4-year surveillance (2016)
Service user experience in adult mental health (2011) NICE guideline CG136

Appendix A: Summary of new evidence from surveillance

Care and support across all points on the care pathway

Recommendations derived from this area

Relationships and communication

1.1.1 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 trusting, supportive, empathic and non-judgemental relationships as an essential part of care. [QS]

1.1.2 When working with people using mental health services:
   - aim to foster their autonomy, promote active participation in treatment decisions and support self-management [QS]
   - maintain continuity of individual therapeutic relationships wherever possible
   - offer access to a trained advocate.

1.1.3 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 (such as using pictures, symbols, large print, Braille, different languages or sign language) if required.

1.1.4 When working with people 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 (that is, which health and social care professionals have access to information about their diagnosis and its treatment and in what circumstances this may be shared with others).

Providing information

1.1.5 When working with people using mental health services:
• 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 text from NICE’s information for the public
• ensure that comprehensive information about other support groups, such as third sector, including voluntary organisations, is made available.

1.1.6 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
• able to discuss and actively support service users to engage with these resources.

Avoiding stigma and promoting social inclusion

1.1.7 When working with people using mental health services:
• take into account that stigma and discrimination are often associated with using mental health services [QS]
• be respectful of and sensitive to service users’ gender, sexual orientation, socioeconomic status, age, background (including cultural, ethnic and religious background) and any disability
• be aware of possible variations in the presentation of mental health problems in service users of different genders, ages, cultural, ethnic, religious or other diverse backgrounds.

1.1.8 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 different cultural, ethnic, religious or other diverse backgrounds
• explaining the possible causes of different mental health problems, and care, treatment and support options
• addressing cultural, ethnic, religious or other differences in treatment expectations and adherence
• addressing cultural, ethnic, religious or other beliefs about biological, social and familial influences on the possible causes of mental health problems
• conflict management and conflict resolution.

1.1.9 Health and social care providers’ boards should work with local authorities and all other local organisations with an interest in mental health (including social services, other hospitals, third sector, including voluntary, organisations, local press and media groups, and local employer organisations) 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. [QS]

Decisions, capacity and safeguarding

1.1.10 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.

1.1.11 Develop advance statements and advance decisions with the person using mental health services if they wish to do so, 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. [QS]

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

1.1.13 Consider service users for assessment according to local safeguarding procedures for vulnerable adults if there are concerns regarding exploitation or self-care, or if they have been in contact with the criminal justice system.

Involving families and carers

1.1.14 Discuss with the person using mental health services if and how they want their family or carers to be involved in their care. Such discussions should take place at intervals to take account of any changes in circumstances, and should not happen only once. As the involvement of families and carers can be quite complex, staff should receive training in the skills needed to negotiate and work with families and carers, and also in managing issues relating to information sharing and confidentiality.

1.1.15 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
• ensure 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.

1.1.16 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 text from NICE’s information for the public
• statutory and third sector, including voluntary, local support groups and services specifically for families and carers, and 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.

1.1.17 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 text from NICE's information for the public
• give the family or carers information about statutory and third sector, including 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.
• bear in mind that service users may be ambivalent or negative towards their family for many different reasons, including as a result of the mental health problem or as a result of prior experience of violence or abuse.

1.1.18 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:

• information about childcare to enable them to attend appointments, groups and therapy sessions
• hospital care in local mother and baby units for women in the late stages of pregnancy and within a year of childbirth
• a family room or space in inpatient units where their children can visit them.

Engaging service users in improving care

1.1.19 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.

1.1.20 Health and social care providers should consider employing service users to be involved in training teams of health and social care professionals and supporting staff (such as receptionists, administrators, secretaries and housekeeping staff) in ‘person-centred 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. [QS] Service users themselves should be provided with training and supervision to undertake this role.

1.1.21 Managers of health and social care providers should consider employing 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. [QS]

1.1.22 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:

• include data that allow direct comparisons of the experience of care according to gender, sexual orientation, socioeconomic status, age, background (including cultural, ethnic and religious background) and disability
• include analyses of data from multiple sources, particularly data collected by service users monitoring service user experience and complaints
• be routinely communicated to the health and social care providers' board. [QS]

Surveillance decision

This review question should not be updated.

2-year Evidence Update

Non-verbal communication

A systematic review and meta-analysis\(^1\) included 26 studies of interactions between patients and any healthcare professionals to address a physical or mental health problem. The study demonstrates the importance of healthcare professionals’ non-verbal communication skills – particularly listening,
warmth and avoiding negativity – in achieving service user satisfaction.

**Black Caribbean women’s perceptions of postnatal mental health services**

A qualitative study\(^2\) from the northwest of England that explored black Caribbean women’s views on factors affecting the under-representation of this group among users of postnatal mental health services was identified. Most women reported that their maternity care was less than ideal, with some indicating poor experiences with hospital midwives and doctors, but better experiences with community midwives. If women perceived a lack of compassion from their healthcare professionals, they were less likely to engage with mental health services or with general health services. Trusting relationships with sympathetic healthcare staff were considered necessary for people to feel able to disclose psychological problems. Perceptions that healthcare staff such as midwives or health visitors are too busy to address psychological needs were also barriers to seeking help. Furthermore, women perceived that healthcare staff seemed to focus on the infant at the mother’s expense, and that interactions were protocol driven and formulaic. Women considered an ideal service to be capable of addressing all needs, from support for people with mild emotional distress to treatment for those with diagnosed mental health problems. Women said care should be delivered in mixed ethnic groups, as opposed to either groups of black women only, or individual treatment. They additionally felt that drug treatments were useful for severe symptoms or if psychological treatments failed. However, they suggested that GPs are interested only in prescribing rather than in providing social support, which reinforced their reluctance to consult their GP. The results from this sample of women may not be generalisable to the rest of the UK outside the area of northwest England in which the study was conducted, or to other ethnic groups. Overall, this study suggests that perceptions of healthcare professionals’ lack of compassion or lack of time to deal with postnatal psychological problems may be barriers to seeking help in black Caribbean women.

**Trust, choice and the power balance in treatment**

A qualitative study\(^2\) in the UK of the experiences and attitudes towards mental health care in people who had received compulsory inpatient treatment for psychosis was identified. In terms of factors enhancing trust, participants noted that trust depends on both the service user and the clinician. Although service users valued clinicians’ professional expertise, they also appreciated clinicians with a caring or kind attitude. Continuity of care was another important theme, which included having a regular or reliable clinician who delivered on promises. Trust was additionally enhanced when clinicians listened to the service user, were honest and positive about the future, or related to the service user by disclosing small details of personal information. Trust was undermined by a history or perception of coercion, perceptions of neglect by services when unwell, clinicians relying only on scientific knowledge, and the nature of the illness itself. Choice in care was enhanced by service users’ knowledge of their illness, time spent with healthcare staff, and having treatments other than medication available. Factors that undermined choice of care were that some service users did not think about choice, or lacked information about choice. The nature of the illness itself, subsequent lack of confidence in decisions, and history or perception of coercion also negatively affected service users’ choice. Service users generally felt that when they had been compulsorily detained, it was necessary, but that consultation with carers and other professionals about compulsory detention may have been worthwhile. Other factors affecting the power balance were service users’ knowledge of their mental health and sharing responsibility for their health with the clinician. The power balance was negatively affected by perceptions of neglect by services when unwell, history or perception of coercion, and the nature of the illness itself. Minor factors that undermined service users’ power were clinicians straying into areas that service users thought they should not, and perceptions that other service users abused their power. The findings from this study suggest that continuity of care is important for service users to build a trusting relationship with their mental healthcare professionals. Improving service users’ knowledge about their illness may help them to actively participate in treatment decisions and maintain their autonomy.

**Relationships and treatment adherence**
A qualitative study from the UK of perspectives of treatment adherence in people who had experienced compulsory drug treatment after partial or complete non-adherence to drug treatment was identified. The pathway of care started when the service user needed mental health care but refused treatment. Several caregivers reported that mental health services were unresponsive to the service user's needs until an emergency admission was necessary. After a compulsory admission, service users felt that they lost their voice and identity and became defined by their mental illness. At that point, if the service user did not yet recognise that their mental function was impaired, they may have recognised that healthcare professionals reward compliant behaviour and the service user may have appeared to be compliant. One participant reported mimicking behaviour that professionals perceived as 'well', and avoiding talking about her issues. Other service users reported partial adherence because the side effects of drug treatment did not allow them to lead normal lives. After repeated relapses, service users reluctantly accepted that they had a mental health problem that needed treatment, including medication. Healthcare professionals who had a collaborative attitude to treatment, such as trying different medication to avoid side effects, were appreciated by service users and felt to enable adherence. Conversely, a non-collaborative attitude towards care from healthcare professionals was likely to result in poor adherence. Non-collaborative care included not giving adequate information, reluctance to listen to service users’ genuine concerns about side effects or over-medication, or treating service users like a nuisance or problem. The results of this study suggest that in service users with a history of compulsory admissions because of non-adherence to treatment, having a collaborative relationship with healthcare professionals may lead to improved attitudes towards future adherence to treatment.

Engaging service users in improving care

A study of a brief self-report measure of service users’ experience of inpatient care, ‘Views on Inpatient Care (VOICE)’ was identified. In the development phase of the study, the inter-rater reliability for coding of information from the focus groups was 97–99%. In the first set of feasibility tests (n=40), 98% of participants found the measure easy to understand and complete. In the second set of feasibility tests (n=106), 82% of participants found VOICE to be an appropriate length, taking 5–15 minutes to complete. Some questions were upsetting for 6 participants, and 2 disliked completing the tool. No significant difference between test–retest scores was seen, and Pearson’s coefficient showed significant correlation between VOICE scores and scores on the Service Satisfaction Scale (r=0.82, p<0.001). Participants who had been admitted compulsorily had significantly worse perceptions of care than others (p<0.001), which remained significant after multivariate analysis. This study suggests that the questionnaire ‘VOICE’ may be easy for service users to complete and understand, and has good validity and internal and test–retest reliability.

4-year surveillance summary

An updated Cochrane review on interventions for providers to promote a patient-centred approach in clinical consultations included 29 new randomised controlled trials. The Cochrane concluded the new evidence confirmed the support for the impact of intervention on consultation processes. The original Guideline Committee stated that there was limited evidence in mental health services since the majority of new studies were not in mental health service this updated review is unlikely to impact the guideline recommendations.

Another updated Cochrane review include 33 new studies on decision aids for people facing health treatment or screening decisions. The results around reducing decisional conflict and increasing patient knowledge remain similar to those in the previous review. However, there now appears to be additional data indicating that decision aids have a positive effect on patient-practitioner communication. The review also reports on secondary outcomes including the effect of decision aids on choice of major surgery and other health decisions such as prostate antigen screening and menopausal hormone therapy. There was no conclusive data on anxiety, condition-specific health outcomes or adherence to treatment.

An update of a third Cochrane review on the effects of interpersonal education included nine new studies. The conclusions of the Cochrane review have not changed since the original Cochrane review.
A pilot study\(^6\) on service users’ experiences of interpreters in psychological therapy was highlighted by a topic expert. The study conducted 7 interviews and showed three themes from the interviews which were: a negative impact on therapy, the interpreter as conduit for therapy and the therapist and interpreter jointly demonstrating a shared enterprise. The study concluded that further research is needed.

**Impact statement**
The evidence identified at the 2 year review and the updated Cochrane reviews identified at the 4 year review is supportive of current guidance and is unlikely to impact on guideline recommendations on care and support across all points on the care pathway. The pilot study on access and communication needs of multilingual patients identified had a small sample size and therefore is unlikely to impact current guideline recommendations at this time.

**New evidence is unlikely to change guideline recommendations**

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**Access to care**

**Recommendations derived from this area**

1.2.1 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 a face-to-face appointment with a professional in mental health services taking place within 3 weeks of referral
- they 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. [QS]

1.2.2 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 where available, and different options about how to get 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 require anything to support their attendance (for example, an interpreter, hearing loop, wider access)
- give a number to ring if they have problems getting to the appointment or wish to change it.

1.2.3 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. [QS]

1.2.4 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.

1.2.5 Local mental health services should work with primary care and local third sector, including voluntary, organisations to ensure that:

- all people with mental health problems have equal access to services based on clinical need and irrespective of gender, sexual orientation, socioeconomic status, age, background (including cultural, ethnic and religious background) and any disability
- services are culturally appropriate. [QS]

**Surveillance decision**

This review question should not be updated.

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**2-year Evidence Update**

**Collaborative care**

A systematic review and meta-analysis\(^1\) of collaborative care models for treating depression in primary care. Overall, the improvement in depression symptoms, compared with no or minimum collaborative care, was considered to be meaningful for improving health (Hedges g=0.34, 95% CI 0.25 to 0.43). Collaborative care was also associated with clinically significant improvements in adherence, response, remission, recovery and satisfaction with care (all p<0.05). Quality of life including functional status was associated with a small effect. In terms of the type of organisation conducting the collaborative care, community-based organisations were associated with the largest improvement in symptoms of depression (Hedges g=0.82), and US Veterans Affairs organisations had the lowest (Hedges g=0.11). Among the different types of healthcare professionals acting as case managers, nurse case managers had the greatest effect on symptoms of depression (Hedges g=0.37). Socioeconomic status did not seem to affect results. The included studies may have had selection bias if they recruited only participants with severe or major depression, because initial severe symptoms increase the potential amount of improvement. Conversely, if participants had only minor symptoms, the chances of remission or recovery may have been increased. No evidence of publication bias was noted. These results suggest that multiprofessional care coordinated by a case manager may result in improvements in symptoms of depression, especially if the case manager is a nurse or is based in the community.

**4-year surveillance summary**

An updated Cochrane review\(^6\) on interventions for providers to promote a patient-centred approach in clinical consultations included 29 new randomised controlled trials. The Cochrane concluded the new evidence confirmed the support for the impact of intervention on consultation processes. The original Guideline Committee stated that there was limited evidence in mental health services since the majority of new studies were not in mental health service this updated review is unlikely to impact the guideline recommendations.

Another updated Cochrane review\(^7\) include 33 new studies on decision aids for people facing health treatment or screening decisions. The results around reducing decisional conflict and increasing patient knowledge remain similar to those in the previous review. However, there now appears to be additional data indicating that decision aids have a positive effect on patient-practitioner communication. The review also reports on secondary outcomes including the effect of decision aids on choice of major surgery and other health decisions such as prostate antigen screening and menopausal...
hormone therapy. There was no conclusive data on anxiety, condition-specific health outcomes or adherence to treatment.

An update of a third Cochrane review on the effects of interpersonal education included nine new studies. The conclusions of the Cochrane review have not changed since the original Cochrane review.

**Impact statement**
The new evidence is supportive of current guidance and is unlikely to impact on guideline recommendations on access to care.

**New evidence is unlikely to change guideline recommendations**

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**Assessment**

**Recommendations derived from this area**

1.3.1 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.

1.3.2 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.

1.3.3 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 in an accessible format about any diagnosis given
- give information about different treatment options, including drug and psychological treatments, and their side effects, to promote discussion and shared understanding
- offer support after the assessment, particularly if sensitive issues, such as childhood trauma, have been discussed. [QS]

1.3.4 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.

1.3.5 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.
1.3.6 Ensure that if a service user needs to wait before an assessment, this is for no longer than 20 minutes after the agreed appointment time; explain the reasons for any delay. [QS]

1.3.7 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.

1.3.8 Inform service users of their right to a formal community care assessment (delivered through local authority social services), and how to access this.

1.3.9 Inform service users how to make complaints and how to do this safely without fear of retribution.

**Surveillance decision**

This review question should not be updated.

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**2-year Evidence Update**

**Assessment of quality of life**

A randomised controlled open-label trial in people with schizophrenia to investigate the effect that feedback to clinicians on quality-of-life assessment had on service users’ satisfaction with care was identified. Participants in the groups having quality-of-life assessments completed self-administered questionnaires before the standard psychiatric assessment was done. In the clinician feedback group, data on current and previous quality-of-life assessments and population norms were provided to clinicians before the standard psychiatric assessment. Two-thirds of participants were men with mild schizophrenia, with a mean age of 41.1 years. Participants had a mean score on the Positive and Negative Syndrome Scale of 63.0, which the authors described as mild illness. At 6 months, the proportion of people who rated their global satisfaction as ‘high’ was significantly different in the quality-of-life feedback group (72.5%) compared with the quality-of-life assessment group (45.2%) and the standard psychiatric assessment group (67.5%, p< 0.025). Similar results were seen for satisfaction with the care structure (77.5%, 50.0% and 70.0% respectively, p< 0.025). Results for satisfaction with staff were not significant. The authors postulated that giving clinicians access to quality-of-life information provided them with useful intelligence and led to better communication between clinicians and service users. However, the study did not measure how the clinicians used the quality-of-life data in consultations with service users. Additionally, the lowest satisfaction was seen in the group that had quality-of-life assessments but no feedback to clinicians. This could mean that completing the quality-of-life assessment may increase service users’ expectations of care with regard to quality of life. If clinicians do not then take account of quality of life in subsequent consultations, service users may be more dissatisfied than if they had no quality-of-life assessment. The evidence suggests that adding a quality-of-life assessment to standard psychiatric assessment may increase service users’ global satisfaction if treating clinicians are provided with the results and a comparison of the score against population norms. However, assessing quality of life without considering the results clinically against population norms could result in potential harm to the service user.

**4-year surveillance summary**

An updated Cochrane review on interventions for providers to promote a patient-centred approach in clinical consultations included 29 new randomised controlled trials. The Cochrane concluded the new evidence confirmed the support for the impact of intervention on consultation processes. The original Guideline Committee stated that there was limited evidence in mental health services since the majority of new studies were not in mental health service this updated review is unlikely to impact the guideline recommendations.

Another updated Cochrane review include 33 new studies on decision aids for people facing health treatment or screening decisions. The results around reducing decisional conflict and increasing patient knowledge remain similar to
those in the previous review. However, there now appears to be additional data indicating that decision aids have a positive effect on patient-practitioner communication. The review also reports on secondary outcomes including the effect of decision aids on choice of major surgery and other health decisions such as prostate antigen screening and menopausal hormone therapy. There was no conclusive data on anxiety, condition-specific health outcomes or adherence to treatment.

An update of a third Cochrane review on the effects of interpersonal education included nine new studies. The conclusions of the Cochrane review have not changed since the original Cochrane review.

**Impact statement**
The new evidence is supportive of current guidance and is unlikely to impact on guideline recommendations on assessment.

**New evidence is unlikely to change guideline recommendations**

### Community care

**Recommendations derived from this area**

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

1.4.2 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
   - provide support to help the service user realise the plan
   - give the service user an up-to-date written copy of the care plan, and agree a suitable time to review it. [QS]

1.4.3 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.

1.4.4 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.

1.4.5 For people who may be at risk of crisis, 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:
   - possible early warning signs of a crisis and coping strategies
   - support available to help prevent hospitalisation
   - where the person would like to be admitted in the event of hospitalisation
   - the practical needs of the service user if they are admitted to hospital (for example, childcare or the care of other dependants, including pets) [QS]
   - details of advance statements and advance decisions (see 1.1.11)
   - whether and the degree to which families or carers are involved
   - information about 24-hour access to services
   - named contacts.
1.4.6 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.

1.4.7 Health and social care providers 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 unnecessarily
- do not undergo multiple assessments unnecessarily. [QS]

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

1.4.9 Mental health services should work with local third sector, including 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 these groups.

1.4.10 Mental health and social care professionals inexperienced in working with service users from different cultural, ethnic, religious and other diverse backgrounds should seek advice, training and supervision from health and social care professionals who are experienced in working with these groups.

**Surveillance decision**

This review question should not be updated.

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**2-year Evidence Update**

**Preference for psychological treatment**

A meta-analysis\(^\text{12}\) of 34 studies (n=90,483) to investigate people’s preferences towards psychological or drug treatment for mental health problems. Overall, 75% (95% CI 68% to 80%) of people preferred psychological treatment, which the authors noted was significantly different (p<0.0001) from the point of equal preference, that is 50% preferring psychological treatment and 50% preferring drug treatment. The preference for psychological treatment in people having treatment for a mental health problem was lower (69%, 95% CI 61% to 77%) but this was still significantly different to the point of equal preference (p<0.001). A funnel plot indicated possible publication bias from unpublished studies. However, the authors calculated that they would need to have missed 22 studies of 130 people in each preference group to discount their findings and concluded that the results were robust to publication bias. This evidence suggests that people seem to prefer psychological treatments to drug treatments for mental health problems, irrespective of whether or not they have experience of mental health problems.

**4-year surveillance summary**

An updated Cochrane review\(^\text{6}\) on interventions for providers to promote a patient-centred approach in clinical consultations included 29 new randomised controlled trials. The Cochrane concluded the new evidence confirmed the support for the impact of intervention on consultation processes. The original Guideline Committee stated that there was limited evidence in mental health services since the majority of new studies were not in mental health service this updated review is unlikely to impact the guideline recommendations.

Another updated Cochrane review\(^\text{7}\) include 33 new studies on decision aids for people facing health treatment or screening decisions. The results around reducing decisional conflict and increasing patient knowledge remain similar to those in the previous review. However, there now appears to be additional data indicating that decision aids have a positive effect on patient-practitioner communication. The review also reports on secondary outcomes including

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Appendix A: Summary of new evidence from 4-year surveillance of Service user experience in adult mental health (2011) NICE guideline CG136
the effect of decision aids on choice of major surgery and other health decisions such as prostate antigen screening and menopausal hormone therapy. There was no conclusive data on anxiety, condition-specific health outcomes or adherence to treatment.

An update of a third Cochrane review on the effects of interpersonal education included nine new studies. The conclusions of the Cochrane review have not changed since the original Cochrane review.

A survey of the level of service user involvement was highlighted by a topic expert. The survey had 302 responses and concluded the both staff and service users viewed service user involvement to be a good policy and it was becoming more widespread. The survey concluded further studies were needed.

Impact statement
The evidence identified at the 2 year surveillance review and the updated Cochrane reviews identified at the 4 year review is supportive of current guidance and is unlikely to impact on guideline recommendations on community care. The survey identified is unlikely to impact on current recommendations at this time since it concluded that further studies were needed into service user involvement.

New evidence is unlikely to change guideline recommendations

Assessment and referral in a crisis

Recommendations derived from this question

1.5.1 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 and advance statements or advance decisions if they have made them. Find out if they have an advocate and contact them if the service user wishes. Ask if the service user has a preference for a male or female health or social care professional to conduct the assessment, and comply with their wishes wherever possible.

1.5.2 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 1.3
- 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).

1.5.3 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. [QS]

1.5.4 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.

1.5.5 When a person is referred in crisis they should be seen by specialist mental health secondary care services within 4 hours of referral. [QS]
1.5.6 Health and social care providers should provide local 24-hour helplines, staffed by mental health and social care professionals, and ensure that all GPs in the area know the telephone number. [QS]

1.5.7 Health and social care providers should ensure that crisis resolution and home treatment teams are accessible 24-hours a day, 7 days a week, and available to service users in crisis regardless of their diagnosis. [QS]

1.5.8 To avoid admission, aim to:

- explore with the service user what support systems they have, including family, carers and friends
- 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.

1.5.9 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 person’s cooperation with treatment.

1.5.10 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.

1.5.11 Health and social care providers should support direct self-referral to mental health services as an alternative to accessing urgent assessment via the emergency department.

**Surveillance decision**

This review question should not be updated.

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**2-year Evidence Update**

No relevant evidence was identified.

**4-year surveillance summary**

An updated Cochrane review on interventions for providers to promote a patient-centred approach in clinical consultations included 29 new randomised controlled trials. The Cochrane concluded the new evidence confirmed the support for the impact of intervention on consultation processes. The original Guideline Committee stated that there was limited evidence in mental health services since the majority of new studies were not in mental health service this updated review is unlikely to impact the guideline recommendations.

Another updated Cochrane review include 33 new studies on decision aids for people facing health treatment or screening decisions. The results around reducing decisional conflict and increasing patient knowledge remain similar to those in the previous review. However, there now appears to be additional data indicating that decision aids have a positive effect on patient-practitioner communication. The review also reports on secondary outcomes including the effect of decision aids on choice of major surgery and other health decisions such as prostate antigen screening and menopausal hormone therapy. There was no conclusive data on anxiety, condition-specific health outcomes or adherence to treatment.
An update of a third Cochrane review\(^6\) on the effects of interpersonal education included nine new studies. The conclusions of the Cochrane review have not changed since the original Cochrane review.

**Impact statement**

The new evidence is supportive of current guidance and is unlikely to impact on guideline recommendations on assessment and referral in a crisis.

New evidence is unlikely to change guideline recommendations

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**Hospital Care**

**Recommendations derived from this question**

1.6.1 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. Ensure that the service user feels safe and address any concerns about their safety.

1.6.2 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.

1.6.3 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). [QS]

1.6.4 Commence formal assessment and admission processes within 2 hours of arrival.

1.6.5 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. If possible, this should include the named healthcare professional who will be involved throughout the person’s stay.

1.6.6 Offer service users in hospital:

- daily one-to-one sessions lasting at least 1 hour with a healthcare professional known to the service user
- regular (at least weekly) one-to-one sessions lasting at least 20 minutes with their consultant
- an opportunity to meet with a specialist mental health pharmacist to discuss medication choices and any associated risks and benefits. [QS]
1.6.7 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 paper and/or electronic record. Service users and their advocates should be encouraged to participate in discussions about their care and treatment, especially those relating to the use of the Mental Health Act (1983; amended 1995 and 2007). However, these meetings should not be used to see service users or carers as an alternative to their daily meeting with a known healthcare professional or their weekly one-to-one meeting with their consultant.

1.6.8 Health and social care providers 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.

1.6.9 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.[QS]

1.6.10 Ensure that service users have access to the internet and telephone during their stay in hospital.

1.6.11 All health and social care professionals who work in a hospital setting should be trained as a team to use the same patient-centred approach to treatment and care.

1.6.12 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.

1.6.13 Ensure that all service users in hospital have access to advocates who can regularly feed back to ward professionals any problems experienced by current service users on that ward. Advocates may be formal Independent Mental Health Advocate (IMHAs), or former inpatients who have been trained to be advocates for other service users not detained under the Mental Health Act (1983; amended 1995 and 2007).

1.6.14 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 and with specific physical health problems. Consider including service users in planning menus.

**Surveillance decision**

This review question should not be updated.

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**2-year Evidence Update**

No relevant evidence was identified.

**4-year surveillance summary**

An updated Cochrane review\(^6\) on interventions for providers to promote a patient-centred approach in clinical consultations included 29 new randomised controlled trials. The Cochrane concluded the new evidence confirmed the support for the impact of intervention on consultation processes. The original Guideline Committee stated that there was limited evidence in mental health services since the majority of new studies were not in mental health service this updated review is unlikely to impact the guideline recommendations.

Another updated Cochrane review\(^7\) include 33 new studies on decision aids for people facing health treatment or screening decisions. The results around reducing decisional conflict and increasing patient knowledge remain similar to those in the previous review. However, there now appears to be additional data indicating that decision aids have a positive effect on patient-practitioner communication. The review also reports on secondary outcomes including the effect of decision aids on choice of major surgery and other health decisions such as...
prostate antigen screening and menopausal hormone therapy. There was no conclusive data on anxiety, condition-specific health outcomes or adherence to treatment.

An update of a third Cochrane review on the effects of interpersonal education included nine new studies. The conclusions of the Cochrane review have not changed since the original Cochrane review.

One study highlighted by topic experts evaluated service user led organisations in England. The study concluded that service user led organisations have an ambiguous place in NHS trusts as they try to keep autonomy and also be an “acceptable voice to managers”

One study on the role of service user involvement in mental health services was highlighted by a topic expert. The study concluded that the current set up for service user governors can lead to conclusion in how issues of accountability and representation can be addressed.

**Impact statement**
The evidence identified at the 2 year surveillance review and the updated Cochrane reviews identified at the 4 year surveillance is supportive of current guidance and is unlikely to impact on guideline recommendations on hospital care. The studies on service user led organisations and service user involvement are unlikely to impact on current recommendations at the current time.

**New evidence is unlikely to change guideline recommendations**

### Discharge and transfer of care

#### Recommendations derived from this question

1.7.1 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, especially discharge, are discussed and planned carefully beforehand with the service user 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.

1.7.2 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.

1.7.3 Before discharge or transfer of care, discuss arrangements with any involved family or carers. Assess the service user's financial and home situation, including housing, before they are discharged from inpatient care.

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

1.7.5 When plans for discharge are initiated by the service, give service users at least 48 hours' notice of the date of their discharge from a ward.

1.7.6 When preparing a service user for discharge, give them information about the local patient advice and liaison service (PALS) and inform them they can be trained as an advocate or become involved in monitoring services if they choose.
Surveillance decision
This review question should not be updated.

2-year Evidence Update
No relevant evidence was identified.

Impact statement
The new evidence is supportive of current guidance and is unlikely to impact on guideline recommendations on discharge and transfer of care.

4-year surveillance summary
An updated Cochrane review\textsuperscript{16}, included an additional 13 new studies on discharge planning from hospital to home, however the conclusions of the Cochrane review have not changed.

Assessment and treatment under the Mental Health Act

Recommendations derived from this question

1.8.1 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:

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

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

1.8.3 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. Ask if the service user would like a family member, carer or advocate with them.

1.8.4 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.

1.8.5 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 (1983; amended 1995 and 2007)
- ensure they have access to an Independent Mental Health Advocate (IMHA).
1.8.6 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; provide information about the structure and likely speed of the appeals process.

1.8.7 Inform 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 should, in the first instance, direct their complaint to the service detaining them. If they are dissatisfied with the service's response to their complaint, inform them they can complain to the Care Quality Commission and explain how to do this.

1.8.8 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. [QS]

1.8.9 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

1.8.10 Control and restraint, and compulsory treatment including rapid tranquillisation, should be used as a last resort, only after all means of negotiation and persuasion have been tried, and only by healthcare professionals trained and competent to do this. Document the reasons for such actions. [QS]

1.8.11 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
- offer to discuss episodes of compulsory treatment with the service user at the time of discharge and do so in a calm and simple manner
- ensure training in restraint involves service users.

1.8.12 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
- ensure that other service users on the ward who are distressed by these events are offered support and time to discuss their experience.

Surveillance decision

No new information was identified at any surveillance review.
Appendix A: Summary of new evidence from 4-year surveillance of Service user experience in adult mental health (2011) NICE guideline CG136

References


