a hospital setting should be trained as a group to use the same patient-centred approach to treatment and care, including 'customer care'. [QS8]

9.5.1.12 Service users receiving community care before hospital admission should be routinely visited while in hospital by the health and social care professionals responsible for their community care.

9.5.1.13 Ensure that all service users in hospital have access to former inpatients who can act as advocates and regularly feed back to ward professionals any problems experienced by current service users on that ward.

9.5.1.14 Ensure that hospital menus include a choice of foods, and that these are acceptable to service users from a range of ethnic, cultural and religious backgrounds. Consider including service users in planning menus.

9.5.2 Practice recommendations relating to hospital care and all points on the pathway

9.5.2.1 When working with people using mental health services and their family or carers:

- ensure that you are easily identifiable (for example, by wearing appropriate identification) and approachable
- address service users using the name and title they prefer
- clearly explain any clinical language and check that the service user understands what is being said
- take into account communication needs, including those of people with learning disabilities, sight or hearing problems or language difficulties and provide independent interpreters (that is, someone who does not have a relationship with the service user) or communication aids if required.

Involving families and carers

9.5.2.2 Ensure that service users who are parents with caring responsibilities receive support to access the full range of mental health and social care services, including:

- childcare to enable them to attend appointments, groups and therapy sessions
- supported accommodation for families
- hospital care in local mother and baby units for women in the late stages of pregnancy and within a year of childbirth.

Engaging service users in improving care

9.5.2.3 When providing training about any aspect of mental health and social care:

- involve people using mental health services in the planning and delivery of training
- ensure that all training aims to improve the quality and experience of care for people using mental health services; evaluate training with this as an outcome.

9.5.2.4 Trusts should consider employing service users to train teams of health and social care professionals and supporting staff who may come into contact with service users such as receptionists, administrators, secretaries and housekeeping staff, in 'person-centred care' or ‘customer care’. Such training should be tailored to the needs of people who attend mental health services and should be evaluated using experience of care as an outcome. [QS5 & QS8]

9.5.2.5 Trust managers should employ service users to monitor the experience of using mental health services, especially inpatient services, for example by paying them to undertake exit interviews with service users who have recently left a service. Offer service users training to do this. [QS5]

9.5.2.6 Service managers should routinely commission reports on the experience of care across non-acute and acute care pathways, including the experience of being treated under the Mental Health Act (1983; amended 1995 and 2007). These reports should be routinely communicated to the trust board. Data should be collected to allow direct comparison of the experience of care for all genders, for different ethnic groups and for other minority groups. [QS5]

9.5.3 Research recommendations

9.5.3.1 For people receiving adult mental health hospital care, what is the impact of an intensive treatment approach, including full access to psychological therapies recommended in NICE guidelines, training staff in person-centred care and providing a good range of occupation and activity 7 days a week? Outcomes would include exit interviews to determine the impact on service user experience, including perceived safety, estimates of quality of life and global functioning, basic clinical outcomes and costs.

9.5.3.2 For people receiving adult mental health hospital care, what activities and occupations do service users want when staying on inpatient wards?

9.5.3.3 For people receiving adult mental health hospital care, what is the effect of incorporating past service users as trained advocates compared to treatment as usual? Outcomes, determined by survey, exit interviews by trained past service users and selected in depth interviews, should include the experience of care, perceived safety, extent of perceived control over clinical decisions by service users, including those treated under the MHA and those treated informally.

10. DISCHARGE AND TRANSFER OF CARE

10.1 INTRODUCTION

This chapter provides evidence about the key problems relating to discharge from hospital or community care, and transfer of care, and the key requirements for high quality service user experience. Recommendations for best practice and recommendations for research can be found at the end of the chapter.

It is understandable that staff working in health and social care services will focus on the treatment and care they provide while they are working with a service user. When an episode of care comes to an end, less consideration may be given to preparing someone to leave or to the new service that others will provide. However, from the perspective of a service user, transfer or discharge to another service is of central part of the experience of the care they receive. The development of new specialist services in Britain means that service users are experiencing a greater number of transfers between different services than ever before. As with most changes, transfers and discharges can be a cause of uncertainty and anxiety. Transfer of care may be made more difficult if it was prompted by deterioration in a person's mental health, for instance when a decision is made that someone who has been receiving out-patient treatment requires more intensive support from a crisis or home treatment team. While discharge from a service is usually prompted by an improvement in a person's mental health some, like discharge from an inpatient unit, may still take place at a difficult time. Other forms of discharge, like that from secondary care to primary care, may result in a reduction in the level of care that people receive. Discharge from secondary care mental health services raises important questions for service users and carers about how they can access services again should the need arise.

Current practice

Previous research has shown that careful consideration of the process through which a person's care is transferred from one service to another is an important part of delivering continuity of care. Failure of communication between staff in different services can lead to service users being asked to repeat information that they have already given or to unnecessary disruption in the treatment they receive. Previous experiences of loss or rejection may lead some service users to fear that a transfer or discharge will lead to their needs not being met or prevent them from accessing services in the future. If a service user has been able to establish a trusting and supportive relationship with their current provider, they may worry about how they will cope when they lose contact with this person.

Evidence about increased vulnerability of service users following discharge from services come from a number of studies which have shown that levels of suicide are high in the period immediately following discharge from inpatient mental health units (Appleby *et al.*, 1999; Crawford, 2004; King *et al.*, 2001). Associations between suicide and 'unplanned' discharge, short admissions and the length of the period that elapses between discharge and follow-up, emphasise the importance of preparation, communication and after care in reducing any negative impact associated with such changes. Discharge from secondary care to primary services is also a significant point in a person's treatment. As well as ensuring that service users and carers have information about medication and other treatments, knowledge of how future contact with secondary care services can be accessed if it is needed is required. Problems that arise in sharing information between primary and secondary care services highlight the need to make sure that service users and carers are given the information they need once they have been discharged from secondary care.

10.2 KEY PROBLEMS REGARDING DISCHARGE AND TRANSFER OF CARE

Evidence from qualitative reviews/analyses and surveys addressed the following domains of person-centred care:

- involvement in decisions and respect for preferences
- clear, comprehensible information and support for self-care
- emotional support, empathy and respect
- fast access to reliable health advice
- involvement of, and support for, family and carers
- continuity of care and smooth transitions.

No evidence was identified that directly addressed:

- effective treatment delivered by trusted professionals
- attention to physical and environmental needs.

For the purposes of the review, themes from the qualitative evidence are summarised only briefly here, with further details provided in Appendix 12. Domains and sources of evidence without themes are not listed below.

10.2.1 Involvement in decisions and respect for preferences

Evidence from qualitative reviews

Facilitator: service user involvement

Service users acknowledged that it was important that they were included in the planning of their aftercare (Self-harm guideline [NCCMH, in preparation]).

10.2.2 Clear, comprehensible information and support for self-care

Evidence from surveys

The mental health acute inpatient services survey (Care Quality Commission, 2009) (see Chapter 4 for further information about the survey) had two questions relevant to the domain 'clear, comprehensible information and support for self-care '(see Appendix 11 for full results). The results indicate that about a quarter (26%) of service users in hospital feel they are not given enough notice about their discharge, and nearly a third (29%) are not given information about how to get help in a crisis after they leave hospital. The benchmark data indicate that there was relatively wide variation in performance between trusts, and all trusts have a room to improve.

10.2.3 Emotional support, empathy and respect

Evidence from qualitative reviews

Barriers: professionals

Service users stated in two studies that aftercare was often not arranged or acknowledged by service staff which led to feelings of abandonment (Self-harm guideline [NCCMH, in preparation]).

Evidence from qualitative analyses

Barriers: lack of support

On leaving hospital, many people could feel abandoned by supportive services but monitored by services in what some people felt was a punitive manner:

> *I was never allowed a, a CPN, I was never allowed a Social Worker, because I, I used to ask for them, and they had said, "No you can make your way to the centre." But sometimes I would be so bombarded with voices and paranoid to go out that I might go missing for six to eight weeks and nobody would ever come and see if I was okay, well me parents would obviously but this, the services just abandoned me at that point.*

> *I mean if you take the medication, okay if you don't take it and there's a problem, like I don't know, you might violent, throw a glass of wine in someone's face. [...] If someone contacts Social Services they also have to get involved, and they have to come and meet you, they have to make an assessment. Is he okay? Is he not okay? What happened? What didn't*

> *happen? With an ordinary member of the public you don't have that hanging over you.* (Experiences of psychosis [Healthtalkonline, 2011])

Facilitators: professionals

Some service users were supported on coming out of hospital to access courses and support groups. Others had regular contact arranged from community teams so they didn't come back into hospital (Experiences of psychosis [Healthtalkonline, 2011]).

10.2.4 Fast access to reliable health advice

Evidence from surveys

The mental health acute inpatient services survey (Care Quality Commission, 2009) (see Chapter 4 for further information about the survey) had one question relevant to the domain 'fast access to reliable health advice' (see Appendix 11 for full results). The results indicate that nearly a third (31%) of service users do not have the phone number of someone from their local NHS Mental Health Service that they can phone out of office hours. The benchmark data indicate that there was considerable variation in performance between trusts, and all trusts have room to improve.

10.2.5 Attention to physical and environmental needs

Evidence from qualitative analyses

Barrier: lack of support

Many service users stressed the difficulties of dealing with housing, benefits, finances and employment when they came out of hospital and would have liked more support to help deal with this:

> *Yeah. It was very difficult, because like life, there's no like, no one's standing there handing it to you on a plate. So you have to be quite resourceful, so I read a lot of websites. I went to book shops and read some books. And recently I've joined a group. Like a help group, which will help, and obviously I had my nurse and my doctor which helped me once, once I came out. So that was good. I had a lot of support with getting the areas of my life fixed up. So finances. Career. That kind of thing. Like a lot of professional support*. (Experiences of psychosis [Healthtalkonline, 2011])

10.2.6 Involvement of, and support for, family and carers

Evidence from surveys

The mental health acute inpatient services survey (Care Quality Commission, 2009) (see Chapter 4 for further information about the survey) had one question relevant to the domain 'involvement of, and support for, family and carers' (see Appendix 11 for full results). The results indicate that a considerable proportion of service users felt that hospital staff did not (21%) or only to some extent (31%) take their family or home situation into account when planning their discharge. The benchmark data indicate that there was relatively wide variation in performance between trusts, and all trusts have a lot of room to improve.

10.2.7 Continuity of care and smooth transitions

Evidence from qualitative reviews

Barrier: change to structure

Service users in two studies felt that leaving a therapeutic community was difficult, particularly adjusting from a 24-hour structure to independent living and being required to leave before feeling ready. Abrupt, unmanaged endings/transfers are problematic and work better if they planned in advance, structured and have opportunities for follow and easier re-entry if needed (BPD guideline [NCCMH, 2009b]).

The need for more continuity of care was found in another guideline that reported on six studies that discussed service users wanting more enhanced continued care and the lack of currently available continued care. The lack of continuity of care impacted negatively on their attitudes towards future help-seeking and to their self-esteem (Self-harm guideline [NCCMH, in preparation]).

Evidence from qualitative analyses

Barrier: lack of support

One service user describes his experience of wanting to leave hospital:

> *I got very bored and asked if I could leave, and they said, "Well we'd really like to keep you a bit longer, but you know, as you're not on a section…" Yes. I could leave whenever I wanted to. I'm looking back on it, I think I wish I stayed a bit longer, because I came home and I got a job, but I couldn't do the job, you know. It was quite a simple job but I couldn't get the hang of it. And I went on the sick and I was just wandering, I just remember wandering around the streets, and because there wasn't any day centres or anything like that to go to. (*Experiences of psychosis [Healthtalkonline, 2011].)

A few service users mentioned that their medication could be late and this had unnecessarily upsetting consequences:

> *I've been discharged or sent home on weekend leave without any medication. And become physically quite ill, and that, and you know, had to ferry myself back in and that to get something back in my system.* (Experiences of psychosis [Healthtalkonline, 2011])

Facilitator: professional

Whilst some service users described difficult challenges and situations they had to face on coming out of hospital, others talked about the support they received:

> *And from being discharged from hospital, I was taken to the care of the local community mental health team. And had a very, very good psychologist, who I used to see every week and just discuss things with. And work things through.*
>
> *...so she [key worker] was very keen to have me go to [name of clinic] because she thought that that would be you know be helpful. So I went there straightaway as like an inpatient for a week but they sort of said you don't need to stay here as an inpatient you can come back to the CBT, into the therapy so I kind of did that quite regularly for at least a couple of months [...] and it was really helpful in a lot of ways, it was a bit stressful, still a bit weird but it was helpful and I was getting to actually talk about some stuff.* (Experiences of psychosis [Healthtalkonline, 2011])

Evidence from surveys

The mental health acute inpatient services survey (see Chapter 4 for further information about the survey) had two questions relevant to the domain 'continuity of care and smooth transitions' (see Appendix 11 for full results). The results indicate that a considerable proportion (22%) of service users have had their discharge delayed. Then after being discharged, 25% are not contacted for at least two weeks. The benchmark data indicate that there was some variation in performance between trusts, especially with regard to the question about delayed discharge, with some trusts performing very well.

10.2.8 Evidence summary

Below is a summary of the evidence found for the key problems associated with discharge of care for service users not detained under the Mental Health Act (HMSO, 2007), categorised according to the dimensions of person-centred care.

Involvement in decisions and respect for preferences

One qualitative review found that an improvement that would enhance service users' experience of care was if they were involved in the planning of their aftercare.

Clear, comprehensible information and support for self-care

No qualitative evidence was found that related to this domain, but the survey results suggest that many service users are not getting adequate information regarding discharge.

Emotional support, empathy and respect

One qualitative review found that a barrier to discharge was when healthcare professionals did not arrange or acknowledge their aftercare.

Fast access to reliable health advice

No qualitative evidence was found that related to this domain, but the survey results suggest that many service users are not given the phone number of someone they can call out of office hours after they are discharged.

Involvement of, and support for, family and carers

No qualitative evidence was found that related to this domain, but the survey results suggest that many service users feel that their family or home situation are not taken into account when discharge is planned.

10.3 KEY REQUIREMENTS FOR THE PROVISION OF HIGH QUALITY SERVICE USER EXPERIENCE

The key requirements (qualitative statements based on the GDG's expert opinion) for the provision of high quality service user experience for discharge and transfer from community care are shown in Table 17. The key requirements for discharge and transfer from hospital care are shown in Table 18.

Table 17: Key requirements for the provision of high quality service user experience (discharge and transfer from community care).

Dimensions of person-centred care	Statement
Involvement in decisions and respect for preferences	• Service users should be involved in all decisions around discharge or transfer planning. • Planning for discharge or transfer should begin at the beginning of the intervention or at the earliest opportunity following this. • Service users should have the opportunity in advance to agree a contingency plan if the intervention prematurely ends (with the service user taking their own unplanned discharge).
Clear, comprehensible information and support for self-care	• Service users should have clear information provided about all possible support options available post-discharge or transfer to enable joint and informed choices to be made. • Service users should be provided with clear information about how they can access the service again if arrangements post-discharge do not work out or things deteriorate. • Service users should have clear information provided about the referral pathways and processes for any services they are being discharged or transferred to (this should include information about possible waiting times, assessment process, intervention type, time-scale of intervention).
Emotional support, empathy and respect	• It should be acknowledged with service users that discharges and transfers are often an anxiety provoking time. Service users should be provided with support through this process, having the opportunities to discuss concerns as well as other issues

	evoked by this ending. • Where an intervention has been medium to long-term then a gradual phasing out of appointments may be preferable with the options of follow-up and top-up made available.
Fast access to reliable health advice	• Service users should be provided with the contact details of the out of hour's service as part of their discharge care. • Service users should be informed of the most effective way to re-refer themselves to the service they are being discharged or transferred from and a re-referral is needed. • Services users should be made aware of their first contact after leaving (either with new service or follow up from service being discharged from) and this should be within 72 hours of leaving a service. • Service users should be made given the date of the next CPA review following discharge or transfer of care. • A simple and direct re-referral route should be made available to service users where appropriate. • Service users should have the opportunity to be reviewed or receive a 'top-up' appointment at the service they have recently been discharged or transferred from. • Service users should have access to a 24 hour telephone out of hours support service.
Effective treatment delivered by trusted professionals	• Service users (and carers where the service user agrees) should agree (and receive) a written discharge plan. A discharge plan should include: i) plans to meet the identified financial, social support, medication, housing and transport needs; ii) a clearly identified and agreed service support package – including a follow up appointment within 72 hours, a named point of contact, access to out of hours support, and information about possible re-referral following crisis or identified need for more treatment.
Attention to physical and environmental needs	• Service users should have their physical and environmental needs addressed as part of CPA and discharge planning; this includes finance, housing, social support, and transport needs. • Service users should be informed of their entitlement to a formal community care assessment and arranged if the service user requests it.
Involvement of, and support for, family and carers	• Family members and carers should have the opportunity to be involved in discharge planning meetings at the service user's choice.
Continuity of care and smooth transitions	• Service users should not be discharged or transferred without a joint discharge planning meeting and written discharge plan. • Discharge or transfer of care should not be abrupt and unplanned - at least 48 hours should be given. • Service users (and carers where the service user wishes) should take part in a joint discharge planning meeting that identifies/considers financial, social and psychological support, medication, housing and transport needs.

Table 18: Key requirements for the provision of high quality service user experience (discharge and transfer from hospital care)

Dimensions of person-centred care	**Statement**
Involvement in decisions and respect for preferences	• Service users should be involved in all decisions around discharge or transfer planning. • Planning for discharge or transfer should begin at the beginning of the intervention or admission or at the earliest opportunity following this. • Service users should have the opportunity in advance to agree a contingency plan if the admission prematurely ends (with the service user taking their own unplanned discharge).
Clear, comprehensible information and support for self-care	• Service users should have clear information provided about all possible support options available post-discharge or transfer to enable joint and informed choices to be made. • Service users should be provided with clear information about how they can access the inpatient service again if arrangements post-discharge do not work out or things deteriorate. • Service users should have clear information provided about the referral pathways and processes for any services they are being discharged or transferred to (this should include information about possible waiting times, assessment process, intervention type, time-scale of intervention).
Emotional support, empathy and respect	• It should be acknowledged with service users that discharges and transfers are often an anxiety provoking time. Service users should be provided with support through this process, having the opportunities to discuss concerns as well as other issues evoked by this ending. • Service users should have the opportunity to experience short term periods of leave with the knowledge that they will still have their bed available if the leave proves unmanageable.
Fast access to reliable health advice	• Service users should be provided with the contact details of the out of hours service as part of their discharge care. • Service users should be informed of the most effective way to re-refer themselves to the inpatient service they are being discharged or transferred from and a re-referral is needed. • Services users should be made aware of their first contact after leaving (either with new service or follow up from service being discharged from) and this should be within 72 hours of leaving a service. • Service users should be made given the date of the next CPA review following discharge or transfer of care. • A simple and direct re-referral route should be made available to service users where appropriate. • Service users should have access to a 24 hour telephone out of hours support service.
Effective treatment delivered by trusted professionals	• Service users (and carers where the service user agrees) should agree (and receive) a written discharge plan. A discharge plan should include: i) plans to meet the identified financial, social support, medication, housing and transport needs; ii) a clearly identified and agreed service support package – including a follow up appointment within 72 hours, a named point of contact, access to out of hours support, and information about possible re-referral following crisis or identified need for more

	treatment.
Attention to physical and environmental needs	• Service users should have their physical and environmental needs addressed as part of CPA and discharge planning; this includes finance, housing, social support, and transport needs. • Service users should be informed of their entitlement to a formal community care assessment and it should be arranged if the service user requests it.
Involvement of, and support for, family and carers	• Family members and carers should have the opportunity to be involved in discharge planning meetings at the service user's choice.
Continuity of care and smooth transitions	• Service users should not be discharged or transferred without a joint discharge planning meeting and written discharge plan. • Discharge or transfer of care should not be abrupt and unplanned (and should not be premature in order to benefit the service/make space available) at least 48 hours should be given. • Service users (and carers where the service user wishes) should take part in a joint discharge planning meeting that identifies/considers financial, social and psychological support, medication, housing and transport.

10.4EVIDENCE TO RECOMMENDATIONS

The qualitative reviews, analyses and surveys outlined a number of key problems. These included a lack of forewarning and inadequate information about discharge, a lack of service user involvement in planning their aftercare, poor continuity of care including a lack of information about how or who to seek help from in a crisis, and a lack of support with returning to work and home. Finally, many service users felt unprepared for discharge due to a lack of planning and abrupt changes to their daily routine.

The GDG recommended a number of targets for improving the experience of discharge and transfer of care in mental health services. Some of the more fundamental targets for improvement included the following: including service users in the planning of their own discharge and transfer of care, including the provision of a clear and explicit discharge plan, discharge and transfers should be planned at the earliest opportunity and at least 48 hours notice should be given between notification of discharge and leaving a ward, clear information about support options, including information about which services could still be accessed, and contact details of the out of hour's service. Some other key requirements were aspirational in nature, such as access to a 24-hour telephone out of hours support service, and joint discharge plans that consider the financial, social and psychological support, medication, housing and transport needs of the service user. Finally, service users should have the opportunity to experience short term periods of leave with the knowledge that they will still have their bed available if the leave proves unmanageable.

On reviewing the key problems and needs of service users the guidance group identified a number of key issues that relate to all points on the care pathway, but were of particular importance to discharge and transfer of care.

The recommendations for these areas of experience of care included promoting active participation in treatment decisions, providing information about treatments and services for their mental health problem and maintaining continuity of individual therapeutic relationships.

Other aspects of improving the experience of care that were of particular importance to discharge and transfer of care included discussing with the service user beforehand, changes that will take place with the withdrawal of treatments and services and the transition from one service to another; having a care plan that provides access to services in times of crisis; understanding the home situation of a service user before they are discharged; ensuring support is provided during the referral and giving at least 48 hours notice before their date of discharge.

10.5 RECOMMENDATIONS

10.5.1 Clinical practice recommendations relating specifically to discharge and transfer of care

10.5.1.1 Anticipate that withdrawal and ending of treatments or services, and transition from one service to another, may evoke strong emotions and reactions in people using mental health services. Ensure that:

- such changes are discussed carefully beforehand with the service user (and their family or carers if appropriate) and are structured and phased
- the care plan supports effective collaboration with social care and other care providers during endings and transitions, and includes details of how to access services in times of crisis
- when referring a service user for an assessment in other services (including for psychological treatment), they are supported during the referral period and arrangements for support are agreed beforehand with them.

10.5.1.2 Agree discharge plans with the service user and include contingency plans in the event of problems arising after discharge. Ensure that a 24-hour helpline is available to service users so that they can discuss any problems arising after discharge. [QS18]

10.5.1.3 Before discharge or transfer of care, ensure that any involved family or carers are informed.

10.5.1.4 Assess the home situation of the service user before they are discharged from inpatient care.

10.5.1.5 Give service users clear information about all possible support options available to them after discharge or transfer of care.

10.5.1.6 Give service users at least 48 hours' notice of the date of their discharge from a ward. [QS18]

10.5.1.7 When preparing a service user for discharge, consider encouraging them to contact the local patient advocacy and liaison service (PALS) to enquire about being trained as an advocate or becoming involved in monitoring services.

10.5.2 Research recommendations

10.5.2.1 For people using adult mental health services, what is the experience of discharge from community teams to primary care, and from inpatient settings to community teams and to primary care? The study would aim to characterise the ways in which discharge currently happens and its impact upon the service users experience, rates of re-admission as these relate to different approaches to discharge, and treatment concordance.

11. DETENTION UNDER THE MENTAL HEALTH ACT

11.1INTRODUCTION

This chapter provides evidence about the key problems relating to assessment, referral and treatment under a section of the Mental Health Act (MHSO, 2007), and the key requirements for high quality service user experience. Recommendations for best practice and recommendations for research can be found at the end of the chapter.

The 1959 Mental Health Act (HMSO, 1959) introduced the possibility of patients being treated informally. Prior to this, all service users in hospital were on an 'order'. The Mental Health Act 1983 (HMSO, 1983) reinforced the status of informal patient, but also gave some rights to those detained, most notably the right to appeal and to have written information on these rights. The 2007 amendments to the 1983 Act (HMSO, 1983; amended 2007) introduced, for the first time, the possibility of compulsory treatment outside hospital – so-called Community Treatment Orders. In the first 18 months after their introduction, just over 2,000 people were subject to these orders, far in excess of what had been predicted.

Although the trend has been for beds to close and admissions to reduce, the trend for involuntary admissions has been upwards since 1983, both in actual numbers and as a proportion of all admissions. Keown and colleagues (2008) studied the decade 1996-2006 and found that involuntary admissions increased by 20% from 42,844 to 51,361. The number of 'place of safety' detentions in the same period increased by 189%. Given the pressure on beds identified in Chapter 9, this means that many wards have a majority of service users who are detained.

Current practice

The Mental Health Acts (HMSO, 1959; 1983; amended 1995 and 2007) are about compulsory detention and compulsory treatment, and the main treatment is medication. The most controversial, for service users, form of compulsory treatment is control and restraint and forced medication. In practice, there are three situations in which this might be used. The first is during admission if the person is being taken from home and the police and a psychiatrist are involved. Secondly, if a service user refuses oral medication, injectable versions may be given by force. This may contain an element of surprise and shock for the service user if there is a time lag between the refusal and the injection as they may have forgotten refusing the oral medication or not expected it to have this consequence. Finally, control and restraint and rapid tranquilisation may be used if an incident of violence, or more rarely self-harm, is anticipated and this is recommended by NICE (see Violence, NICE clinical guideline 25) in the case of an imminent violent. The Royal College of Psychiatrists counsels that this practice should be a 'last resort' but anecdotal evidence is that it is more widespread than this.

There is evidence that staff and patients have different views of what leads to compulsory treatment episodes. Duxbury (2002) found that staff attributed violent incidents to characteristics of the patients – their illness or demographic features such as being a young man. Service users, on the other hand, saw compulsory medication as a heavy-handed response to understandable pressures such as being cooped up all day in a stuffy hospital ward where they did not want to be. Furthermore, service users may find treatment, especially some forms of medication, more harmful than helpful for them, and this augments their negative feelings about being detained.

No area of mental health services is more controversial or challenging than detention and compulsion. It is a serious matter to deprive someone of their liberty and a serious matter to use physical force even if both of these are justified by appeals to the patient's 'best interest' and backed up by law. It is not possible to use control and restraint and rapid tranquilisation with 'dignity and respect'. Nor is it possible to know which of the drugs the patients are forcibly prescribed will suit them and which they will do literally anything to avoid, including, but not limited to, escaping or absconding. This is hardly surprising when side effects such as akathisia have been linked with suicide (Van Putten & Marder, 1987). This can also be the case with newer drugs. No other group of patients in medicine are subject to this and so safeguards for this group are of paramount importance.

11.2KEY PROBLEMS REGARDING DETENTION UNDER THE MENTAL HEALTH ACT

An important finding from both the qualitative and survey evidence was that people often do not know whether they were being voluntarily or compulsorily assessed, referred, admitted and treated under a section of the Mental Health Act (HMSO, 2007). Therefore, it is difficult to classify some themes from the qualitative evidence as being appropriate to this chapter or previous chapters. What evidence from qualitative reviews/analyses and surveys that could be classified here, addressed the following domains of person-centred care:

- involvement in decisions and respect for preferences
- clear, comprehensible information and support for self-care
- effective treatment delivered by trusted professionals
- emotional support, empathy and respect
- attention to physical and environmental needs.

No evidence was idenfied that directly addressed:

- fast access to reliable health advice
- involvement of, and support for, family and carers
- continuity of care and smooth transitions.

For the purposes of the review, themes from the qualitative evidence are summarised only briefly here, with further details provided in Appendix 12. Domains and sources of evidence without themes are not listed below.

11.2.1 Involvement in decisions and respect for preferences

Evidence from qualitative analyses

Barrier: control

Service users not only spoke about the importance of medication and forcible detention but also about the smaller freedoms they were or were not permitted in hospital:

> *It took me two or three years of being the good girl and obeying everything to my suddenly saying bollocks, I'm not doing this any more. I'll do what I want to do, and you're not going make me do anything I don't want to do. Which made life a lot easier. And there's these petty rules, like you must draw your curtains all the way back in the daytime. Why? Exactly?* (Experiences of psychosis [Healthtalkonline, 2011])

Evidence from surveys

The survey conducted by MIND (Rogers *et al.*, 1993) (see Chapter 4 for further information about the survey) showed that 52% of respondents received unwanted treatment (principally drugs, followed by ECT).

11.2.2 Clear, comprehensible information and support for self-care

Evidence from qualitative analyses

Barrier: poor information

Many service users were unaware that they had been detained, or only told they were detained if they tried to walk off an inpatient ward:

> *Yeah. It was awful. Because I was like, who are they? How do they have the right to do this? They've got no right to do this. It must be the most awful thing. Like I hadn't heard much about that kind of thing happening before,*

> *but, so that's why it was very frightening. Because I was like, what the hell?* (Experiences of psychosis [Healthtalkonline, 2011])

Some people felt they hadn't been given enough information about the side-effects of psychiatric medication or didn't have any control over which psychiatric medication they were given:

> *...the last time I was in hospital, they were trying me on different medications then and you had very little choice then, because you know, you're under section and you can't really refuse medication. So I was getting a lot of, quite a few side effects from the medication I had in hospital. Like tremors were again quite, tremors and also I was biting on my teeth a lot, to the point where I cracked my own teeth, because I was biting that hard down. I couldn't control when that happened.* (Experiences of psychosis [Healthtalkonline, 2011])

Evidence from surveys

The mental health acute inpatient service users survey (see Chapter 4 for further information about the survey) had one question relevant to the domain of 'clear, comprehensible information and support for self-care' (see Appendix 11 for full results). The results indicate that the majority (60%) of service users feel they did not have their rights completely explained to them in a way they could understand when they were detained under the Mental Health Act (HMSO, 2007). The benchmark data indicate that there was some variation in performance between trusts, and all trusts have a lot of room to improve.

The survey conducted 20 years ago by MIND (Rogers *et al.*, 1993) (see Chapter 4 for further information about the survey) showed that most (63%) service users considered that the reason for admission had not been adequately explained to them. Furthermore, 68% were not satisfied with the explanation they were given about their condition. When in hospital, 80% of service users considered they had not received enough information about their treatment generally, and 70% thought they had not received enough information on the side-effects of treatment. Of those receiving antipsychotic drugs, 60% were not informed of their purpose. Of this group, 70% were unhappy about the amount of information they had received about their medication. With regard to ECT, 14% were given information about the purpose of the treatment, and 9% recall being told of any potential side-effects.

11.2.3 Emotional support, empathy and respect

Evidence from qualitative analyses

Barrier: loss of respect and dignity

The experience of being detained was for many people highly traumatic. People were unsure on being admitted to hospital what their rights were and what was happening. Having to have injections of antipsychotics was specifically mentioned by some people as being an unpleasant experience:

> *And I know in particular the injections, you tend to lose your dignity to, I mean you do to an extent in a psychiatric ward anyway, although it's not going to be as bad as prison. But yes, the injections, sometimes you know, you do tend to feel that you're not in control at all.*
>
> *And I was sort of wandering up to the ward with sort of blood dripping down and this nurse came up and she was wonderful. And she just said, "Oh [name], where have you been?" And I said, "Look what I've done." And she said, "Oh silly person. Come to me." And then I got to the nursing station. I didn't want to be touched. I refused to let them touch me, and the doctor was really angry with me. I don't know why he was so angry. But he was. And he took me away to be stitched up and he made a point of saying he wasn't giving me an anaesthetic when he was going to stitch me up. Which may be you don't need it if you're on high does Largactil. I was on a 1000mgs of Largactil by then, which is a very high dose, so I didn't feel much anyway, but it felt quite humiliating when he said it. (*Experiences of psychosis [Healthtalkonline, 2011])

11.2.4 Effective treatment delivered by trusted professionals

Evidence from qualitative analyses

Barrier: medicine

For some people antipsychotic medication made a dramatic impact on their quality of life, for others it did not take away the symptoms and had serious psychological and physical side effects:

> *it's a very kind of difficult subject area. Because I can see how it helps so many people, medication. But I also can see it, it might not be the thing for other people, and it might be doing them more damage actually. That's what I said to, when I first was in hospital, I said, "Why are you giving me medication, you know, I need help with my diet. I need...taking medication doesn't stop me being abused and getting distressed from the abuse. It's just putting the distress on pause. It doesn't tackle anything really."* (Experiences of psychosis [Healthtalkonline, 2011])

Talking about being detained and having to take antipsychotic medication:

> *Oh it was awful. It set me back. It was like, frightening. I thought they had no right to do that. I, I think that it's a very brutal approach. I know why they do it. Because they know that if you go on the medicine for a month, you'll be better. And then after that you progressively get better, the more you take the medicine.*

> *And, it was a never ending cycle of in and out of hospital and they always tried to blame me, they said that, you know, I was non-compliant but the drugs didn't work and I didn't see how the drugs not working made me non-compliant I think it made the drugs not work.* (Experiences of psychosis [Healthtalkonline, 2011])

One man talked about his experiences of taking antipsychotic drugs in hospital:

> *I was very tired all the time, very drowsy, very zonked out, you know, very medicated sedated. And also strangely enough, my throat constricted. The muscles in my throat constricted so it made it very difficult to speak.* [...]

After changing his medication:

> *Things did get better but that problem with my speech which, you know, which I had no help from the psychiatrist [who] refused to believe it was a recognisable [side effect].* (Experiences of psychosis [Healthtalkonline, 2011])

Evidence from surveys

The survey conducted by MIND (Rogers *et al.*, 1993) (see Chapter 4 for further information about the survey) showed that 80% of those who had taken antipsychotic drugs reported suffering side-effects, the majority of these (62%) being rated as 'severe'. Around 86% of this group also indicated that they would have liked to have been offered an antipsychotic self-help group. Only 23% of those who had stopped their drugs reported having any help from staff about the withdrawal.

11.2.5 Attention to physical and environmental needs

Evidence from qualitative analyses

Barrier: lack of attention to physical and environmental needs

Many people found the hospital environment frightening at worst and boring at best. Physical health often suffered in this environment:

> *And they tried me on different drugs every week, Risperidone, what else? Haloperidol, Olanzapine. I went through the book, and I was putting on more and more weight, because of hospital food and they wouldn't take me out to do any exercise, because it was winter and they didn't want to go out. And you're not allowed out on your own if you're under Section, particularly not if you're blind. And then they put me on Clozapine, but they didn't warn me, what could happen. And I went up to about seventeen stone. Not because I was a piglet, just because I was on Clozapine and eating hospital food, and not getting any exercise.* (Experiences of psychosis [Healthtalkonline, 2011])

A few people described the environment in hospitals as disorientating and distressing:

> *I think it's a well-established fact that you have less rights in hospital than the prisoners do in prison. So you have, there's a loss of freedom. You know, isolation or disorientation, all those things really and [er] it's quite hard to, it's quite hard to live with. I think you have to be a very strong type to have those many admissions and then come back, and you know, do the things I've managed to do with my life really.* (Experiences of psychosis [Healthtalkonline, 2011])

11.2.6 Other themes

Evidence from qualitative analyses

The shock that people felt when they discovered they could be detained and treated against their will was something that people often spoke about in great depth. After experiencing being detained, people often felt they wanted to do anything they could to avoid it happening again:

> *I woke up in the middle of the night, and I think, I thought to myself, no they've made a mistake. So when I went to the office where the night nurse were. She was there and like that sleeping and I saw her, and I said, "Excuse me love. Excuse … I think you've made a mistake. Have you got my clothes? I need to go. I think you've made a wrong mistake." And I remember she buzzed. She pressed a buzzer underneath the desk. I saw four big blokes run down the corridor. They got hold of me and held me down on the floor, and injected me with tranquillizer and it knocked me out for four days.* (Experiences of psychosis [Healthtalkonline, 2011])

11.2.7 Evidence summary

Below is a summary of the evidence found for the key problems associated with detention under the Mental Health Act, categorised according to the dimensions of person-centred care.

Involvement in decisions and respect for preferences

The survey results show that many service users are not asked for consent before treatment. The qualitative evidence suggested that compulsory treatment and control impacted on the experience of care. In addition, service users report being exposed to sometimes petty controls and staff can be patronising.

Clear, comprehensible information and support for self-care

No qualitative evidence was related to this domain, but the survey results suggests that many service users are not having their rights completely explained in a satisfactory way when detained under the Mental Health Act, and are not receiving sufficient information about treatment. Service users report not being given information about side effects, especially from antipsychotics, which can be severe. This appears to have not changed from 20 years ago.

Emotional support, empathy and respect

The experience of control, restraint and compulsion is experienced as traumatic with a loss of dignity and respect. Service users report sometimes being blamed for treatment failures. Overall, the impression is that service users subject to the Mental Health Act do not feel any significant empathy, emotional support or respect from staff.

Effective treatment delivered by trusted professionals

The survey results suggest that many service users experience troubling side-effects from medication and do not get the support they want from staff or self-help groups. In some cases, service users feel that staff do not believe them when they report side effects, including descriptions of what are likely to be dystonic reactions to antipsychotics.

Environment

Service users report that the environment on in patient units is experienced as frightening when they are detained under the Mental Health Act, often feeling disoriented. They are also reported to be often quite ‘boring’, with little to do.

Continuity of care and smooth transitions

No data on this from the review.

11.3KEY REQUIREMENTS FOR THE PROVISION OF HIGH QUALITY SERVICE USER EXPERIENCE

The key requirements (qualitative statements based on the GDG’s expert opinion) for the provision of high quality service user experience for assessment and referral in crisis under the Mental Health Act (HMSO, 2007) are shown in Table 19. The key requirements for receiving compulsory treatment under the Mental Health Act are shown in Table 20.

Table 19: Key requirements for the provision of high quality service user experience (assessment and referral in crisis under the Mental Health Act 2007).

Dimensions of person-centred care	Statement
Involvement in decisions and respect for preferences	• Service users can expect a healthcare professional to attend to them, respecting remaining capacity and exploring other options where possible apart from hospital admission. Where previously discussed, these are respected. • Service users with impaired capacity should have their care records checked for advance decisions and advance statements before

	treatment is started. •
Clear, comprehensible information and support for self-care	• Service users are informed of their rights under the Mental Health Act (MHA, 1983; amended 1995 and 2007), including the right to appeal within 14 days. The service user can expect timely completion of paperwork and careful explanation of necessary processes. • Accessible and clear information must be provided to service users regarding their (legal) rights during their hospital admission.
Emotional support, empathy and respect	• Service users can expect that special attention is given to engaging often disoriented service users in an empathic way whenever this is possible. There is a greater need to emotionally engage service users who are detained, and to treat them with dignity and respect whenever possible.
Fast access to reliable health advice	• Service users can expect to speak in a timely way to an expert informed professional who will recognise mental health problems and refer appropriately.
Effective treatment delivered by trusted professionals	• Service users can expect to meet someone fully trained and proficient, will give good advice and do what is best in the situation, answerable to the service user and their friends and relatives.
Attention to physical and environmental needs	• Service users can trust staff to look after them and their possessions in a personal way.
Involvement of, and support for, family and carers	• Service users can expect someone in charge of his/her care to communicate with his/her next of kin and offer support.
Continuity of care and smooth transitions	• Transfer to hospital should be done in a calm and orderly way, including relatives where this is possible and only involving the police if this cannot be done safely in any other way.

Table 20: Key requirements for the provision of high quality service user experience (receiving compulsory treatment under the Mental Health Act 2007).

Dimensions of person-centred care	Statement
Involvement in decisions and respect for preferences	• Control, restraint and rapid tranquilisation should be used as a last resort and reasons for it documented.
Clear, comprehensible information and support for self-care	• No matter how distressed, service users should be given an explanation of why the compulsory treatment is being used.
Emotional support, empathy and respect	• Recognise that in the eyes of the service user, compulsory treatment may be seen as a violation of rights.
Fast access to reliable health advice	
Effective treatment delivered by trusted	• Use minimum force.

professionals	- Involve staff whom the service user trusts.
Attention to physical and environmental needs	- Make sure the service user is physically safe.
Involvement of, and support for, family and carers	- Explain reasons for the episode of treatment to family members.
Continuity of care and smooth transitions	- Discuss episodes of compulsory treatment at discharge in a calm and simple way.

11.4EVIDENCE TO RECOMMENDATIONS

The review of qualitative evidence and surveys suggest that some people do not have their rights properly explained to them, and some do not realise they are, in fact, detained under the Mental Health Act (HMSO, 2007); consent to treatment is largely ignored when a person is detained under the Mental Health Act, and there are reports of service users finding healthcare professionals patronising and petty in their approach. Moreover, information is sorely lacking, both about their status and about side effects. There are some reports of service users experiencing acute dystonic reactions which are effectively trivialised and ignored by staff. It is important to note that the experience of unexpected side effects and these being ignored appears in the MIND survey (Rogers *et al.*, 1993) of 20 years ago, as well as in more recent qualitative evidence, suggesting that this remains a problem today. Overall, the experience of being detained is, at least for some, a traumatic one, with a loss of dignity and respect and a feeling of not being cared for; with little account taken of how disoriented the detained person is, and how disorienting the environment of many wards continue to be. For some service users, they are simply being detained.
The GDG concurred with these descriptions from the literature, and furthermore highlighted the plight of families and carers who often do not know much about what is going on and receive little information from medical or nursing staff. Also, both the qualitative reviews and the GDG raised concerns about safety of the individual and their property.

In identifying the key elements for excellent care, the GDG highlighted the need to maintain, or to restore as quickly as possible following any form of compulsory treatment, dignity and respect, accommodating preferences and choice wherever possible, despite being subject to the Mental Health Act (HMSO, 2007). Within the context of the Act, GDG members were of the view that there should be a much greater emphasis on, and awareness of, the Mental Capacity Act (MHSO, 2005) than is currently the case. Greater account should be taken of the disorienting effects of crisis and illness and the need for professionals to repeat explanations and uphold the persons rights, backed up by very good written and verbal information. Service users and their carers need access to experts, such as consultants, and greater care of possessions. If control and restraint and compulsory treatment are used, then this should be explained wherever possible and revisited, including before discharge: the use of restraint is often traumatic and seen by the service user as an infringement of their rights, paying due regard to ensuring the service user is safe and feels safe; and when control or compulsion are used, the to restore a sense of safety as soon as is practicable and possible.

When formulating the recommendations, taking into account both the key evidence about current experience and their aspirations for excellence, the GDG added a number of practical recommendations such as aiming to avoid the use of the Mental Health Act (HMSO, 2007) through the use of effective, non-custodial alternatives to admission, such as crisis houses, home treatment and respite care. Also, when a person is admitted to a place of safety, the guidance group considered that 4 hours should be the maximum time a person should wait for a Mental Health Act assessment to take place; and when someone has been detained, then transfer to an inpatient facility should be done in a careful supportive and safe way, and without resorting to the use of the police if possible. The GDG placed significant emphasis on rights and the provision of good information and incorporating families and carers where agreed by the service user.

On reviewing the aspirations and the key problems the guidance group focused attention on some broad issues that apply across all points on the care pathway, but were of particular importance to detention under the Mental Health Act. Health and social care professionals should ensure that they can understand and apply the principles of the Mental Capacity Act (2005). If the service user has impaired capacity ensure that their care records are checked for advanced decisions and advanced statements before treatment is offered. All these issues were placed in care across all points on the care pathway in the NICE guidance.
When using control, restraint and compulsory treatment, healthcare professionals should understand what this is like for the service user, include families in decisions where they can and explain what’s happening regularly. The evidence concerning injections forced or not, was discussed by the group which endorsed the finding that these can be humiliating. When given as rapid tranquillisation then it is difficult to see how ‘empathy and respect’ can be sustained. It was clear from the evidence that some service users accept medication they feel is harmful to them in order to avoid it being given by force. In addition, the GDG reiterated the need to use the service user care record, so the service user can record their views afterwards.

11.5 RECOMMENDATIONS

11.5.1 Practice recommendations relating specifically to assessment and treatment under the Mental Health Act

11.5.1.1 Carry out an assessment for possible detention under the Mental Health Act (1983; amended 1995 and 2007) in a calm and considered way, whenever possible, respond to the service user's needs and treat them with dignity and respect.

11.5.1.2 Explain to service users, no matter how distressed, why the compulsory detention or treatment is being used. Repeat the explanation if the service user appears not to have understood or is pre-occupied or confused.

11.5.1.3 When detaining a service user under the Mental Health Act (1983; amended 1995 and 2007) inform the receiving mental health service about the service user so they are expecting them and ready to welcome them to the service.

11.5.1.4 When detaining a service user under the Mental Health Act (1983; amended 1995 and 2007):

- give them verbal and written information appropriate to the section of the Act used, including 'patient rights leaflets' detailing what is happening to them and why, and what their rights are
- repeat this information if they appear not to have understood or are pre-occupied or confused
- give them, and their families or carers if they agree, information about the legal framework of the Mental Health Act.

11.5.1.5 Inform service users detained under the Mental Health Act (1983; amended 1995 and 2007) of their right to appeal to a mental health tribunal and support them if they appeal.

11.5.1.6 Tell the service user that if they are dissatisfied with their care and wish to make a complaint while under the Mental Health Act (1983; amended 1995 and 2007) they can do so to the Care Quality Commission.

11.5.1.7 Detain service users under the Mental Health Act (1983; amended 1995 and 2007) only after all alternatives have been fully considered in conjunction with the service user if possible, and with the family or carer if the service user agrees. Alternatives may include:

- crisis houses

- home treatment
- acute day facilities
- respite care
- medicines review.

11.5.1.8 When a service user is admitted to a 'place of safety' ensure they are assessed for the Mental Health Act (1983; amended 1995 and 2007) as soon as possible, and certainly within 4 hours. [QS6]

11.5.1.9 After application of the Mental Health Act (1983; amended 1995 and 2007) ensure that:

- transition to the inpatient unit is smooth, efficient and comfortable
- family and carers can travel with the service user if safe to do so
- the police are involved only if the safety of the service user, family, carers, dependent children or health and social care professionals is an important consideration and cannot be managed by other means, such as involving more professionals.

Control and restraint, and compulsory treatment

11.5.1.10 Control and restraint, and compulsory treatment including rapid tranquillisation, should be used as a last resort and only by healthcare professionals trained and competent to do this. Document the reasons for such actions. [QS19]

11.5.1.11 When a service user is subject to control and restraint, or receives compulsory treatment including rapid tranquillisation under the Mental Health Act (1983; amended 1995 and 2007):

- recognise that they may consider it a violation of their rights
- use minimum force
- try to involve healthcare professionals whom the service user trusts
- make sure the service user is physically safe
- explain reasons for the episode of compulsory treatment to the service user and involved family members or carers
- discuss episodes of compulsory treatment with the service user at the time of discharge in a calm and simple manner. **[QS20]**

11.5.1.12 After any episode of control and restraint, or compulsory treatment including rapid tranquillisation, explain the reasons for such action to the service user and offer them the opportunity to document their experience of it in their care record, and any disagreement with healthcare professionals. [QS20]

11.5.2 Practice recommendations relating to detention under the Mental Health Act 2007 and all points on the pathway

Consent, capacity and treatment decisions

11.5.2.1 Health and social care professionals should ensure that they:

- understand and can apply the principles of the Mental Capacity Act (2005) appropriately
- are aware that mental capacity needs to be assessed for each decision separately
- can assess mental capacity using the test in the Mental Capacity Act (2005)
- understand how the Mental Health Act (1983; amended 1995 and 2007) and the Mental Capacity Act (2005) relate to each other in practice.
- .

11.5.2.2 When a service user has impaired capacity, check their care record for advance decisions and advance statements before offering or starting treatment. [QS11]

11.5.3 Research recommendations

11.5.3.1 For people using adult mental health services, how is compulsory treatment and 'control and restraint' used in different settings and what is the impact on the service user?

12. INTERVENTIONS TO IMPROVE SERVICE USER EXPERIENCE

12.1 INTRODUCTION

This chapter provides the review protocol, information about the source of evidence and findings from the review of interventions to improve service user experience of care. The associated recommendations for best practice and for research can be found at the end of the chapter.

Historically health services in Britain have tended to focus on efforts to provide treatment that is effective and safe. This has also been true for mental health services, where concerns about patient and public safety have sometimes been the driving force for policy and service developments. In other countries where healthcare services are delivered in a 'free-market', greater emphasis has been placed on efforts to enhance service user experience. In such countries providers of health care services have had to try to ensure that 'consumers' of services are satisfied with the care they receive.

Over the last 30 years an increasing emphasis has been placed on service user experience within the NHS. In 1991 a 'Patients' Charter ' was published which set out basic rights that users of the NHS should expect to receive (Department of Health, 1991). These included a right to information about treatment options and a right to be included in decisions about the care that people should receive. Subsequent Government initiatives and policies have continued to emphasise 'patient experience' in determining whether the NHS is providing an effective service. In the document 'NHS Next Stage Review' (Department of Health, 2008), patient experience was placed alongside patient safety and access to effective treatments as one of the three central aims of the NHS. In addition, the NHS Institute for Innovation and Improvement developed a network to '…share ideas and practice to drive improvement in patient experience'[8].

Non-governmental groups have also looked at initiatives and strategies to improve the experience of people who use healthcare services. For example, the Picker Institute recently reviewed what works to engage people in healthcare[9], and a Salzberg Global Seminar, in collaboration with the Foundation for Informed Medical Decision Making, looked at the 'role patients can and should play in healthcare decisions'[10]. In mental health specifically, evidence suggests that service users do wish to participate in

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[8] http://www.institute.nhs.uk/share_and_network/pen/welcome.html

[9] http://www.investinengagement.info/PatientExperiencetop

[10] http://press.psprings.co.uk/bmj/march/SalzburgStatement.pdf

decisions about their medical treatment, particularly if they have previously experienced being treated involuntarily (Hamann *et al.*, 2005).

Current practice

Providers of mental health services use a broad range of methods to try to gauge the experiences of service users. These include monitoring the content of complaints, feedback from Patient Advice and Liaison Services and results of inspections such as those by the Mental Health Commission. While satisfaction and other surveys have long been conducted by Trusts, greater emphasis has been placed on this methods of obtaining feedback from service users as a result of national patient surveys (most recently those completed on behalf of the Care Quality Commission[11]).

Mental Health Trusts also obtain direct feedback from service users through consultation with user groups and forums. Foundation Trusts are required to have service user members on their Governing body and may appoint service user representatives to Trust management and planning groups. While there is a good deal of information about how mental health Trusts go about obtaining the views of service users of their services, a lot less is known about how they can improve service user experience (Crawford *et al.*, 2004). Trusts will regularly make changes to service provision following feedback from service users and are increasingly training staff in 'customer services'. Some have argued that the best way to improve service user experience is to provide people with choices about the service they use (Coulter, 2010). Others have argued a focus on individual choice can be lead to confusion and ultimately disempower users of public services (Barnes & Prior, 1995).

12.1.1 Review protocol (interventions)

The review protocol, including the review questions, information about the search strategy, and the eligibility criteria used for this section of the guidance, can be found in Table 21.

Table 21: Review protocol for the review of interventions to improve service user experience

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[11] http://www.nhssurveys.org/

Component	Description
Review question	2.1 For people who use adult NHS mental health services, do interventions that aim to improve the experience of care, when compared to standard care, produce meaningful improvements in the experience of care?
Sub-question	2.2 For people who use adult NHS mental health services, what service-level team configurations, when compared to standard care, improve the experience of care? 2.3 For team configurations shown to improve the experience of care, what are the common characteristics that appear to be associated with good service user experience?
Objectives	To determine whether interventions aiming to improve the experience of users of mental health services produce meaningful improvements in the experience of care.
Population	All people who use inpatient and community adult mental health services.
Intervention(s)	Interventions that aim to improve the experience of care, including: • Interventions aiming to change health provider behaviour (for example, interventions for healthcare professionals that aim to promote person-centred approaches in clinical consultations) • Interventions aiming to improve the relationship between the service user and healthcare professional (for example, shared decision making interventions) • Service-level team configurations that have been recommended for use in a NICE mental health guideline (General care: community mental health teams, crisis resolution and home treatment teams, the care programme approach, acute day hospital care; Specialist services: assertive outreach, early intervention services)
Comparison	Standard care or any other control
Critical outcomes	Any valid measure of service user experience of care (for example, Consumer Assessment of Healthcare Providers and Systems Hospital survey[1]), satisfaction, or evaluation of care.
Search strategy	Reviews cited by Goodrich & Cornwell (2008) or included in the Cochrane Consumers and Communication Group or the Cochrane Effective Practice and Organisation of Care Group list of reviews were assessed for eligibility and included where relevant. Additionally, the following websites were checked for eligible reviews: • Health Issues Centre • The Studer Group • Planetree • The Picker Institute • The Commonwealth Fund • The Schwartz Center • Implementation Science • Canadian Agency for Drugs and Technologies in Health
Date searched	The search for existing reviews was completed by March 2011.

	An update search for RCTs was conducted in April 2011.
Study design	Systematic reviews, RCTs and observational studies
Review strategy	A simplified matrix (see Chapter 3) was used to classify existing reviews of interventions. Reviews that included people with mental health problems are described first, followed by reviews of non-mental health disorders. The search strategy used by the most general review of service user focused interventions (Coulter & Ellins, 2006), was updated to identify recent RCTs of interventions to improve the experience of care. A narrative synthesis was used to summarise the evidence across reviews and RCTs.

Note. NHS = National Health Service.

[1] Darby C, Hays RD, Kletke P. Development and evaluation of the CAHPS hospital survey. Health Serv Res 2005;40: 1973-6.

12.1.2 Studies considered[12]

Seventeen reviews met eligibility criteria for the review of interventions. Of these, four included studies of people with mental health problems (see Table 22 and Table 23), and thirteen included studies of people with non-mental health problems (see Table 25, Table 27, Table 28, Table 29, Table 30). In addition, two RCTs were identified by the search for recent evidence (see Table 24). For further information about each included study, see Appendix 8. A number of other reviews were identified as potentially eligible, but on further inspection were excluded for a number of reasons (see Appendix 10 for further information).

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[12] Here and elsewhere in the guideline, each study considered for review is referred to by a study ID (primary author and date of study publication, except where a study is in press or only submitted for publication, then a date is not used).

Table 22: Study information and results table for systematic reviews evaluating interventions to improve service user experience (mental healthcare specific or includes related studies)

Study ID	**COULTER2006**	**DUNCAN2010**
Pathway	Both acute (not MHA) and non-acute	Acute (not MHA) and non-acute
Domain	The relationship between individual service users & professionals/ The way that services and systems work	The relationship between individual service users & professionals/ The way that services and systems work
Method used to synthesise evidence	Narrative synthesis	Narrative synthesis
Design of included studies	Systematic reviews, RCTs, quasi-experimental studies, controlled observational studies, uncontrolled observational studies	Cluster RCT
Dates searched	1998 to 2006	Inception to Nov 2008
No. of included studies	35 (2 mental health; Bekker *et al*., 1999; Warner *et al*., 2000)	2 (Hamann *et al*., 2006; Loh *et al*., 2007)
Participant characteristics	Service users	Inpatients with schizophrenia/people with depression treated in primary care (N=518)
Intervention	'Patient-focused' interventions	Shared decision making aids (participants received decision aids, staff received training)
Comparison	Various	Control participants and staff did not receive the intervention
Outcome(s)	Service users' experience, including communication and psychological outcomes	Satisfaction
Risk of bias	The review was well conducted, but included studies had variable risk of bias	The review was well conducted, but included studies had significant risk of bias

Note. Acute (not MHA) = assessment and referral in crisis, hospital care, discharge/ transfer of care (not under Mental Health Act 2007); Non-acute = access, assessment, community care, discharge back to primary care.

Table 23: Study information and results table for systematic reviews evaluating interventions to improve service user experience (mental healthcare specific or includes related studies)

Study ID	**HAMANN2003**	**NICOLSON2009**
Pathway	Acute (not MHA) and non-acute	Non-acute
Domain	The relationship between individual service users & professionals	The relationship between individual service users & professionals
Method used to synthesise evidence	Narrative synthesis	Narrative synthesis
Design of included studies	Observational study	RCT
Dates searched	Not reported	Dates varied according to database searched. Most databases were searched from Jan 1970 to Mar 2007
No. of included studies	4 (Bedi *et al*., 2000; King *et al*., 2000; Rokke *et al*., 1999; Bunn *et al*., 1997)	25 (2 mental health: Peveler *et al*., 1999; Robinson *et al*., 1986). Note: a further two studies received medication for mental health problems but the population were outside the scope of the guideline (one study included those with learning disabilities and the other excluded patients with psychiatric problems).
Participant characteristics	Depression; mixed anxiety and depression; schizophrenia	Patient characteristics of included studies: inpatients, outpatients and primary care patients who had received written information about a prescribed or over-the-counter medicine (N=4788). Patient characteristics of studies that focused on mental health problems: psychiatric inpatients and primary care patients with depression.
Intervention	Shared decision making interventions/ elements of shared decision making	Interventions where patients received written information about an individual medicine (for example, medicine pack insert, information contained on websites).
Comparison	None used	No information at all; spoken information only; manufacturer information only
Outcome(s)	Satisfaction	Satisfaction; satisfaction with information (note, the mental health

		studies did not report satisfaction or related outcomes)
Risk of bias	The review had some limitations due to search strategy and inclusion of poor quality studies	The review was well conducted, but included studies of variable risk of bias
Note. Acute (not MHA) = assessment and referral in crisis, hospital care, discharge/ transfer of care (not under Mental Health Act 2007); Non-acute = access, assessment, community care, discharge back to primary care.		

Table 24: Study information table for recent RCTs evaluating interventions to improve service user experience (mental healthcare specific)

	Structured 'patient-clinician' communication	Facilitated psychiatric advance directive session
Pathway	Non-acute	Acute (not MHA) and non-acute
Domain	The relationship between individual service users & professionals	The relationship between individual service users & professionals
k (total N)	1 (507 service users; 134 clinicians)	1 (469 service users)
Study ID	PRIEBE2007	SWANSON2006
Participants	Adults (18-65 years) with a diagnosis of schizophrenia or related disorder	Adults (18-65 years) with a diagnosis of schizophrenia or related disorder, bipolar disorder or depression with psychotic features
Length of intervention	Mean number of meetings = 5.21	Median = 21 days
Length of follow-up	12 months	1 month
Setting	Community psychiatric services (Spain)	Community and hospital psychiatric services (USA)
Study design	Cluster randomised controlled trial	Randomised controlled trial
Outcome	Satisfaction (Client Satisfaction Questionnaire, CSQ–8)	Perception of whether need for treatment was met (1-item on the Mental Health Statistics Improvement Program Consumer Survey index of treatment satisfaction)

Note. Acute (not MHA) = assessment and referral in crisis, hospital care, discharge/ transfer of care (not under Mental Health Act 2007); Non-acute = access, assessment, community care, discharge back to primary care.

Table 25: Study information and results table for systematic reviews evaluating interventions to improve service user experience (non-mental health studies)

Study ID	**CHAUDHURY2005**	**DEVLIN2003**
Pathway	Acute (not MHA)	Acute (not MHA)
Domain	The way that services and systems work	The way that services and systems work
Method used to synthesise evidence	Narrative synthesis	Narrative synthesis
Design of included studies	Search not restricted to particular design – covers all types of studies	Not stated
Dates searched	Not stated	Not stated
No. of included studies	Not stated (8 studies focus on patient satisfaction)	Not stated
Participant characteristics	Inpatients, health care professionals	Inpatients, health care professionals
Intervention	Single-occupancy rooms	'Patient-centred' interventions that focus on aspects of the physical environment.
Comparison	Multiple-occupancy rooms	Not stated
Outcome(s)	Satisfaction	Satisfaction
Risk of bias		Potential risk of bias due to the unsystematic nature that studies were searched and selected and due to the limited detail on the quality of the included studies.
Note. Acute (not MHA) = assessment and referral in crisis, hospital care, discharge/ transfer of care (not under Mental Health Act 2007).		

Table 26: Study information and results table for systematic reviews evaluating interventions to improve service user experience (non-mental health studies)

Study ID	KINNERSLEY2007	LEWIN2001
Pathway	Non-acute	Acute (not MHA) and non-acute
Domain	The relationship between individual service users & professionals	The relationship between individual service users & professionals
Method used to synthesise evidence	Narrative synthesis of all studies, and meta-analysis of five outcomes	Narrative synthesis
Design of included studies	RCT	Randomised controlled trials, controlled clinical trials, controlled before and after studies, and interrupted time series studies
Dates searched	Dates varied according to database searched. All databases were searched from 1986 or earlier to Sep 2006	Dates varied according to database searched. All databases were searched from 1987 or earlier to Dec 1999
No. of included studies	33	17
Participant characteristics	Patients and/or their representatives (or carers) before 'one-to-one' consultations with doctors or nurses in healthcare settings (N=8244)	Healthcare providers (both qualified and in training); some interventions were also directed at patients as well as healthcare providers.
Intervention	Interventions helping service users to address their information needs in a consultation (for example, question prompt sheets, coaching sessions)	Interventions directed at healthcare providers and intending to promote person-centred care within clinical consultations
Comparison	Dummy interventions; usual care	No training; minimal information
Outcome(s)	Experience or perception of care (for example, satisfaction)	Satisfacion
Risk of bias		

Note. Acute (not MHA) = assessment and referral in crisis, hospital care, discharge/ transfer of care (not under Mental Health Act 2007); Non-acute = access, assessment, community care, discharge back to primary care.

Table 27: Study information and results table for systematic reviews evaluating interventions to improve service user experience (non-mental health studies)

Study ID	**MURRAY2005**	**OCONNOR2009**
Pathway	Non-acute	Non-acute
Domain	The relationship between individual service users & professionals	The relationship between individual service users & professionals
Method used to synthesise evidence	Meta-analysis	Meta-analysis – update to previous (2003) review
Design of included studies	RCT	RCT
Dates searched	1990 to 2003	Inception to Jul 2006
No. of included studies	24	55
Participant characteristics	Adults and children with chronic disease (community patients, primary care patients, outpatients, inpatients included) (N=3739)	Service users making decisions about screening or treatment options for themselves, for a child, or for an incapacitated significant other
Intervention	IHCAs (interactive health communication applications) – defined as any package requiring the user to interact directly with any form of computer, and containing health information plus at least one of peer support, decision support or behaviour change support	Decision aid interventions – any intervention designed to help people make specific and deliberative choices among options (including the status quo) by providing (at the minimum) information on the options and outcomes relevant to a person's health status and implicit methods to clarify values
Comparison	Normal care; non-interactive forms of patient education (for example, written, audiotape, video, group or one-to-one didactic sessions led by peers or professionals); interactive educational sessions led either by peers or professionals	No intervention; usual care; alternative interventions; or a combination
Outcome(s)	Satisfaction	Satisfaction
Risk of bias		

Note. Non-acute = access, assessment, community care, discharge back to primary care.

Table 28: Study information and results table for systematic reviews evaluating interventions to improve service user experience (non-mental health studies)

Study ID	**PARRY2008**	**PITKETHLY2008**
Pathway	Acute (not MHA) and non-acute	Non-acute
Domain	The relationship between individual service users & professionals	The relationship between individual service users & professionals
Method used to synthesise evidence	Narrative synthesis	Narrative synthesis
Design of included studies	Primary studies: case-control, within-subjects multiple baseline, cohort; and systematic reviews.	RCT, quasi-experimental
Dates searched	Inception to Jul 2006	Two updates conducted. Update #1: databases searched from various dates to Jan 2003 Update #2: databases searched from various dates to May 2007
No. of included studies	5 primary studies and 9 systematic reviews.	16
Participant characteristics	Qualified/trainee allied health professionals	Adults or children diagnosed with cancer and their close families (N=2318)
Intervention	Interventions enhancing communication or encompassing clinical skills more broadly, with communication a major component	Interventions offering or giving cancer patients video recordings, audio recordings or written summaries of their consultations with practitioners
Comparison	N/A	No recording or summary given/consultation as usual; standardised information given not related to consultation
Outcome(s)	Satisfaction	Experience of health care (satisfaction; participation in subsequent consultations; complaints and litigation, etc)
Risk of bias		

Note. Acute (not MHA) = assessment and referral in crisis, hospital care, discharge/ transfer of care (not under Mental Health Act 2007); Non-acute = access, assessment, community care, discharge back to primary care.

Table 29: Study information and results table for systematic reviews evaluating interventions to improve service user experience (non-mental health studies)

Study ID	**REEVES2008**	**SAULTZ2004**
Pathway	Acute (not MHA)	Acute (not MHA) and non-acute
Domain	The relationship between individual service users & professionals	The relationship between individual service users & professionals
Method used to synthesise evidence	Narrative synthesis	Narrative synthesis
Design of included studies	RCT, controlled before and after (CBA)	RCTs, cohort studies, correlation studies and reviews
Dates searched	1999 to 2006	1966 to 2002
No. of included studies	6	30 (22 original research reports from 20 studies +8 reviews)
Participant characteristics	Health and social care professionals (for example, chiropodists/podiatrists, complementary therapists, dentists, dieticians, doctors/physicians, hygienists, psychologists, psychotherapists, midwives, nurses, pharmacists, physiotherapists, occupational therapists, radiographers, speech therapists, and social workers), patients	Healthcare professionals (for example, doctors, midwives, pharmacists), patients and carers.
Intervention	Interprofessional education interventions	Interpersonal continuity of care
Comparison	Control groups which received no education intervention.	Control groups with no focus on continuity of care
Outcome(s)	Satisfaction	Satisfaction
Risk of bias		Moderate: 14 out of 20 studies had quality score of 5/10 or more but confounding factors limit the conclusions that can be drawn.

Note. Acute (not MHA) = assessment and referral in crisis, hospital care, discharge/ transfer of care (not under Mental Health Act 2007); Non-acute = access, assessment, community care, discharge back to primary care.

Table 30: Study information and results table for systematic reviews evaluating interventions to improve service user experience (non-mental health studies)

Study ID	**SHEPPERD2010**	**WETZELS2007**
Pathway	Acute (not MHA)	Non-acute
Domain	The way that services and systems work	The relationship between individual service users & professionals
Method used to synthesise evidence	Meta-analysis	Narrative synthesis
Design of included studies	RCT	RCT, quasi-randomised
Dates searched	Inception to 2009 (Cochrane databases, MEDLINE, EMBASE); inception to 1996 for other databases.	Inception to Jun 2004
No. of included studies	21	3
Participant characteristics	Hospital inpatients (N=7234)	Older patients (all patients to be >= 65 years), patients' caregivers/family members, GPs (N=433)
Intervention	Discharge plans tailored to the individual patient	Patient-focused interventions with the intention of increasing patients' involvement in the primary medical care consultation (administered either before, during, or after the patient/heatlhcare provider consultation)
Comparison	Routine discharge care not individualised	Untrained/usual care
Outcome(s)	Satisfaction	Satisfaction; patients' evaluations of care and procedures used for complaints and comments
Risk of bias	The systematic review was carried out well; individual studies had low risk of bias.	The systematic review was carried out well. Included studies were few and generally small, with short-term follow-up, and moderate risk of bias.

Note. Acute (not MHA) = assessment and referral in crisis, hospital care, discharge/ transfer of care (not under Mental Health Act 2007); Non-acute = access, assessment, community care, discharge back to primary care.

Table 31: Study information and results table for systematic reviews evaluating interventions to improve service user experience (non-mental health studies)

Study ID	**ZWARENSTEIN2009**
Pathway	Acute (not MHA)
Domain	The relationship between individual service users & professionals
Method used to synthesise evidence	Narrative synthesis
Design of included studies	RCT
Dates searched	Inception to 2007
No. of included studies	5
Participant characteristics	Health and social care professionals, service users
Intervention	Tools or routines designed to improve practice-based interprofessional collaboration (IPC)
Comparison	No intervention/alternative intervention
Outcome(s)	Satisfaction
Risk of bias	The systematic review was well-conducted. Of the five included RCTs, one was rated as high quality by the review authors and four as moderate quality.

Note. Acute (not MHA) = assessment and referral in crisis, hospital care, discharge/ transfer of care (not under Mental Health Act 2007).

12.2 EVIDENCE REVIEWED – MENTAL HEALTH

12.2.1 Existing reviews

COULTER2006

Coulter and Ellins (2006) produced, what they describe as, a policy overview of 'patient-focused' interventions. They defined these interventions as "those that recognise the role of patients as active participants in the process of securing appropriate, effective, safe and responsive healthcare". The review was structured using seven quality improvement goals: 1) improving health literacy; 2) improving clinical decision-making; 3) improving self-care; 4) improving service user safety; 5) improving access to health advice; 6) improving the care experience; 7) improving service development. The evidence was sourced from searches of the major electronic databases and websites, including Medline, Embase, CINAHL, DH-DATA, PsychINFO, AMED, British Nursing Index, Cochrane Library, DARE, King's Fund, National Electronic Library for Health, NHS Research Register, WHO, AHRQ. Specialist websites were also scanned. The search was limited to English language papers published between 1998-2006.

Of the 35 included studies (reviews and primary studies), two included people with mental health disorders and were relevant to the current guidance. Of these, one was included in the section on improving clinical decision-making (Bekker *et al.*, 1999). This paper was a systematic review of 541 studies that evaluated interventions that may affect "informed patient decision-making". Of the included studies, 15 were classified by the authors as being in mental health, but further research was needed to reach a conclusion about the effect of informed decision-making interventions. The other mental health study included by Coulter and Ellins (2006), in the section on improving self-care, was a RCT evaluating 'patient- held' shared care records in 90 people with long-term mental illness (Warner *et al.*, 2000). After 12 months, patient-held records did not lead to improved satisfaction with services when compared to the control group.

DUNCAN2010

Duncan and colleagues (2010) conducted a systematic review of interventions aimed to increase 'shared decision making' to improve service user satisfaction with their experience of care. Shared decision making was defined as the sharing of treatment preferences and decisions by both the professional and the service user. To be included into the review, decision making had to involve at least two participants and had to focus on enhancing any of the following four criteria: 1) the involvement of two or more people in the decision making process; 2) the sharing of information between participants; 3) both parties must have participated in the decision making process; and 4) a decision must have been made or been actively deferred. The study focused on individuals diagnosed with a mental health condition as classified by, for example, the International Classification of Diseases (WHO, 1992) or the Diagnostic and Statistical Manual of Mental Disorders (APA, 2000). The following sources were searched: the Cochrane Library 2008; MEDLINE; EMBASE; PsycINFO; British Nursing Index and Archive; and SIGLE. The review also handsearch online trial registers and the reference list of included studies. Authors were also contacted to identify further studies to include into the review. The search was last conducted in 2008.

Two cluster RCTs (N=518) were identified that met the review's inclusion criteria (Hamann *et al.,* 2006; Loh *et al.,* 2007*);* both studies were conducted in Germany. The review found inconsistent evidence regarding the effectiveness of shared decision making on service users' satisfaction with care. In one study, Loh *et al.* (2007) found that primary care service users newly diagnosed with depression were significantly more satisfied with their care compared with treatment as usual (p= 0.014). While Hamann *et al.* (2006) found that that inpatients with a diagnosis of schizophrenia or schizoaffective disorder who received shared decision making were not significantly more satisfied with care, compared with treatment as usual (p=0.42). However this study found that the provider delivering the intervention was statistically significantly more satisfied with care compared with treatment as usual (p=0.02).

HAMANN2003

A further systematic review (Hamann *et al.,* 2003) also explored the impact of shared decision making on service users' satisfaction with care. The review's inclusion criteria were not clearly reported but the results suggest that it included studies where participants were allowed to choose between treatment options rather than being randomised to treatment or control groups and therefore included an element of 'shared decision making'; and also included studies where a formal model of shared decision making was evaluated. The review searched Medline for relevant studies; the dates of the search were not provided.

No good quality studies were identified that directly examined shared decision making interventions compared to an adequate control. Three studies (Bedi *et al.,* 2000; King *et al.,* 2000; Rokke *et al.,* 1999) were identified where participants with depression choose between different treatment options rather than being randomised to different groups. The authors of the review reported that there were no statistically significant differences between treatment groups in service users' satisfaction with care. However, the conclusions which can be drawn from these studies are limited because participants in both groups choose what treatment they received. The review also included one study the explored the effectiveness of a formal model of shared decision making to patients with schizophrenia to decide between the continuation or discontinuation of an antipsychotic depot medication. However, this study did not explore service users' satisfaction with care when a shared decision making intervention was utilised.

NICOLSON2009

In a systematic review, Nicolson *et al.* (2009) explored the effectiveness of providing written information about individual medicines on service user-related outcomes. The interventions included information contained in a medicine pack insert or a supplementary leaflet, or non-print written information such as the information contained on websites, that are intended for the use of service users. The sources searched were MEDLINE, EMBASE, CINAHL, The Cochrane Library, PsycINFO and other databases up to March 2007. The review also hand searched five journals and the reference lists of the included studies. Experts in the field were also contacted for relevant studies.

The review included 25 RCTs, two of which included participants with mental health problems (Robinson *et al*., 1986; Peveler *et al*., 1999) which compared receiving written information with not receiving written information. The studies that focused on mental health problems did not report data on service user experience of care and/or satisfaction with care. However, there were three non-mental health studies that explored service users' satisfaction with care of which two found that receiving information resulted in greater satisfaction with the information provided compared with not receiving information. However, this difference was only statistically compared in one trial (which found a statistically significant difference, Gibbs *et al*, 1989), and was not tested in a second trial (McBean & Blackburn, 1982). The third study found that service users were more satisfied when they received numerical risk information about side effects compared with verbal information; this difference was statistically significant for one of two side effects ($p < 0.05$; Knapp *et al.,* 2004).

12.2.2Recent studies

PRIEBE2007

Priebe *et al.* (2007) used a cluster randomised controlled trial to investigate the effect of an intervention supporting 'patient-clinician' communication on care outcomes for 507 people with schizophrenia or related disorders. Key workers (N = 134) were allocated to either the intervention, consisting of a computer-mediated procedure to structure 'patient-clinician' dialogue, or treatment as usual. At twelve-month follow-up, service users who received the intervention had significantly higher treatment satisfaction (p=.01) compared with participants in the control group.

SWANSON2006

Swanson and colleagues (2006) explored the impact that psychiatric advance directives have on the working alliance between service users and clinicians and on service users' receipt of needed mental health services. People with severe mental illness (N = 469) were randomly assigned to a facilitated intervention involving a guided discussion of choices involved in anticipatory mental health treatment planning or a control group that received written information about psychiatric advance directives and referral to resources in the public mental health system. At one-month follow-up, participants in the facilitated session had a greater working alliance with their clinicians and were more likely than those in the control group to report receiving the mental health services they believed they needed (Odds Ratio=1.57, p<0.05).

12.2.3 Evidence summary for mental healthcare

There is a paucity of evidence about interventions aiming to improve the experience of people using mental health services. What limited evidence there is, concerns interventions to improve the decision-making process or communication between healthcare professionals and service users.

For shared decision making interventions, the evidence is inconclusive with three studies demonstrating positive influences and two failing to show an influence on satisfaction with treatment. Observational studies that have looked inside the black box of shared decision-making offer insights into why this may the case. In a conversation analysis study of how decisions are made about long-term antipsychotic prescribing, based on tape recordings of 92 outpatient consultations, Quirk and colleagues (2008; 2009; in press) found that some shared decisions are considerably more 'pressured' than others and are unlikely to have been experienced by the service user as having been shared – even though they had been fully involved and agreed with the outcome. The research identified some of the more subtle forms of control used by psychiatrists to pressure or steer patients into 'choosing' what the psychiatrist regards as the best treatment option. Consultations may depart from a shared decision making model in other respects as well with psychiatrists responding poorly to service users' complaints about sedation and mental clouding (Seale *et al.*, 2007). Hence the inconclusiveness of the literature on the impact of shared decision making on outcome, especially treatment satisfaction, may be partly explained by the complexity of the decision making process. A decision that is defined as shared by a clinician or research team in practice may not be experienced as such by the service user, in which case the benefits of shared decision making (e.g., 'patient global satisfaction' in DUNCAN2010) will be lost.

12.3 EVIDENCE REVIEWED – NON-MENTAL HEALTH

12.3.1 Existing reviews

CHAUDHURY2005

Chaudhury *et al.* (2005) in a systematic review explored the impact of single-occupancy rooms for service users compared with multiple-occupancy rooms in hospitals on outcomes including service users' satisfaction with care. The review searched electronic databases such as Medline, EBSCO, Web of Science, PsycINFO, Science Direct, EMBASE, Pubmed and Social Sciences Citation Index (other databases were also searched). In addition, relevant journals, magazines and the reference lists of included studies were searched. The dates that the searches were conducted were not reported.

The total number of studies included in this review was not reported. There were however, eight studies with data relating to service user satisfaction; only these studies are reported below. The authors of the review noted that studies on service user satisfaction demonstrated that single occupancy rooms were positively associated with patients' satisfaction with their hospital stay (Cleary *et al.* 1988; Gotlieb, 2000, 2002; Harris, *et al.,* 2002; Kaldenberg, 1999; Lawson and Phiri, 2000; Morgan and Stewart, 1999; Nguyen *et al.,* 2002). The review did not report the risk of bias, or the study design, of the included studies (including other study characteristics information) limiting the conclusions which can be drawn from this review.

DEVLIN2003

Devlin & Arneil (2003) in a non-systematic review explored the literature on person-centred care. The review was concerned with the impact of person-centered care in increasing service users' control over their healthcare environment and the impact this has on service user outcomes. The review did not provide details on how the studies were searched and selected; there was also no information on the review's primary outcomes.

The total number of included studies was not reported. Only those studies that reported outcomes relating to service user satisfaction are described below. The authors of the review report that there is preliminary results from one study (Martin *et al.,* 1990) that suggest that Planetree units, which are person-centered care programmes that emphasise a homelike environment, result in greater satisfaction in care among service users compared with traditional medical-surgical units. The data and study design used to support this conclusion was not provided. In randomised trial, Martin and colleagues (1998) demonstrated that service users who were assigned to a Planetree unit were more satisfied with their stay than were those who were assigned to other units. This satisfaction included greater satisfaction with the extent to which nurses were involved in their care and with the opportunity to see their support network (family and friends). However, there were no statistically significant differences in clinical outcomes such as greater involvement of physicians in their care. Lastly, a study that evaluated the presence or absence of a window and the affect on service users' experiences in hospital suggest that satisfaction is generally achieved when window area occupies 20-30% of the window wall (Keep, 1977); details of the study design were not reported by the review authors. The conclusions that can be drawn from this review are limited as there is a potential risk of bias due to the unsystematic nature that studies were searched and selected and due to the limited detail on the quality of the included studies.

KINNERSLEY2007

A systematic review (Kinnersley *et al.,* 2007) explored the effectiveness of interventions directed at service users which were delivered before healthcare consultations, to help them gather information during their consultation. These included for example, written materials such as prompt sheets with questions and coaching sessions delivered in the waiting room before service users' consultations. It did not include decision aids, which are reported on earlier in this chapter. The review searched for studies in CENTRAL, MEDLINE, EMBASE, PsycINFO, and other databases, with no language restriction. The reference lists of included articles and related reviews, and selected journals were also hand-searched. The search was last conducted in 2006.

The review identified 33 RCTs of which 23 studies reported outcomes relating to service user satisfaction. The review found a small but statistically significant effect on service user satisfaction (SMD 0.09, 95%CI 0.03 to 0.16) when an intervention was delivered before consultation to help service users address their information needs compared with a control condition (attention-control or standard care). In a sub-group analysis by the type of intervention delivered, interventions delivered via coaching produced a small and statistically significant effect (SMD 0.23, 95% CI 0.08 to 0.38). Further sub-group analyses found effects that were unlikely to be meaningful.

LEWIN2001

Lewin *et al.* (2001) in a systematic review investigated the effects of interventions for healthcare providers (including those in training to qualify as healthcare providers) that aimed to promote person-centred approaches in clinical consultations. For the intervention to be considered as person-centred it had to encourage shared control over the consultation where decisions about interventions had to be made with the service user and/or the focus of the consultation had to take into account that service users have individual preferences situated within social contexts. The review searched MEDLINE, HEALTH STAR, PsycLIT, CINAHL, EMBASE and the reference list of studies were assessed for inclusion. The search was last updated in 1999.

Seventeen studies were included in the review (15 RCTs and two controlled trials), 10 of which measured service user satisfaction. The review found inconsistent evidence from seven studies that compared the effectiveness of person-centred training with no intervention on service users' satisfaction. Two of the seven studies demonstrated that in at least two measures on service user satisfaction, there was a statistically significant difference in the group where healthcare providers received person-centred training compared with no intervention (Cope *et al.,* 1986; Smith *et al.* 1995). However, the remaining five studies demonstrated that there was no statistically significant difference between the treatment and control group on serve users' satisfaction with the consultation process (Langewitz *et al.* 1998; Putnam *et al.* 1988; Roter *et al.,* 1998; Smith *et al.,* 1998; Thom *et al.,* 1999).

There was also similar inconsistent evidence on service user satisfaction in a further three studies that compared person-centred training for providers plus person-centred materials for service users compared with no intervention. One study found a statistically significant difference in service user satisfaction among children who received the intervention compared with the control group, but did not find a statistically significant difference in parents' satisfaction (Lewis *et al.*, 1991). Another study found a statistically significant improvement before and after the consultation period in the control group but not in the treatment group (Pill *et al.*, 1998). While the teaming study found no statistically significant difference between groups (Joos *et al.*, 1996).

MURRAY2005

Murray *et al.* (2005) in a systematic review assessed the effectiveness of Interactive Health Communication Applications (IHCAs) which were defined as computer-based (usually web-based) information packages for service users that combined online peer support, decision support, or help with behaviour change to adults or children with chronic illness. The review searched electronic databases including The Cochrane Library, MEDLINE, EMBASE, PsycINFO and CINAHL, from 1990 to 2003. The grey literature and the reference list of included studies were also searched.

Twenty-four studies were included in the review but satisfaction with care and/or service users' experience of care were not summarised in the review. However, the review did find that IHCAs had a statistically significant positive effect on knowledge (SMD = 0.46, 95% CI 0.22 to 0.69) and social support (SMD = 0.35, 95% CI 0.18 to 0.52) compared with a control group. There was also a positive effect on self-efficacy in favour of IHCA compared with a control group (SMD = 0.24, 95% CI 0.00 to 0.48).

OCONNOR2009

A systematic review of RCTs evaluated the efficacy of decision aids for people facing difficult treatment or screening decisions (O'Connor *et al.,* 2009). Decision aids were defined as interventions designed to help people make specific and deliberative choices among options by providing, at the minimum, information on the options and outcomes relevant to a person's health status and that uses implicit methods to clarify values. The review searched MEDLINE, CENTRAL, CINAHL, EMBASE and PsycINFO; expert researchers were also contacted. There were no language restrictions; the search was last updated in 2006.

Fifty-five studies were included in the review, 11 of which measured the effectiveness of decision aids compared with a control group on service user satisfaction with: the decision made; the process of decision making; the opportunities to participate in decision making; and/or satisfaction with outcomes. The review found inconsistent evidence regarding the effectiveness of decision aids compared with a control group (no intervention, standard care, alternative interventions, or a combination) on service users' satisfaction with care. Six out of 11 studies found statistically significant improvements in satisfaction in the treatment group compared with the control group, however, the remaining five studies found no statistically significant differences between groups.

PARRY2008

Parry *et al.* (2008) conducted a systematic review on the effectiveness of training to improve communication performance amongst healthcare professionals. Interventions included training that had a substantial or sole focus on communication skills and were delivered to healthcare workers, who at least some of whom were allied health professionals. The review searched for primary studies in CINAHL, EMBASE, Medline, PsycINFO and ERIC (other electronic databases); hand searched the reference list of included studies; and contacted key researchers. The review also conducted a search for systematic reviews published in the Cochrane Library databases from 1997 to 2006. The results for the primary studies and systematic reviews are reported separately.

Five primary studies and nine systematic reviews were included in the review. The authors suggest that there have been no large-scale, blinded, and adequately powered controlled studies evaluating effects of communication skills interventions for healthcare professionals. In addition, that the evidence was limited and of variable quality. However, the authors suggest that there was some preliminary evidence from two small-scale, within-subjects controlled design studies (Ducharme & Spencer, 2001; Mozzoni & Bailey, 1996) that found that targeted training for professionals may improve clinicians' performance and service user outcomes. However, their impact on service user experience of care was not detailed. While the evidence from the systematic reviews indicates that there was some evidence of effectiveness for interventions aimed at improving clinical communication performance including aspects of trainees' attitudes, trainees' behaviours, and some service user-related measures, in particular service users' satisfaction. The conclusions that can be drawn from this review are limited because no quantitative data were provided to support the conclusions of the review.

PITKETHLY2008

Pitkethly *et al.* (2008) systematically reviewed the efficacy of providing recordings or summaries of service users' consultations to people with cancer and their families. These interventions could include offering or giving people with cancer video recordings, audio recordings or written summaries. The review updated a previous review (Scott *et al.* 2003) by searching the Cochrane Library, MEDLINE, CINAHL, Dissertation Abstracts, EMBASE, PsycINFO, AMED, British Nursing Index, SCI-EXPANDED, SSCI and Sociological Abstracts. The search was last conducted in 2007.

The review included 15 RCTs and one quasi-randomised controlled trial. The authors of the review noted that the data on satisfaction was heterogeneous as many studies measured service users' satisfaction in different domains including satisfaction with information received, with the consultation, with interpersonal aspects of medical care, with medical care in general and/or with service user-physician communication. The review did find that in three out of ten studies that measured satisfaction, service users with a recording or summary of the consultation were statistically more satisfied than the control group (Damian & Tattersall, 1991, $p=0.014$; Dunn *et al.* 1993, $p< 0.05$; Ong *et al.* 2000, $p< 0.05$). In a further study (Sepucha *et al.* 2000), there was higher satisfaction with a written summary compared to control but this was not statistically significant ($p=0.073$). In a comparison of audio-taped summaries compared with written information, two studies reported that a tape was a more effective reminder than written information (Tattersall, 1994, $p < 0.05$; Bruera, 1999, $p=0.04$). The remaining comparison groups found no statistically significant differences between groups including consultation tapes compared with standardised tape (Hack *et al*, 2007) and information plus consultation tape compared information alone and compared with a control group (Reynolds *et al.,* 1981). Limited conclusions could be drawn from the remaining studies.

REEVES2008

In a systematic review, Reeves *et al.* (2008) evaluated the effectiveness of interprofessional education which was defined as an intervention when members of more than one health and/or social care profession learnt interactively together with the explicit purpose of improving interprofessional collaboration and/or improving outcomes for service users. The review searched Cochrane Effective Practice and Organisation of Care Group specialised register, MEDLINE and CINAHL, for the years 1999 to 2006. Selective journals were also searched as were the reference lists of the included studies.

Six studies were included in the review, four RCTs and two controlled before and after studies. Two of the six studies measured service user satisfaction and found inconsistent evidence regarding the effectiveness of interpersonal education compared with receiving no educational intervention. One study demonstrated that interpersonal education had a statistically significant positive effect on service user satisfaction compared with control ($p < 0.001$; Campbell, 2001). While the second demonstrated that an interprofessional education programme did not result in statistically significant differences between groups, however, mean scores were higher in the control group (mean score = 0.072, 95% CI, -0.010 to 0.154) compared with the treatment group (mean score = 0.030 95% CI, -0.060 to 0.120).

SAULTZ2004

Saultz and Albedaiwi (2004) searched MEDLINE and citation lists in included studies to identify reviews and primary research reports that evaluated the effects of interpersonal continuity of care on service user satisfaction. The search was run in 2002. Included studies were reviews, RCTs, cohort studies and correlation studies.

A total of 30 reports were included, of which 22 reported results from 20 primary research studies and 8 were reviews. Four RCTs found significantly higher satisfaction scores with clinics offering continuity of care compared with no continuity in parents of low-income children in the US (Alpert *et al*., 1976; Becker *et al*., 1974), in men aged 55 and over attending Veterans Administration (VA) clinics (Wasson *et al.,* 1984) and in pregnant women in Australia (Rowley *et al.,* 1995), with follow-up times of up to 18 months. However, no quantitative data from the studies were reported in the review to support the reviewer's conclusions. Four cohort studies also found an association between continuity of care and increased service user satisfaction, and 10 out of 12 correlation studies reported a positive association between continuity of care or a stronger professional-service user relationship and service user satisfaction. The review is limited by not reporting study data and by heterogeneity of primary studies, meaning that continuity of care was measured in different ways and was often one component of a larger programme, so the precise effects of continuity of care itself are unclear.

SHEPPERD2010

Shepperd and colleagues (2010) conducted a systematic review of RCTs on the effects of discharge planning for inpatients on acute healthcare use, service user and caregiver satisfaction, service user health outcomes, and costs of care. A search was run in the Cochrane EPOC Group Register (including CENTRAL and HealthSTAR), MEDLINE and EMBASE to 2009, and CINAHL, EconLit, SIGLE and PsycLit to 1996, and the authors also searched citation lists from identified studies and individual trialists were contacted for additional data and unpublished studies.

Twenty-one studies met the inclusion criteria, three of which (Moher *et al.*, 1992; Laramee *et al.*, 2003; Weinberger *et al.*, 1996) reported increased service user satisfaction with discharge planning compared with control. Laramee and colleagues (2003) reported significantly higher service user satisfaction scores with hospital care, hospital discharge and recovery at home, and Weinberger and colleagues (1996) reported greater satisfaction with continuity of care and non-financial access to medical care. Bolas and colleagues (2004) reported improved information exchange between healthcare professionals with use of a pharmacy discharge letter, although Nazareth *et al.* (2001) found no difference in satisfaction with this intervention.

WETZELS2007

Wetzels and colleagues (2007) carried out a systematic review of interventions designed to improve older service users' involvement in primary care episodes. Studies were included if they involved service users aged 65 and over taking an active role in deciding about and planning their own medical care; were set in primary care in relation to single consultations with a doctor or to healthcare use; and focused on 1) informing service users about appropriate use of healthcare and how to choose a healthcare provider ; 2) supplying service user data and preparation for contact with a care provider; 3) providing tailored service user information and improving communication during the contact with the healthcare provider or 4) evaluating care and collecting service users' complaints and comments about care. Studies were included if they were RCTs or quasi-randomised studies, identified from a search of the Cochrane Consumers and Communication Review Group Specialised Register, the Cochrane Central Register of Controlled Trials, EMBASE, PsycINFO, DARE, ERIC, CINAHL, MEDLINE, Sociololgical abstracts and Dissertation Abstracts International. The search was last conducted in 2004.

Three studies met the inclusion criteria, one of which reported data relevant to service user satisfaction with care (Tennstedt, 2000). Tennstedt (2000) offered the intervention group a 2-hour session to learn about and practice desirable behaviours with cue cards and a preparation booklet where they could list problems and medication, and found that service users were more satisfied with interpersonal aspects of their care than those in a control group, although overall satisfaction scores were the same. The authors concluded that interventions to educate elderly service users can have positive effects in the short term, but there were few studies of adequate size and follow-up, so no overall conclusions were made.

ZWARENSTEIN2009

Zwarenstein and colleagues (2009) conducted a systematic review on the effects of practice-based interventions on professional practice and healthcare outcomes. Studies were included if they were RCTs that assessed practice-based tools or routines aimed at improving collaboration between one or more health or social care professional. This update of the original systematic review searched a number of electronic databases including the Cochrane Library (CDSR, CCTR and DARE), the EPOC register, MEDLINE from 1950 and CINAHL from 1982. Hand searching of the Journal of Interprofessional Care and citation lists of identified studies was also carried out. Studies in any language were included. The search was last carried out in September 2007.

A total of five studies were included in the updated review. Although service user satisfaction was a primary outcome of the review, the studies included did not routinely measure this outcome or it did not meet the review's outcome criteria and was therefore not extracted. However, there was some evidence that audit activity and quality of care may increase when external facilitators encourage collaborative working (Cheater *et al.*, 2005). The authors concluded that the small number and methodological limitations of the studies, the narrow range of interventions investigated, and the absence of studies set in primary care or chronic care, limits the conclusions that can be drawn from the review.

12.3.2 Evidence summary for non-mental healthcare

The evidence reviewed suggests that there are some interventions that may improve service user experience of care in non-mental health settings, although it is often difficult to interpret due to limitations in study design, heterogeneity of interventions and outcome measures, and little data reported in the existing reviews quantifying the magnitude of the effect. Nevertheless, Coulter and Ellins (COULTER2006) suggest that person-centred care programmes can improve service user experience of care. In particular, there is evidence that interventions that target the domain of 'clear, comprehensible information and support for self-care', such as communications skills training for healthcare professionals (COULTER2006), Interactive Health Communication Applications (MURRAY2005), interventions delivered before consultation to help service users address their information needs (KINNERSLEY2007), may improve the experience of care for service users. Coulter and Ellins also suggested that interventions, such as provider choice, outreach clinics and walk-in centres, and public involvement in service development may increase satisfaction or self-efficacy.[13]

Several other interventions had some evidence for improved satisfaction, but it was inconsistent. These included the following: decision aids (OCONNOR2009), discharge planning for inpatients (SHEPPERD2010), interprofessional education (REEVES2008), person-centred training for healthcare professionals (LEWIN2001), person-centred training for healthcare professionals plus person-centred materials for service users (LEWIN2001), and recordings or summaries of service users' consultations (PITKETHLY2008).

12.4EVIDENCE TO RECOMMENDATIONS

The GDG discussed the lack of research conducted in mental health settings, and agreed that further research should be a priority in this area. Although shared decision making interventions were not strongly supported by evidence, it is an important element of person-centred care, therefore the GDG agreed that health and social care professionals, and services, should be encouraged to maintain this principle of good practice. More generally, the GDG strongly supported the use of approaches that facilitate person-centred care, and thought it appropriate to recommend options that show promise, and that should be evaluated if used.

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[13] In healthcare, Bandura's self-efficacy theory suggests that service users 'are empowered and motivated to manage their health problems when they feel confident in their ability to achieve this goal' (Coulter & Ellins, 2006).

12.5 RECOMMENDATIONS

12.5.1 Research recommendations

12.5.1.1 For people using adult mental health services, what is the effect of training community mental health teams (CMHTs) and inpatient ward staff in the use of the national quality standard and underpinning guidance on service user experience, when compared to no training, on service users' experience of care?

12.5.1.2 For people using adult mental health services, what are the key aspects of 'shared decision making' that they prefer, and does a training programme for health and social care professionals designed around these key aspects, when compared to no training, improve service users' experience of care?

12.5.1.3 For people using adult mental health services, what is the effect of 'customer care' training for professionals on service user experience of care? The intervention would be provided to health and social care professionals and supporting staff who may come into contact with service users such as receptionists, administrators, secretaries and housekeeping staff. Outcomes, determined by survey, exit interviews by trained past service users and selected in depth interviews, should include the experience of care, perceived safety, extent of perceived control over clinical decisions by service users, including those treated under the Mental Health Act and those treated informally. The appropriateness of this approach for different types of services (i.e., inpatient, community, outpatient clinic) should be evaluated.

12.5.1.4 For people using adult mental health services, what is the effect of 'person-centred care' training for professionals on service user experience of care? The intervention would be provided to health and social care professionals and supporting staff who may come into contact with service users such as receptionists, administrators, secretaries and housekeeping staff. Outcomes, determined by survey, exit interviews by trained past service users and selected in depth interviews, should include the experience of care, perceived safety, extent of perceived control over clinical decisions by service users, including those treated under the Mental Health Act and those treated informally. The appropriateness of this approach for different types of services (i.e., inpatient, community, outpatient clinic) should be evaluated.

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14. APPENDICES

APPENDIX 1: SCOPE FOR THE DEVELOPMENT OF THE GUIDANCE

Final version

1 Service user experience in adult mental health: improving the experience of care for people using adult NHS mental health services

1.1 Service user experience in adult mental health

2 Introduction

2.1 Guidance

This guidance will make recommendations on the appropriate treatment and care of people within the NHS. The recommendations are based on the best available evidence.

This scope defines what the guidance will (and will not) examine, and what the guidance developers will consider. The scope is based on the referral from the Department of Health.

2.2 Quality standards

Quality standards are a set of specific, concise quality statements and measures that act as markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions.

For this topic a NICE quality standard will be produced based on the guidance recommendations. The guidance and the quality standard will be published at the same time.

This scope defines the areas of care for which specific quality statements and measures will (and will not) be developed.

3 The remit

The Department of Health has asked NICE: 'to produce a quality standard and guidance on patient experience in adult mental health'.

4 Need for guidance

Background

a. Over the past few years several documents and initiatives have highlighted the importance of the service user's experience and the need to focus on improving these experiences where possible.

- Lord Darzi's report 'High quality care for all' (2008) highlighted the importance of the entire service user experience within the NHS, ensuring people are treated with compassion, dignity and respect within a clean, safe and well-managed environment.
- The development of the NHS Constitution (2009) was one of several recommendations from Lord Darzi's report. The Constitution describes the purpose, principles and values of the NHS and illustrates what staff, service users and the public can expect from the service. Since the Health Act came into force in January 2010, service providers and commissioners of NHS care have had a legal obligation to take the Constitution into account in all their decisions and actions.

b. The King's Fund charitable foundation has developed a comprehensive policy resource – 'Seeing the person in the patient: the point of care review paper' (2008). Some of the topics explored in the paper will be used in the development of this guidance and quality standard.

c. National initiatives aimed at improving service users' experience of healthcare include NHS Choices, a comprehensive information service that helps people to manage their healthcare and provides service users and carers with information and choice about their care. Local initiatives, such as patient advice and liaison services (PALS), have also been introduced.

d. Despite these initiatives, there is evidence to suggest that further work is needed to deliver the best possible experience for users of NHS services.

e. In 2005 the Department of Health published 'Delivering race equality in mental health care: an action plan for reform inside and outside services and the government's response to the independent inquiry into the death of David Bennett'. The report contained recommendations about the delivery of mental health care to service users, in particular those from black and minority ethnic communities. The recommendations also address wider issues in mental health settings, such as the safe use of physical interventions.

f. High quality care should be clinically effective, safe and be provided in a way that ensures the service user has the best possible experience of care. This service user experience guidance, and the quality standard that will be developed from it, will aim to ensure that users of mental health services have the best possible experience of care from the NHS.

4.2 Current practice

Current practice varies across all healthcare settings.

5 The guidance and quality standard

The guidance and quality standard will outline a level of service that people using NHS mental health services should expect to receive. It is recognised that some people or groups may have had poor experiences of healthcare and need further consideration in the delivery of high quality care (for example, because of their age, disability, race, religion or belief). The specific needs of such people or groups will not be addressed within this guidance and quality standard, but the principles may be of use in local strategies to narrow inequalities in service user experience.

5.1 Population

5.1.1 Groups that will be covered

a. People who use adult NHS mental health services.

5.1.2 Groups that will not be covered

a. Mental health service users using NHS services for physical health problems.

b. Carers of people using NHS services. The guidance and quality standard will examine the role of carers have in the experience of people using NHS mental health services but will not address carers' experiences of services.

5.2 Healthcare setting

a. Community and inpatient mental health settings.

5.3 Objectives

a. Develop recommendations and quality standards to provide a framework that describes the key requirements for providing a high quality service user experience. We do not expect the guidance to make recommendations on all elements of the framework.

b. Identify quality measures that set the expected degree of achievement. The NICE Quality Standards team will be responsible for the development of the quality measures.

c. Identify key areas for improvement in current service user experience.

d. Identify key areas for further research that are likely to improve our understanding of how to measure and improve the experience of care within adult mental health services.

5.4 Methods

a. The National Collaborating Centre for Mental Health will develop a framework of service user experience.

b. A number of frameworks and reviews of frameworks already exist, developed and tested through differing approaches. The principles of these frameworks will be considered but a comparison will not be made between them.

c. The Guideline Development Group will consider these frameworks and their common themes, and agree a list of key themes from which recommendations will be developed. The quality standards will be framed by these recommendations. This process will be informed by the information gathered in 4.4 e and f.

d. NICE will also use the framework to develop quality measures.

e. A high level literature review will be conducted to identify and synthesise qualitative and quantitative studies that have examined service user experience and interventions to improve it.

f. NICE clinical guidelines and public health guidance published in the past 5 years will be reviewed to identify questions, evidence reviews and recommendations that the Guideline Development Groups considered important for improving service user experience.

g. The GDG will identify domains which underpin the experience of care for which quality standards will be developed. Descriptive statements will be developed for these domains. These are likely to be domains for which recommendations have already been included in NICE guidelines and where there is an evidence base to inform quality standards. The GDG will decide on those areas where the NCCMH will develop reviews to inform quality standards.

h. The guidance, and the quality statements and measures developed for the quality standard, will be structured by a care pathway through adult mental health including compulsory treatment under the Mental Health Act.

i. Stakeholders will be invited to comment on the draft recommendations and quality standard through a formal consultation.

5.5 Economic aspects

Developers will take into account both the clinical and cost effectiveness of interventions. If interventions are identified that may improve service user experience, a cost impact analysis will be undertaken.

If there is sufficient evidence to offer a choice between alternative interventions, then a cost effectiveness analysis will be undertaken using existing NICE methods. The preferred unit of effectiveness for this will be the quality-adjusted life year (QALY), and the costs considered will usually be only from an NHS and personal social services (PSS) perspective.

5.6 Status

5.6.1 Scope

This is the final scope.

5.6.3 Timing

The development of the guidance recommendations will begin in January 2011. Publication of the guidance and quality standard is expected in October 2011.

6 Related NICE guidance

NICE is currently developing the following related guidance (details available from the NICE website):

- Patient experience in generic terms. NICE guidance and quality standard. Publication expected October 2011.

APPENDIX 2: DECLARATIONS OF INTERESTS BY GDG MEMBERS

With a range of practical experience relevant to service user experience in the GDG, members were appointed because of their understanding and expertise in this area.

To minimise and manage any potential conflicts of interest, and to avoid any public concern that commercial or other financial interests have affected the work of the GDG and influenced guidance, members of the GDG must declare as a matter of public record any interests held by themselves or their families which fall under specified categories (see below). These categories include any relationships they have with the healthcare industries, professional organisations and organisations for service users and their families/carers.

Individuals invited to join the GDG were asked to declare their interests before being appointed. To allow the management of any potential conflicts of interest that might arise during the development of the guideline, GDG members were also asked to declare their interests at each GDG meeting throughout the guideline development process. The interests of all the members of the GDG are listed below, including interests declared prior to appointment and during the guideline development process.

Categories of interest

Paid employment

Personal pecuniary interest: financial payments or other benefits from either the manufacturer or the owner of the product or service under consideration in this guideline, or the industry or sector from which the product or service comes. This includes holding a directorship, or other paid position; carrying out consultancy or fee paid work; having shareholdings or other beneficial interests; receiving expenses and hospitality over and above what would be reasonably expected to attend meetings and conferences.

Personal family interest: financial payments or other benefits from the healthcare industry that were received by a member of your family.

Non-personal pecuniary interest: financial payments or other benefits received by the GDG member's organisation or department, but where the GDG member has not personally received payment, including fellowships and other support provided by the healthcare industry. This includes a grant or fellowship or other payment to sponsor a post, or contribute to the running costs of the department; commissioning of research or other work; contracts with, or grants from, NICE.

Personal non-pecuniary interest: these include, but are not limited to, clear opinions or public statements you have made about individuals with psychosis and substance misuse problems, holding office in a professional organisation or advocacy group with a direct interest in psychosis and substance misuse, other reputational risks relevant to psychosis and substance misuse.

Guideline Development Group - Declarations of interest	
Dr Mike Crawford (chair)	
Employment	Reader in Mental Health Services Research, Imperial College London
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Non-personal non-pecuniary interest	None
Action Taken	None
Dr Diana Rose (chair)	
Employment	Reader in User-Led Research, Co-director Service User Research Enterprise (SURE), Institute of Psychiatry, King's College, London
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Non-personal non-pecuniary interest	None
Action Taken	None
Dr. Tim Kendall	
Employment	Director, NCCMH Medical Director, Sheffield Health and Social Care Trust Consultant Adult Psychiatrist
Personal pecuniary interest	Grant holder for £1.44 million per year (approx) from NICE for guidelines work. Work with NICE International. Undertake some research into mental health, and the mental health workforce for DH, Royal College of Psychiatrists and the academy of medical royal colleges.
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Dr Janice Allister	
Employment	GP, Peterborough
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	I am the Royal College of General Practitioners Child Safeguarding Lead.(unpaid).

	My husband is the Bishop of Peterborough I am a member of the Church of England (no subscription); the Balint Society, the Primary Care Child Safeguarding Forum and the Christian Medical Fellowship. For the later societies I pay subscriptions.
Action Taken	None
Ms Siobhan Armstrong	
Employment	Lead Nurse-Intensive Case Reviews, Newcastle and North Tyneside Primary Care Trusts and Northumberland Care Trust
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Mr Adam Black	
Employment	Representing service user and carer interests
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Ms Beverley Costa	
Employment	CEO and clinical director, Mothertongue counselling and listening service
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	As the CEO of Mothertongue multi- ethnic counselling service I have an interest in culturally sensitive mental health provision and in improving the quality of Mental health interpreting commissioning , provision and regulation.
Action Taken	None
Dr Jane Cronin-Davis	
Employment	Senior Lecturer, Occupational Therapist, York St John University
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Ms Jan Cubison	
Employment	Clinical Service Manager, Sheffield Perinatal Mental Health Service, Sheffield Health & Social Care Foundation Trust
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None

Action Taken	None
Ms Victoria Green	
Employment	Representing service user and carer interests
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Ms Mary Nettle	
Employment	Mental Health User Consultant
Personal pecuniary interest	I am paid lay member for a number of boards/committees: • The Mental Health Act commission now part of the Care Quality Commission - ensuring patients rights are upheld under the Mental Health Act 1983 revised 2007. • The Health Technology Assessment panel assessing research proposals for psychological and community therapies. • The Involve standing group. • Service User Recovery Forum and Policy Committee of Royal College of Psychiatrists. • Service Users in Research for MHRN (Mental Health Research Network) as HOE Heart of England Hub representative • Worcestershire Mental Health Partnership NHS Trust supporting workforce to implement Big Recovery programme. • FRA (Fundamental Rights Agency) as member of advisory board on research project for ENUSP (European Network of Users (ex) users and Survivors of Psychiatry) • MHE (Mental Health Europe) - evaluating their work under the EU Progress Project.
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Mr Leroy Simpson	
Employment	Representing service user and carer interests
Personal pecuniary interest	None
Personal family interest	None

Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Dr Clive Travis	
Employment	Representing service user and carer interests
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	I am interested in mitigating against suicide caused by drug side effects, and also in incentives, personal budgets and universal benefits.
Action Taken	None
Mr Peter Woodhams	
Employment	Carer
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
NCCMH Staff	
Mr Benedict Anigbogu	
Employment	Health Economist, NCCMH
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Ms. Marie Halton	
Employment	Research Assistant, NCCMH
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Ms. Katherine Leggett	
Employment	Project Manager
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Ms Melinda Smith	
Employment	Research Assistant, NCCMH
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None

Personal non-pecuniary interest	None
Action Taken	None
Ms. Sarah Stockton	
Employment	Senior Information Scientist, NCCMH
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Dr Clare Taylor	
Employment	Editor, NCCMH
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None
Dr. Craig Whitttington	
Employment	Senior Systematic Reviewer, NCCMH
Personal pecuniary interest	None
Personal family interest	None
Non-personal pecuniary interest	None
Personal non-pecuniary interest	None
Action Taken	None

APPENDIX 3: SPECIAL ADVISORS TO THE GUIDANCE DEVELOPMENT GROUP

Joanna Goodrich
Glenn Robert
Laura Griffith
Sarah Carr

APPENDIX 4: STAKEHOLDERS AND EXPERTS WHO SUBMITTED COMMENTS IN RESPONSE TO THE CONSULTATION DRAFT OF THE GUIDANCE

Stakeholders

Experts

1 APPENDIX 5: REVIEW PROTOCOLS

	Key problems in current service user experience
Review question(s)	RQ 1.1 For people who use adult NHS mental health services, what are the key problems associated with their experience of care?
Secondary question(s)	RQ 1.2 For people who use adult NHS mental health services, what would help improve the experience of care?
Objectives	To identify the key problems in current service user experience of NHS mental health services
Criteria for considering studies for the review	
Types of participants (population)	All people who use NHS inpatient and community adult mental health services
Intervention	Inpatient and community adult mental health services
Comparator	N/A
Critical outcomes	Key problems associated with the experience of care (including examples of poor experience)
Study design	Qualitative research and surveys/complaints about service user experience
Include unpublished data?	Yes
Restriction by date?	No
Minimum sample size	N/A
Study setting	Community and inpatient adult mental health services
Search strategy	Search all existing NICE mental health guidelines for qualitative research and surveys of service user experience (including complaints from service users)
Other resources	• http://www.healthtalkonline.org/ • Care Quality Commission Surveys: • Community mental health survey (2010): http://www.nhssurveys.org/surveys/511 • Inpatient Service User Survey (2009): http://www.nhssurveys.org/surveys/520 • Survey conducted by MIND (Rogers A, Pilgrim D, Lacey R (1993) *Experiencing Psychiatry: User Views of Services*. Macmillan/ Mind Publications, London.) • Quality Care commission report: http://www.cqc.org.uk/_db/_documents/20100315_Mental_health_5_year_action_plan_FINAL.pdf
The review strategy	1. Narrative synthesis of reviews of qualitative research published in existing NICE mental health guidelines: • Alcohol dependence and harmful alcohol use (includes a review of published qualitative studies) • Antisocial personality disorder (ASPD) (includes review of studies exploring the views and experiences of people with personality disorder) • Bipolar disorder (includes review of qualitative literature and surveys) • Borderline personality disorder (BPD) (includes review of qualitative literature) • Depression update (includes review of qualitative literature) • Drug misuse: psychosocial interventions (DMP) (includes overview of 'treatment journeys' based both on interviews conducted by Salter and colleagues (2005) • Psychosis with substance abuse (PSM) (includes review of qualitative

	research) - Self-harm – longer term management (under development) The narrative synthesis will utilise the matrix of service user experience (see Appendix 6) to help categorise themes. Step 1: Characterise the evidence base from each guideline using a study characteristics table - this will be used to provide an overview of the type of analysis done for each guideline (include: the guideline search strategy, the eligibility criteria, the number of studies included, the size and design of the included studies, the location [country & setting] of each included study, plus any other relevant details) Step 2: For each guideline, extract all themes into the relevant matrix (1 per guideline). Then highlight relevant themes. Step 3: Transfer relevant themes from each matrix into text (use a subsection for each point on the pathway, with sub-headings for each domain). Step 4: Write an overall narrative summary of the key themes for each point on the pathway (triangulated across guidelines and evidence type). Step 5: Draft the chapter including a subsection for step 1, and then subsections for each key point on the pathway (the narrative summaries produced at step 4 will appear at the end of each of these subsections). 2. Narrative synthesis of qualitative analyses conducted for the current guidance (Healthtalkonline – Experience of psychosis) or conducted for previous NICE mental health guidelines using healthtalkonline or similar website (Depression/DCHP/PSM/DMP). 3. Analysis of NHS surveys of mental health service user experience. Where gaps in the evidence base were identified, other survey results (e.g., Survey conducted by MIND of users' views of services). 4. Triangulation of common themes from steps 1-3.
Additional notes	Problems clearly associated with treatment in primary care will not be included. Problems to do with prison services will not be included.

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	Interventions for improving service user experience
Review question(s)	RQ 2.1 For people who use adult NHS mental health services, do interventions that aim to improve the experience of care, when compared to standard care, produce meaningful improvements in the experience of care?
Secondary question(s)	RQ 2.2 For people who use adult NHS mental health services, what service-level team configurations, when compared to standard care, improve the experience of care? RQ 2.3 For team configurations shown to improve the experience of care, what are the common characteristics that appear to be associated with good service user experience?
Objectives	To determine whether interventions aiming to improve the experience of users of mental health services produce meaningful improvements in the experience of care.
Criteria for considering studies for the review	
Types of participants (population)	All people who use inpatient and community adult mental health services
Intervention	Interventions that aim to improve the experience of care, including: Interventions aiming to change health provider behaviour (e.g., interventions for healthcare professionals that aim to promote person-centred approaches in clinical consultations) Interventions aiming to improve the relationship between the service user and healthcare professional (e.g., shared decision making interventions) Service-level team configurations that have been recommended for use in a NICE mental health guideline (General care: community mental health teams, crisis resolution and home treatment teams, the care programme approach, acute day hospital care; Specialist services: assertive outreach, early intervention services)
Comparator	Standard care or any other control
Critical and important outcomes	Any valid measure of service user experience of care (e.g., Consumer Assessment of Healthcare Providers and Systems Hospital survey[14] [15] [16]), satisfaction, or evaluation of care.
Other outcomes (not regarded as critical or important)	Measures of quality of life, number of people leaving the study early for any reason.
Study design	Any
Include unpublished data?	Yes
Restriction by date?	1985 (based on advice from the Chairs, research conducted before 1983-85 is unlikely to be applicable to the modern healthcare service)
Minimum sample size	N/A
Study setting	Community and inpatient adult mental health services

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[14] Darby C, Hays RD, Kletke P. Development and evaluation of the CAHPS hospital survey. Health Serv Res 2005;40: 1973-6.

[15] Goldstein E, Farquhar 5. M, Crofton C, Darby C, Garfinkel S. Measuring hospital care from the patients' perspective: an overview of the CAHPS Hospital Survey
development process. Health Serv Res 2005;40:1977-95.

[16] Cleary, P. 1999. ''The Increasing Importance of Patient Surveys.'' British Medical Journal 319: 720–1.

Search strategy	Reviews cited by Goodrich & Cornwell (2008) [17] or included in the Cochrane Consumers and Communication Group or the Cochrane Effective Practice and Organisation of Care Group list of reviews will be assessed for eligibility and included where relevant. Additionally, the following websites will be checked for eligible reviews: • Health Issues Centre • The Studer Group • Planetree • The Picker Institute • The Commonwealth Fund • The Schwartz Center • Implementation Science • Canadian Agency for Drugs and Technologies in Health
Searching other resources	• Reference lists of all identified papers will be searched. • The GDG will be asked if they know of any evidence not identified during search. • Experts identified during the search/GDG meeting will be contacted. • Snowballing/reference tracking. • Grey literature searches. • Hand searching key journals.
Existing reviews	
Updated	Coulter A, Ellins J (2006). Patient-focused Interventions: A review of the evidence. London: Health Foundation.
Not updated	Goodrich & Cornwell (2008)
General search filter used	Service User Experience
Question specific search filter	TBC
Amendments to filter/ search strategy	TBC
The review strategy	A simplified matrix (based on Appendix 6) will be used to classify existing systematic reviews that meet minimum criteria for methodological quality. Reviews of people with mental health problems will be used where available, otherwise studies of people without mental health problems will be utilised. A narrative synthesis will then be used to summarise the evidence across reviews.

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[17] Extract from report: "A significant proportion of the evidence on patients' experience of care, along with descriptive reports of interventions and 'promising practice', is published in non-peer reviewed nursing, medical and management journals. In recent years, the nursing press in particular has been intensely preoccupied with debates about patients' experience, the causes of substandard nursing care (Corbin 2008, Maben 2008), and campaigns to protect the dignity of patients (Royal College of Nursing 2008, Levenson 2007). In addition, important information about practice, guidance packs and tool kits can be found on the websites of organisations dedicated to health care improvement such as the NHS Institute for Innovation and Improvement (www.institute.nhs.uk), the Institute for Healthcare Improvement (www.ihi.org), the Commonwealth Foundation (www.commonwealthfoundation.com) and more specialised sites such as those of Marie Curie Palliative Care Institute (for the Liverpool Care Pathway – www.mcpcil.org.uk/ liverpool_care_pathway) and campaigning organisations and patients' groups (eg, www.helptheaged.org.uk, www.bgs.org.uk/campaigns/dignity.htm)."

Additional assessments	TBC

APPENDIX 6: MATRIX OF SERVICE USER EXPERIENCE

Non-acute care

Dimensions of person-centred care (adapted from Picker Institute, 2009)		**Key points on the pathway of care**			**Themes that apply to all points on the pathway**
		Non-acute care			
		Access	**Assessment**	**Community care (including discharge back to primary care)**	
The relationship between individual service users & professionals	Involvement in decisions & respect for preferences				
	Clear, comprehensible information & support for self-care				
	Emotional support, empathy & respect				
The way that services and systems work	Fast access to reliable health advice				
	Effective treatment delivered by trusted professionals				
	Attention to physical & environmental needs				
	Involvement of, & support for, family & carers				
	Continuity of care & smooth transitions				
Other themes					

Acute care (not under the Mental Health Act)

Dimensions of person-centred care (adapted from Picker Institute, 2009)		**Key points on the pathway of care**			**Themes that apply to all points on the pathway**
		Acute care			
		Assessment and referral in crisis	**Hospital care**	**Discharge/ transfer of care**	
The relationship between individual service users & professionals	Involvement in decisions & respect for preferences				
	Clear, comprehensible information & support for self-care				
	Emotional support, empathy & respect				
The way that services and systems work	Fast access to reliable health advice				
	Effective treatment delivered by trusted professionals				
	Attention to physical & environmental needs				
	Involvement of, & support for, family & carers				
	Continuity of care & smooth transitions				
Other themes					

Acute care (under the Mental Health Act)

Dimensions of person-centred care (adapted from Picker Institute, 2009)		**Key points on the pathway of care**		**Themes that apply to all points on the pathway**
		Assessment/ admission under the MHA	**Receiving compulsory treatment under the MHA**	
The relationship between individual service users & professionals	Involvement in decisions & respect for preferences			
	Clear, comprehensible information & support for self-care			
	Emotional support, empathy & respect			
The way that services and systems work	Fast access to reliable health advice			
	Effective treatment delivered by trusted professionals			
	Attention to physical & environmental needs			
	Involvement of, & support for, family & carers			
	Continuity of care & smooth transitions			
Other themes				