

# Coexisting severe mental illness and substance misuse: community health and social care services

NICE guideline

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## Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the [Yellow Card Scheme](#).

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should [assess and reduce the environmental impact of implementing NICE recommendations](#) wherever possible.

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This guideline is the basis of QS188.

This guideline should be read in conjunction with CG120.

## Overview

This guideline covers how to improve services for people aged 14 and above who have been diagnosed as having coexisting severe mental illness and substance misuse. The aim is to provide a range of coordinated services that address people's wider health and social care needs, as well as other issues such as employment and housing.

NICE has also produced a [guideline on coexisting severe mental illness \(psychosis\) and substance misuse: assessment and management in healthcare settings](#).

## Who is it for?

- Commissioners and providers including those working in primary care
- Staff working in all services who come into contact with this group
- The criminal justice system
- Voluntary and community sector organisations
- People aged 14 and above diagnosed as having coexisting severe mental illness and substance misuse and who live in the community, their families and carers

# Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [NICE's information on making decisions about your care](#).

[Making decisions using NICE guidelines](#) explains how we use words to show the strength (or certainty) of our recommendations, and has information about prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

This guideline should be read in conjunction with [NICE's guideline on coexisting severe mental illness \(psychosis\) and substance misuse: assessment and management in healthcare settings](#). This covers the assessment of, and support for, adults and young people (aged 14 and older) who have a suspected or known clinical diagnosis of psychosis with coexisting substance misuse.

The following should ensure service specifications take into account the recommendations in this guideline:

- commissioners of mental health, substance misuse and primary care
- local authorities when commissioning support services, including housing and other services provided by the public, community and voluntary sectors.

## 1.1 First contact with services

These recommendations are for all staff who may be the first point of contact with young people and adults with coexisting [severe mental illness](#) and [substance misuse](#) working in:

- health (including urgent care and liaison services)
- social care
- public health

- voluntary and community sector organisations
  - housing (for example, homeless shelters or temporary accommodation)
  - criminal justice system.
- 1.1.1 Identify and provide support to people with coexisting severe mental illness and substance misuse. Aim to meet their immediate needs, wherever they present. This includes:
- looking out for multiple needs (including physical health problems, homelessness or unstable housing)
  - remembering they may find it difficult to access services because they face stigma.
- 1.1.2 Be aware that the person may have a range of chronic physical health conditions including:
- cardiovascular, respiratory, hepatic or related complications
  - communicable diseases
  - cancer
  - oral health problems
  - diabetes.
- 1.1.3 Be aware that people's unmet needs may lead them to have a relapse or may affect their physical health. This could include: social isolation, homelessness, poor or lack of stable housing, or problems obtaining benefits.
- 1.1.4 Provide direct help, or get help from other services, for any urgent physical health, social care, housing or other needs.
- 1.1.5 Ensure the safeguarding needs of all people with coexisting severe mental illness and substance misuse, and their carers and wider family, are met. (See also the section on safeguarding issues in the NICE guideline on coexisting severe mental illness [psychosis] and substance misuse: assessment and management in healthcare settings.)

- 1.1.6 Ensure the person is referred to and followed up within secondary care, and that mental health services take the lead for assessment and care planning (see sections 1.2 and 1.3).

## 1.2 Referral to secondary care mental health services

- 1.2.1 Ensure secondary care mental health services:

- Do not exclude people with severe mental illness because of their substance misuse.
- Do not exclude people from physical health, social care, housing or other support services because of their coexisting severe mental illness and substance misuse.
- Adopt a person-centred approach to reduce stigma and address any inequity to access to services people may face (see NICE's guidelines on coexisting severe mental illness [psychosis] and substance misuse: assessment and management in healthcare settings and service user experience in adult mental health for the principles of using a person-centred approach).
- Undertake a comprehensive assessment of the person's mental health and substance misuse needs (see also NICE's guideline on coexisting severe mental illness [psychosis] and substance misuse – the section recognition of psychosis with coexisting substance misuse and the recommendations on assessment in secondary care mental health services).

### On acceptance to secondary care mental health services

- 1.2.2 Provide a care coordinator working in mental health services in the community to:
- act as a contact for the person
  - identify and contact their family or carers

- help develop a care plan with the person (in line with the [Department of Health's Care Programme Approach guidance](#)) and coordinate it (see the [section on the care plan](#)).

The Care Programme Approach is a way that services are assessed, planned, coordinated and reviewed for someone with mental health problems or a range of related complex needs.

- 1.2.3 Ensure the care coordinator works with other services to address the person's social care, housing, physical and mental health needs, as well as their substance misuse problems, and provide any other support they may need.

## **Involving people with coexisting severe mental illness and substance misuse in care planning**

- 1.2.4 Involve the person (and their family or carers if the person wants them involved) in developing and reviewing the care plan (as needed) to ensure it is tailored to meet their needs. This includes offering the person information about the services available so they can decide which ones would best meet their jointly identified needs and goals. Also involve practitioners from:

- adult or child and adolescent mental health teams and substance misuse services
- other health and social care disciplines such as medicine, pharmacy, nursing, social work, occupational therapy and housing.

- 1.2.5 Ensure the care plan:

- Is based on a discussion with the person about how their abilities (such as the extent to which they can take part in the activities of daily living) can help them to engage with services and recover.
- Takes into account the person's past experiences (such as their coping strategies to deal with crises).

- Lists how the person will be supported to meet their identified needs and goals. This includes listing any carers they have identified to help them, and the type of support the carer can provide. (Also see the [recommendation on ensuring interventions meet individual needs in the NICE guideline on behaviour change: individual approaches](#)).
  - Takes into account the concerns of the person's family or carers.
  - Recognises and, if possible, reconciles any goals the person may have decided for themselves if they differ from those identified by their service provider.
  - Is optimistic about the prospects of recovery.
  - Is reviewed at every contact.
- 1.2.6 Share a copy of the care plan with the person's family or carers (if the person agrees). In line with local information sharing agreements, share copies with other services as needed (see the [section on information sharing](#)).

## Carers

- 1.2.7 Ensure carers (including young carers) who are providing support are aware they are entitled to, and are offered, an assessment of their own needs (see [NICE's guideline on supporting adult carers](#)). If the carer wishes, make a referral to their local authority for a carer's assessment (in line with the [Care Act 2014](#)). When undertaking an assessment, consider:
- carers have needs in their own right
  - the effect that caring has on their mental health
  - carers may be unaware of, or excluded from, any plans or decisions being taken by the person
  - any assumptions the person with coexisting severe mental illness and substance misuse has made about the support and check that they agree the level of support their carer will provide.
- 1.2.8 Based on the carer's assessment:

- Advise the carer that they may be entitled to their own support. For example, using a personal budget to buy care or to have a break from their caring responsibilities.
- Give information and advice on how to access services in the community, for example respite or recreational activities or other support to improve their wellbeing.

See [NICE's guideline on supporting adult carers](#).

## 1.3 The care plan: multi-agency approach to address physical health, social care, housing and other support needs

- 1.3.1 The person's care coordinator should adopt a collaborative approach with other organisations (involving shared responsibilities and regular communication) when developing or reviewing the person's care plan. This includes substance misuse services, primary and secondary care health, social care, local authorities and organisations such as housing and employment services.
- 1.3.2 Ensure the care plan includes an assessment of the person's physical health, social care and other support needs, and make provision to meet those needs. This could include:
- personal care and hygiene
  - family and personal relationships
  - housing
  - learning new skills for future employment or while in employment (including those administering social security benefits)
  - education
  - pregnancy and childcare responsibilities.
- 1.3.3 Consider covering behaviours in the care plan that may affect the

person's physical or mental health, in addition to their [substance misuse](#) (see the [NICE topic pages on drug misuse](#) and [alcohol](#)). Pay particular attention to:

- diet (see the [NICE topic page on diet, nutrition and obesity](#))
- physical activity (see the [NICE topic page on physical activity](#))
- smoking (see the [NICE guideline on tobacco: preventing uptake, promoting quitting and treating dependence](#))
- consequences of drug or alcohol misuse practices (see the [NICE topic page on hepatitis](#) and the [NICE guideline on needle and syringe programmes](#))
- sexual practices (see the [NICE topic page on sexual health](#)).

1.3.4 Explore any barriers to self-care to help the person look after their own physical health. Address these barriers in the care plan.

1.3.5 Consider incorporating activities in the care plan that can help to improve wellbeing and create a sense of belonging or purpose. For example, encourage sport or recreation activities, or attendance at community groups that support their physical health or social needs. Ensure activities take account of a range of different abilities. Consider, for example:

- the gym
- education opportunities
- volunteering
- use of personal budgets (if applicable) for learning new skills, such as those that might support a return to employment.

1.3.6 Consider the following approaches to keep people involved in their care plan:

- Practical one-to-one support, for example in relation to housing, education, training or employment.

- Support to develop self-care skills, for example, to help them develop their budgeting skills so they know how to allocate enough money to buy food. Or support to help them develop their cooking skills.
  - Practical help with tasks that are important to the person, for example, housework or occupational support.
  - Support at appointments, for example:
    - arranging or travelling with them to hospital outpatient appointments or attendance at support groups
    - arranging for an advocate to accompany them at their appointments and provide independent advocacy (see the [section on maintaining contact between services and people with coexisting severe mental illness and substance misuse who use them in the NICE guideline on coexisting severe mental illness and substance misuse](#)).
- 1.3.7 Consider the suitability of the type of housing (for example, high to low support or independent tenancies), employment, detox, rehabilitation services or other support identified for the person, in collaboration with relevant providers. Take the person's preferences into account.
- 1.3.8 Ensure agencies and staff communicate with each other so the person is not automatically discharged from the care plan because they missed an appointment. All practitioners involved in the person's care should discuss a non-attendance.

## Review

- 1.3.9 Hold multi-agency and multidisciplinary case review meetings annually, as set out in the [Department of Health's Care Programme Approach guidance](#) or more frequently, based on the person's circumstances. (A care coordinator in the secondary care mental health team should usually arrange this.) Use this to check the person's physical health needs (including any adverse effects from medications), social care, housing or other support needs. Involve practitioners from a range of disciplines, including:
- secondary care mental health

- substance misuse
- primary care
- emergency care (if applicable)
- voluntary sector
- housing
- adult and young people's social care.

1.3.10 Ensure the care plan is updated in response to changing needs or circumstances.

## Discharge or transition

1.3.11 Before discharging the person from their care plan (the [Department of Health's Care Programme Approach guidance](#)) or before they move between services, settings or agencies (for example, from inpatient care to the community, or from child and adolescent mental health services to adult mental health services) ensure:

- All practitioners who have been, or who will be, involved are invited to the multi-agency and multidisciplinary meetings (see recommendation 1.3.9) and the discharge or transfer meeting.
- There is support to meet the person's housing needs.
- The discharge plan includes strategies for ongoing safety or risk management and details of how they can get back in contact with services.
- There are crisis and contingency plans in place if the person's mental or physical health deteriorates (including for risk of suicide or unintentional overdose).
- Providers share information on how to manage challenging or risky situations (see also [NICE's guideline on violence and aggression: short-term management in mental health, health and community settings](#)).

1.3.12 Reassess the person's needs to ensure there is continuity of care when they are at a transition point in their life. Particular groups who may need

additional support include:

- young people who move from child and adolescent mental health services to adult health or social care services (see also [NICE's guideline on transition from children's to adults' services](#) and the [section on specific issues for young people with psychosis and coexisting substance misuse in NICE's guideline on coexisting severe mental illness \[psychosis\] and substance misuse](#))
- looked after children
- people who move from adult to older adult mental health or social care services.

Also see [NICE's guideline on transition between inpatient mental health settings and community and care home settings](#).

## 1.4 Partnership working between specialist services, health, social care and other support services and commissioners

1.4.1 Work together to encourage people with coexisting [severe mental illness](#) and [substance misuse](#) to use services. Consider:

- using an agreed set of local policies and procedures that is regularly reviewed by key strategic partners
- working across traditional institutional boundaries
- being responsive to requests for advice and joint-working arrangements
- sharing the response to risk management.

1.4.2 Ensure joint strategic working arrangements are in place so that:

- services can offer continuity of care and service provision (for example, when commissioning contracts are due to expire)
- services are based on a local needs or a joint strategic needs assessment

- service quality is monitored and data sharing protocols are in place (see also recommendations 1.4.6 and 1.4.7).
- 1.4.3 Consider including the needs of people with coexisting severe mental illness and substance misuse in other local needs assessment strategies, for example, on housing, employment projects, alcohol, drug services or crime prevention.
- 1.4.4 Agree joint care pathways to:
- Meet the health, social care or other support needs and preferences of people with coexisting severe mental illness and substance misuse, wherever they may present.
  - Give people access to a range of primary healthcare and social care providers including GP practices, pharmacies, podiatrists, dentists, social workers, housing, housing support or benefit advisers.
  - Ensure people have prompt access to local services (including direct referrals if possible).
  - Ensure staff follow people up to make sure their needs are being met.
  - Ensure continuity of care to support people at different transition points in their lives.
- 1.4.5 Ensure referral processes and care pathways within and across agencies are consistent and that governance arrangements are in place. This includes local care pathways to meet the physical health, social care, housing and support needs of people with coexisting severe mental illness and substance misuse.

## Information sharing

- 1.4.6 Agree a protocol for information sharing between secondary care mental health services and substance misuse, health, social care, education, housing, voluntary and community services (see the [Caldicott Guardian Manual](#)).
- 1.4.7 Adopt a consistent approach to getting people with coexisting severe

mental illness and substance misuse help from the most relevant service by:

- sharing information on support services between agencies
- ensuring all providers know about and can provide information on the services
- taking responsibility, as agreed in referral processes, providing timely feedback and communicating regularly about progress.

## 1.5 Improving service delivery

### Making health, social care and other support services more inclusive

- 1.5.1 Ensure existing health and social care services (including substance misuse services) are adapted to engage with and meet the needs of people with coexisting severe mental illness and substance misuse.
- 1.5.2 Involve people with coexisting severe mental illness and substance misuse, their family or carers in improving the design and delivery of existing services (see the section on referral to secondary care mental health services in NICE's guideline on coexisting severe mental illness and substance misuse). This may include them providing training, developing interventions to help people or taking part in steering committees.
- 1.5.3 Provide local services in places that are easily accessible, safe and discreet. Bear in mind any perceived stigma involved in being seen to use the service. Consider flexible opening times, drop-in sessions, or meeting people in their preferred locations.
- 1.5.4 Ensure people with coexisting severe mental illness and substance misuse, their family or carers are given accurate information about relevant local services (including, for example, community or family support groups). Also ensure they are given help to make initial contact with services. This could include information on how to access services, ways to contact the service, opening hours and how long the waiting list

may be.

- 1.5.5 Raise staff awareness of the needs of people with coexisting severe mental illness and substance misuse, including the fact that they may be traumatised. Ensure staff can meet their needs.

## Adapting existing secondary care mental health services

- 1.5.6 Adapt existing specialist services to meet both a person's coexisting severe mental illness and substance misuse needs and their wider health and social care needs. Do not create a specialist 'dual diagnosis' service.
- 1.5.7 Offer interventions that aim to improve engagement with all services, support harm reduction, change behaviour and prevent relapse. Take advice from substance misuse services (if applicable) about these interventions. (See the NICE guidelines on coexisting severe mental illness [psychosis] and substance misuse, psychosis and schizophrenia in children and young people, psychosis and schizophrenia in adults, bipolar disorder, self-harm, alcohol-use disorders, and drug misuse in over 16s: psychosocial interventions.)
- 1.5.8 Offer individual, face-to-face or phone appointment sessions to encourage people with coexisting severe mental illness and substance misuse to use services. Offer phone sessions to their family or carers. Sessions could cover:
- how the person is coping with their current mental health and substance use and its impact on their physical health and social care needs
  - progress on current goals or changes to future goals
  - ways to help the person stay safe
  - monitoring symptoms
  - getting support from (and for) their family, carers or providers.

Determine how often the sessions take place based on the person's needs.

- 1.5.9 Consider the following:

- Crisis and contingency plans for the person with coexisting severe mental illness and substance misuse and their family or carers. Ensure these are updated to reflect changing circumstances.
- Support to sustain change and prevent relapse.
- Discharge planning, including planning for potential relapses, so the person with coexisting severe mental illness and substance misuse knows which service to contact and the service can provide the right ongoing support. (See also [NICE's guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.](#))

## Support for staff

- 1.5.10 Ensure the care coordinator in secondary care mental health services is supervised and receives professional development to provide or coordinate flexible, personalised care.
- 1.5.11 Recognise that different attitudes towards, or knowledge of, mental health and drug- or alcohol-related problems may exist between agencies and that this may present a barrier to delivering services. To overcome this:
- challenge negative attitudes or preconceptions about working with people with coexisting severe mental illness and substance misuse
  - develop leadership skills so staff can challenge attitudes and preconceptions (for an example, see the [study by Hughes \[2006\] Closing the gap: a capability framework for working effectively with people with combined mental health and substance use problems](#)).
- 1.5.12 Ensure practitioners have the resilience and tolerance to help people with coexisting severe mental illness and substance misuse through a relapse or crisis, so they are not discharged before they are fully equipped to cope or excluded from services (see the [section on maintaining contact between services and people with coexisting severe mental illness and substance misuse who use them](#)).

## 1.6 Maintaining contact between services and

## people with coexisting severe mental illness and substance misuse who use them

- 1.6.1 Recognise that even though building a relationship with the person and seeing even small improvements may take a long time, it is worth persevering. It involves:
- showing empathy and using a non-judgemental approach to listen, identify and be responsive to the person's needs and goals
  - providing consistent services, for example, if possible keeping the same staff member as their point of contact and the same lead for organising care
  - staying in contact by using the person's chosen method of communication (for example, by letter, phone, text, emails or outreach work, if possible).
- 1.6.2 Explore with the person why they may stop using services that can help them. This may include:
- fragmented care or services
  - inflexible services (for example, not taking into account that the side effects the person may experience from medication may affect their attendance at appointments)
  - inability to attend because, for example, services are not local, transport links are poor, or services do not provide childcare
  - not being allowed to attend, for example because they have started misusing substances again
  - fear of stigma, prejudice or being labelled as having both mental health and substance misuse problems
  - feeling coerced into using treatments or services that do not reflect their preferences or their readiness to change
  - previous poor relationships with practitioners
  - other personal, cultural, social, environmental or economic reasons.

- 1.6.3 Help those who may find it difficult to engage with services to get into and stay connected with services. Start and maintain contact using proactive, flexible approaches (see [recommendation 1.3.6 on approaches to keep people involved in their care plan](#)).
- 1.6.4 Recognise that people with coexisting [severe mental illness](#) and substance misuse are at higher risk of not using, or losing contact with, services. There are specific populations who are more at risk. These include men, young people, older people and women who are pregnant or have recently given birth. It also includes:
- people who are homeless
  - people who have experienced or witnessed abuse or violence
  - people with language difficulties
  - people who are parents or carers who may fear the consequences of contact with statutory services.
- 1.6.5 Ensure any loss of contact or non-attendance at any appointment or activity is viewed by all practitioners involved in the person's care as a matter of concern. Follow-up actions could include:
- contacting the person to rearrange an appointment
  - visiting the person at home
  - contacting any other practitioners involved in their care, or family or carers identified in the person's care plan (see [recommendation 1.2.4 on involving the person in developing and reviewing the care plan](#))
  - contacting the person's care coordinator within mental health services in the community immediately if there is a risk of self-harm or suicide, or at least within 24 hours if there are existing concerns.

## Terms used in this guideline

This section defines terms that have been used in a specific way for this guideline.

## **Contingency management**

Contingency management is a set of techniques that focus on changing specific behaviours. For example, in drug misuse, it involves offering incentives for positive behaviours such as abstinence or a reduction in illicit drug use, and participation in health-promoting interventions.

## **Dual diagnosis**

Dual diagnosis usually refers to mental illness combined with substance misuse. But it may also be used to describe a number of other conditions, including physical health problems. In the UK social care sector, the term is sometimes used for people who have both a learning disability and a mental illness.

## **Relapse**

A recurrence or exacerbation of a person's mental health problems, a return to substance misuse, or both.

## **Severe mental illness**

Severe mental illness includes a clinical diagnosis of: schizophrenia, schizotypal and delusional disorders, or bipolar affective disorder, or severe depressive episodes with or without psychotic episodes.

## **Specialist services**

Specialist services refers to secondary care mental health services and dual diagnosis services.

## **Substance misuse**

Substance misuse refers to the use of legal or illicit drugs, including alcohol and medicine, in a way that causes mental or physical damage. This may include low levels of substance use that would not usually be considered harmful or problematic, but may have a significant effect on the mental health of people with a mental illness such as psychosis.

# Putting this guideline into practice

NICE has produced [tools and resources](#) to help you put this guideline into practice.

Some issues were highlighted that might need specific thought when implementing the recommendations. These were raised during development of this guideline. They are:

- Lower caseloads are needed to provide consistent, coordinated and optimum services, but this has cost implications.
- Joint training could lead to a more consistent approach across mental health and substance misuse services.
- Leadership is needed from commissioners across health and social care services.

Putting a guideline fully into practice can take time. How long may vary from guideline to guideline, and depends on how much change in practice or services is needed. Implementing change is most effective when aligned with local priorities.

Changes should be implemented as soon as possible, unless there is a good reason for not doing so (for example, if it would be better value for money if a package of recommendations were all implemented at once).

Different organisations may need different approaches to implementation, depending on their size and function. Sometimes individual practitioners may be able to respond to recommendations to improve their practice more quickly than large organisations.

Here are some pointers to help put NICE guidelines into practice:

1. **Raise awareness** through routine communication channels, such as email or newsletters, regular meetings, internal staff briefings and other communications with all relevant partner organisations. Identify things staff can include in their own practice straight away.
2. **Identify a lead** with an interest in the topic to champion the guideline and motivate others to support its use and make service changes, and to find out any significant issues locally.

3. **Carry out a baseline assessment** against the recommendations to find out whether there are gaps in current service provision.
4. **Think about what data you need to measure improvement** and plan how you will collect it. You may need to work with other health and social care organisations and specialist groups to compare current practice with the recommendations. This may also help identify local issues that will slow or prevent implementation.
5. **Develop an action plan** with the steps needed to put the guideline into practice, and make sure it is ready as soon as possible. Big, complex changes may take longer to implement, but some may be quick and easy to do. An action plan will help in both cases.
6. **For very big changes** include milestones and a business case, which will set out additional costs, savings and possible areas for disinvestment. A small project group could develop the action plan. The group might include the guideline champion, a senior organisational sponsor, staff involved in the associated services, finance and information professionals.
7. **Implement the action plan** with oversight from the lead and the project group. Big projects may also need project management support.
8. **Review and monitor** how well the guideline is being implemented through the project group. Share progress with those involved in making improvements, as well as relevant boards and local partners.

NICE provides a comprehensive programme of support and resources to maximise uptake and use of evidence and guidance. See [NICE's into practice pages](#) for more information.

Also see Leng G, Moore V, Abraham S, editors (2014) [Achieving high quality care – practical experience from NICE](#). Chichester: Wiley.

## Context

Adults and young people with coexisting severe mental illness and substance misuse have some of the worst health, wellbeing and social outcomes (see the Social Care Institute for Excellence's briefing on the relationship between dual diagnosis: substance misuse and dealing with mental health issues).

It is not clear how many people in the UK have a coexisting severe mental illness and misuse substances, partly because some people in this group do not use services or get relevant care or treatment.

The Department of Health's Refocusing the Care Programme Approach identifies people with coexisting severe mental illness and substance misuse as one of the groups in need of an enhanced Care Programme Approach. That is because they are not being identified consistently and services are sometimes failing to provide the support they need. The policy highlights the need for a whole systems approach to their care, involving a range of services and organisations working together. This guideline aims to address this need.

Groups covered in this guideline include: young people (aged 14 to 25) and adults who have been diagnosed as having a severe mental illness and who misuse substances and who live in the community. The age cut-off for young people has been set at 14 to reflect the small numbers affected below this age – and the fact that many early intervention services usually start at age 14.

In this guideline, severe mental illness includes a clinical diagnosis of:

- schizophrenia, schizotypal and delusional disorders **or**
- bipolar affective disorder **or**
- severe depressive episodes with or without psychotic episodes.

Substance misuse refers to the use of legal or illicit drugs, including alcohol and medicine, in a way that causes mental or physical damage.

## Finding more information and committee details

To find NICE guidance on related topics, including guidance in development, see the [NICE topic pages on alcohol, drug misuse, mental health and wellbeing and behaviour change](#). For specific recommendations on monitoring and promoting recovery of physical health, see our [guidelines on coexisting severe mental illness \(psychosis\) and substance misuse: assessment and management in healthcare settings, psychosis and schizophrenia in adults, psychosis and schizophrenia in children and young people, bipolar disorder and alcohol-use disorders](#).

For full details of the evidence and the guideline committee's discussions, see the [evidence reviews](#). You can also find information about [how the guideline was developed](#), including [details of the committee](#).

NICE has produced [tools and resources to help you put this guideline into practice](#). For general help and advice on putting our guidelines into practice, see [resources to help you put NICE guidance into practice](#).

# The committee's discussion

Evidence statement numbers are given in square brackets. For an explanation of the evidence statement numbering, see the [evidence reviews](#) section.

## Section 1.1 First contact with services

### Recommendations 1.1.1 to 1.1.6

The discussion below explains how we made [recommendations 1.1.1 to 1.1.6](#).

#### Current practice

Committee members were aware from their experience that people with coexisting [severe mental illness](#) and [substance misuse](#) may present in crisis (for example, at A&E). But they may also be found opportunistically in other settings (for example, homeless shelters) and identified as needing immediate assistance with a range of needs. This includes their mental or physical health, substance misuse or social care needs.

They noted that the physical health and social care needs of this group are often overlooked because of the challenging nature of dealing with both mental health and substance misuse issues. They also noted that this group is often excluded from services because no one wants to take responsibility for them and they need help to access a wide range of services.

In addition, members noted that a policy guide in 2002 ([Department of Health's Dual diagnosis good practice guide](#)) has advised that care for people with coexisting severe mental illness and substance misuse should be delivered within mental health services.

#### Evidence

The committee noted from the evidence and members' experience that people with coexisting severe mental illness and substance misuse are a vulnerable group, who often have poor physical health, are unemployed, homeless or are at risk of other people taking advantage of them. The latter includes being subjected to sexual exploitation or being

taken advantage of in relation to their housing or financial situation.

It noted there was strong evidence from a meta-analysis of 3 cohort and case-control UK studies (2 high quality [++] and 1 low quality [-]) that people with coexisting severe mental illness and substance misuse (compared with those with severe mental illness only) were more likely to have a history of homelessness or housing problems. There was also evidence from 1 high-quality UK case-control study that this group of people are more likely to live in the most deprived areas. There was moderate evidence from 3 high-quality UK cohort studies that showed a greater number of people with coexisting severe mental illness and substance misuse are unemployed than those with severe mental illness only [ES1.1.9].

The committee noted that a meta-analysis of 2 UK case-control studies (1 high and 1 moderate quality [+]) showed no difference in social functioning between this group and people with a severe mental illness only. However, 1 high-quality UK cohort study showed poorer social functioning in people with coexisting severe mental illness and substance misuse than in those with substance misuse [ES1.1.9].

The committee also noted that this evidence was mainly from people in contact with secondary care mental health services and may not reflect the needs of the wider population of people with coexisting severe mental illness and substance misuse [ES1.1.9].

The committee noted inconsistent evidence for educational outcomes [ES1.1.9]. But members also noted from their experience that the point at which a person is diagnosed would have an effect on their educational attainment.

The committee was aware, from the evidence and its experience, that this group is often stigmatised by staff or because of the type of services they are using. For example, this may be a negative attitude towards substance misuse within mental health settings or vice versa. This is based on evidence from 7 qualitative studies (2 high, 3 moderate and 2 low quality) reporting on barriers related to stigma and attitudes towards this group [ES2.1.3].

Six qualitative studies showed that people with coexisting severe mental illness and substance misuse face a number of barriers or facilitators when accessing social care services, particularly housing support. Of the 4 studies that identified barriers to accessing housing support, 1 high-quality qualitative study reported that people with coexisting severe mental illness and substance misuse often feel there is a social stigma associated with seeking help [ES2.2.1]. Also, services are often not easy to access.

The committee felt that it is important for all services to address these issues from an inequalities perspective and to prevent further deterioration in the person's mental and physical health, social care and substance misuse needs. It was also aware from 7 qualitative studies (2 high, 3 moderate and 2 low quality) reporting on fragmented care, that a consequence of fragmented care is a negative impact on a person's experience of care and willingness to engage with services [ES2.2.4].

So it made a strong recommendation that all staff coming into contact with this group should be able to understand their needs and help them access services.

Committee members were aware from their practice and the evidence from 1 high-, 3 moderate- and 2 low-quality qualitative studies (3 set in the UK) that mental health and substance misuse services often fail to take responsibility for people with coexisting severe mental illness and substance misuse [ES2.1.10].

The committee also noted the evidence from 1 low-quality UK qualitative study that highlighted commissioners' views that the health and wellbeing of this group need to be addressed [ES2.1.2]. The committee noted that wherever people with coexisting severe mental illness and substance misuse present, a similar approach to helping them access care is needed.

The committee advised that secondary care mental health services need to be the lead organisation responsible for delivery of services and therefore made a recommendation to refer people with coexisting severe mental illness and substance misuse to secondary care mental health services.

The committee heard from an expert about the physical health issues that can affect people with coexisting severe mental illness and substance misuse [EP4]. It noted that although the expertise was from a perspective of primary care services for homeless people, the range of health needs identified could be transferable to the wider population of people with coexisting severe mental illness and substance misuse. So the committee made a weak recommendation on the range of physical health conditions (for example, cardiovascular, cancer or communicable diseases) that staff need to be aware of. However, it noted that this is not an exhaustive list.

It also reflected on the lack of evidence on the prevalence of coexisting physical health problems [ES1.1.8] and agreed further research is needed (see the [recommendation for research on needs assessment](#)).

The committee noted that because of the complexity of their needs, people with coexisting severe mental illness and substance misuse are at increased risk of poor self-care, losing contact with family and friends, social isolation or living in poor housing or having their homes abused by others as venues for substance misuse or drug dealing.

Based on moderate to strong evidence from 4 cohort and 6 case-control studies, committee members were aware of the range of social care needs of people with coexisting severe mental illness and substance misuse in the UK [ES1.1.9]. They were also aware from expert testimony [EP2], and their own experience of working with this group, of the detrimental effects that unmet needs (such as social isolation or poor housing) can have on a person's health and recovery, which could lead to relapse [ES2.2.1, EP2]. This was based on 2 high-quality and 1 moderate-quality qualitative studies reporting on barriers when seeking housing support.

The committee was aware that these unmet needs may lead to physical health problems, offending behaviour or disengagement from services. It was also aware that a person may have issues with both poor housing and physical health and that this may not always be a 'cause-effect' relationship.

## **Cost effectiveness**

There was no evidence for cost effectiveness for this set of recommendations.

## **Additional factors taken into account**

Committee members agreed that recommendation 1.1.1 is for staff working in all general services. But they also noted that it would be applicable to other services, such as criminal justice system and urgent care.

Committee members were aware that the criminal justice system was not included in the scope and that the evidence reviews did not specifically search for studies on the transition between criminal justice systems and healthcare services. They were also aware that NICE is developing guidance on the mental health of adults in contact with the criminal justice system. However, they felt it was important to include because it is a potential route for people with coexisting severe mental illness and substance misuse to come into contact with healthcare services. This was also reflected in the expert testimony on primary care services for homeless people [EP4].

The committee was aware from its experience of the importance of highlighting safeguarding issues for this vulnerable population. It felt that this point needs to be for general services. The committee acknowledged that safeguarding has been made a statutory duty under the [Care Act 2014](#). It was also aware of statutory safeguarding arrangements specific to children (see the [Department of Education's guidance on working together to safeguard children](#)) and statutory guidance to the 1989 and 2004 Children Acts (see [Ofsted's report What about the children?](#) ). The committee was also aware of the safeguarding needs of dependents and carers.

## Section 1.2 Referral to secondary care mental health services

### Recommendation 1.2.1

The discussion below explains how we made [recommendation 1.2.1](#).

#### Current practice

The committee was advised by the topic experts that secondary care mental health services are usually the lead agency that supports people with coexisting severe mental illness and substance misuse.

#### Evidence

Although this guideline focuses on people with diagnosed coexisting severe mental illness and substance misuse, the committee felt it was important to address the general issue of ensuring people are properly assessed so they can be offered an effective care plan.

The committee noted from 1 moderate-quality study, 1 low-quality UK study and members' experience that timely assessments can help people to access services and stay involved with their care plan [ES2.1.1].

The committee agreed with the recommendations on the principles of recognition and assessment in [NICE's guideline on coexisting severe mental illness \(psychosis\) and substance misuse: assessment and management in healthcare settings](#), even though it has a narrower focus than this guideline. The committee also agreed that the recommendations on identification and diagnosis were useful (identification and diagnosis

was outside the scope of this guideline). Although the psychosis with substance misuse guideline was specific to psychosis and not the range of severe mental illnesses covered in this guideline, members agreed it would be useful for readers to refer to both recommendations.

The committee agreed to develop a recommendation on what needs to happen once a person is referred to and accepted into secondary care mental health services based on the evidence, expert testimony and members' own experience.

## Cost effectiveness

There was no evidence for cost effectiveness for this recommendation.

## Additional factors taken into account

The committee agreed that substance misuse should not be a reason to exclude people from secondary care mental health services. Based on the evidence and from members' experience this is a common problem [EP2]. The committee also noted from members' experience that the person's wider needs are often not recognised, or they are not given a routine assessment of their mental health or substance misuse needs to develop a care plan.

From their experience, committee members were aware of the importance of a person-centred approach. This was reinforced by review 2. The committee was also aware of [NICE's guidelines on coexisting severe mental illness \(psychosis\) and substance misuse and service user experience in adult mental health](#). Both outline the need for a non-judgemental and empathetic approach built on trust and respect. The committee felt it was important to take a person-centred approach when developing and reviewing the care plan and made a strong recommendation on involving people in their care planning. This was based on evidence from:

- 5 qualitative studies (2 high, 2 moderate and 1 low quality) reporting on facilitators related to the relationship between people who use services and practitioners. 1 of these studies was conducted in the UK [ES2.1.4]
- 7 qualitative studies, of these 2 qualitative studies (1 moderate and 1 low quality) reporting on benefits of consistent care. 1 of the studies reporting on facilitators was conducted in the UK [ES2.2.4]

- 8 qualitative studies (2 high, 3 moderate and 3 low quality) reporting on barriers and facilitators to engagement with healthcare and support services. 3 of these studies were conducted in the UK [ES2.2.7].

## On acceptance to secondary care mental health services

The discussion below explains how we made [recommendations 1.2.2 and 1.2.3](#).

### Current practice

The committee agreed that secondary care mental health services take the lead in coordinating services and developing a care plan. The committee noted that care planning is usually led by a care coordinator because this is part of the [Department of Health's Care Programme Approach](#).

### Evidence

The committee was aware of the importance of continuing care. It was also aware that the continuity provided by a key contact encourages people to keep in touch with services (evidence review 2). This was based on the evidence from:

- 5 qualitative studies (1 moderate- and 4 low-quality) reporting on barriers or facilitators associated with organisation and continuity of care, 3 based in the UK [ES2.1.11]
- 7 qualitative studies (2 high, 3 moderate and 2 low quality) reporting on barriers or facilitators associated with the impact of fragment care provision on continuity of care [ES2.2.4].

### Cost effectiveness

There was no evidence for cost effectiveness for this set of recommendations.

### Additional factors taken into account

Based on their expertise and the responsibilities outlined in the Care Programme Approach, committee members made a strong recommendation that a care coordinator from community mental health services is assigned once a person has been referred to

secondary care mental health services.

They agreed that the care coordinator should take the lead in developing and reviewing the care plan and should take responsibility for organising delivery of a range of services, with the support of a wider team.

## **Resource implications and implementation issues**

Committee members advised that the role of care coordinator already exists within secondary care mental health services. They noted that care coordinators are part of a multidisciplinary team. But they also noted that overall responsibility (for example, for discharging a person) would lie with a consultant psychiatrist.

## **Involving people with coexisting severe mental illness and substance misuse in care planning**

The discussion below explains how we made [recommendations 1.2.4 to 1.2.6](#).

### **Evidence**

The committee agreed that it is important to take a person-centred approach, by focusing on actions that are agreed with the person and by offering, not imposing, services on them. So it developed a set of recommendations on 'involving people' in care planning. These recommendations are deliberately separate from the recommendations on the actual content of the care plan (see the [section on the care plan: multi-agency approach to address physical health, social care, housing and other support needs](#)).

The committee took into account qualitative evidence from 3 studies reporting on the barriers or facilitators that face people with severe mental illness and substance misuse face when trying to make decisions about their care [ES2.2.9]:

- 1 low-quality UK study about encouraging the person to be involved in their care plan decisions
- 2 moderate-quality qualitative studies about respecting their preferences.

It felt that these factors can help a person adhere to their care plan.

The committee was also aware from the evidence (5 qualitative studies: 2 high quality, 2 moderate quality and 1 low quality) and their experience that a good relationship between the health or social care professional and the person with coexisting severe mental illness and substance misuse is key to effective delivery of health and social care services [ES2.1.4]. Members noted that a good relationship can affect a person's willingness to engage with and respond to care, and can also affect their recovery.

Bearing in mind all these factors, it made a strong recommendation on the need to take them all into account when developing a care plan.

### **Additional factors taken into account**

The committee noted from members' experience that providers need to understand what is having an effect on the person each time they see them, so that they can provide the right level of support, including information, each time. It noted that the frequency of contact can vary depending on the person's circumstances. It also noted the importance of sharing the care plan between services.

The committee noted that people can recover. But it also noted that for this group of people, 'recovery' may not necessarily only be about reducing their substance use but about leading a productive life. The members felt that although recovery may take time, providers need to always convey a sense of optimism whenever possible.

The committee was aware that changing behaviour may be a lengthy process and that [NICE's guideline on behaviour change: individual approaches](#) may provide useful strategies on personalising messages.

### **Cost effectiveness**

There was no evidence for cost effectiveness for this set of recommendations.

### **Carers**

The discussion below explains how we made [recommendations 1.2.7 and 1.2.8](#).

### **Current practice**

The committee was aware of current legislation that entitled carers to an assessment of

their needs ([Care Act 2014](#)).

## Evidence

The committee was aware from the evidence and members' experience, that a carers assessment may be particularly important if the carers are children [ES2.1.9; 1 UK study of low quality]. Members' experience highlighted that a point of contention for carers is that they may not be privy to the person's plans and wishes. Evidence from 2 qualitative studies (1 moderate quality and 1 UK study of low quality) highlighted the barriers faced by families and carers in relation to receiving support for themselves [ES2.2.10]. So the committee developed a recommendation based on the evidence, expert testimony and their expert knowledge to highlight young people and adult carers' needs and ways to support them [review 2, EP2].

## Cost effectiveness

There was no evidence on cost effectiveness for this set of recommendations.

## Additional factors taken into account

The committee was aware, from its own experience, that carers may not be offered the opportunity to decline caring responsibilities that are beyond their capacity when they are being assessed. That is why it is important to highlight that carers may be entitled to further support, even though this is specified in the Care Act.

# Section 1.3 The care plan: multi-agency approach to address physical health, social care, housing or support needs

## Recommendations 1.3.1 to 1.3.8

The discussion below explains how we made [recommendations 1.3.1 to 1.3.8](#).

## Current practice

Social care needs should be assessed in line with the [Care Act 2014](#). Provision of an

advocate is in line with this legislation.

## Evidence

The committee noted from the evidence from 1 high-, 4 moderate- and 3 low-quality qualitative studies (including 4 studies in the UK) that the lack of a shared approach between services could act as a barrier to providing health and social care services [ES2.1.7]. The committee heard from an expert on local partnership working and experts working with people with coexisting severe mental illness and substance misuse who are homeless [EP1, EP2]. The experts highlighted factors that could help with a coordinated approach.

Based on the evidence, expert testimonies and their own experience, members agreed that important factors in providing a coordinated approach included a shared vision, joint responsibilities and regular communication [ES2.1.7, EP1, EP2].

The committee highlighted the range of agencies or providers the care coordinator in secondary mental health services would need to work with to ensure people receive care for their wider health or social care, housing or support needs. The committee highlighted the physical health, social care, housing and other support needs that need to be considered when developing and reviewing a care plan.

Members reflected on the evidence, expert testimony and their own experience to inform their recommendations on social care, housing and other support needs [ES1.1.9, ES2.2.1, ES2.2.2, EP2]. The committee referred to evidence previously noted in the [discussion for section 1.1](#) [ES1.1.9, ES2.2.1]. It also considered the evidence from 2 qualitative studies (1 high quality and 1 moderate) which described the barriers faced by this group in relation to employment support [ES2.2.2].

Members reflected on expert testimony and existing NICE guidelines on a range of health behaviours [EP4]. Based on this and their knowledge and experience they made a weak recommendation to decide on how a person's physical health could be improved and provided examples of how this may be achieved. This included addressing health behaviours (such as improving diet, quitting smoking or increasing physical activity) and minimising risky behaviours (such as unprotected sex, sharing needles). They realised this is not an exhaustive list and that the care plan may need to address other behaviours.

The committee also noted that care coordinators may need to help people with practical

tasks so that the person can look after their own physical health. The examples were based on the committee's expertise on the type of tasks undertaken by care coordinators. So the committee made a weak recommendation on approaches to keep people involved in their care plan.

In addition, the committee noted the importance of encouraging activities to improve physical wellbeing (for example football or walking groups). But it was aware of the risk of widening inequalities if this only reaches people who already use services. The committee agreed that potential inequalities could be addressed by recommending providing inclusive services and strategies to improve engagement.

The committee made a weak recommendation on practical strategies that may help improve uptake of services and prevent relapse. This was based on evidence, expert testimony and the committee's expertise [ES2.2.3, EP2]. The committee was aware from 1 moderate and 1 low-quality study (set in the UK) of barriers or facilitators associated with providing information or training [ES2.2.3]. One moderate-quality study showed supporting people to develop self-care skills helped with daily living. The committee used this evidence combined with their experience to give other examples of practical skills to include in the recommendation.

## **Additional factors taken into account**

Recommendations on how to encourage use of services and the suitability of different types of support were based on evidence review 2, expert testimony and the committee's expertise. The committee noted that people with coexisting severe mental illness and substance misuse are particularly at risk of being taken advantage of, so it is important to ensure the type of support they are offered is suitable for them [EP2].

The committee was aware from members' experience and expert testimony that communication between services is often poor [EP2]. The committee was also aware, from members' experience, that people are often discharged early or denied access to services because of missed appointments. There is often a good reason why the appointment was missed – for example, because the person was having side effects from their medication – but this has not been shared among the agencies involved. This was also highlighted in 2 qualitative studies (1 high, 1 moderate quality) in review 2. Members made a strong recommendation, noting that this can be addressed by making sure practitioners communicate and share information with each other, particularly in relation to non-attendance, so that it does not lead to an automatic discharge.

## Cost effectiveness

There was no evidence for cost effectiveness for this set of recommendations.

## Review

The discussion below explains how we made recommendations 1.3.9 and 1.3.10.

## Evidence

Committee members were aware from their experience and from the evidence of the barriers or facilitators associated with an integrated approach to care from 1 high-quality, 6 moderate-quality, and 2 low-quality qualitative studies (2 set in the UK) [ES2.2.6]. They noted from members' experience, expert testimony and the evidence that this could increase engagement and result in positive improvements in health, functioning and wellbeing. Although the UK studies were low quality, the committee felt the findings were relevant because they reflected the views of providers and users in voluntary sector services.

They also noted the importance of different disciplines working collaboratively, and taking part in case review meetings. This was based on the evidence from 8 qualitative studies reporting on barriers or facilitators associated with the management of cases with members of the same team and across different health and social care agencies [ES2.1.7].

The committee noted that the frequency of case review meetings would vary and would involve multidisciplinary team members and several different agencies. This is important to make sure a person's care plan is up to date and relevant. The strong recommendation to review the plan annually was based on the Care Programme Approach. But the committee recognised that this would depend on the person's level of need and circumstances and so recommended review meetings could be more frequent, if needed.

The committee noted the importance of regular monitoring of physical health, including for adverse effects of medications [EP4]. It was aware of strong evidence from 3 UK studies (2 case control and 1 cohort) that people with coexisting severe mental illness and substance misuse are less likely to adhere to medications than those with severe mental illness only [ES1.1.8].

The committee heard expert testimony about the side effects of medication and was

aware from members' experience that this includes weight gain and other adverse effects [EP4]. Members felt this could be a barrier to adhering to treatment and could have a negative impact on a person's mental or physical health.

Committee members acknowledged that the evidence on working collaboratively and the views expressed in the expert testimony reflected their own experiences of working with people with coexisting severe mental illness and substance misuse [ES2.1.7, EP4]. They noted that changes in circumstances need to be taken into account in a person's care plan and physical health or social care, support or housing needs revised accordingly.

### **Cost effectiveness**

There was no evidence for cost effectiveness for this recommendation.

### **Discharge or transition**

The discussion below explains how we made [recommendations 1.3.11 and 1.3.12](#).

### **Current practice**

Committee members noted from their experience that transfer between services and discharge from the Care Programme Approach are key points when a person can lose touch with services.

### **Evidence**

The committee felt that a robust relapse prevention plan and re-entry into the system would help to mitigate the risk of suicide or death from unintentional overdose. The committee agreed that housing needs are a priority before discharge and referred to evidence previously noted in the [discussion for section 1.1](#) and [discussion for section 1.3](#) [ES1.1.9, ES2.2.1].

The committee noted that the discharge plan should also include information on managing risky situations because of the challenging nature of working with people who may be intoxicated or in withdrawal. This was based on members' experience and evidence from 2 moderate-quality and 1 low-quality studies [ES2.1.8]. The committee was aware of [NICE's guideline on violence and aggression](#) and agreed it was a useful source for providers.

Members noted the evidence on challenges people can face when moving between services and felt this was applicable to other key points in a person's life [ES2.2.1]. The committee acknowledged the need to take a 'life course' approach. So it strongly recommended that provision for continuity of care needs to be in place when transition between services occurs and at key points in a person's life. This was based on members' experience and evidence from 4 qualitative studies (2 high and 2 moderate quality) [ES2.2.4]. The members highlighted particular groups who may need additional support based on their expertise and existing NICE guidelines.

### **Cost effectiveness**

There was no evidence for cost effectiveness for this set of recommendations.

### **Additional factors taken into account**

The committee heard expert testimony on the importance of making sure the guideline included the referral of young people to adult services [EP3]. It also reflected on members' experience and noted that groups such as looked after children and older people may need additional help. So handover of care on discharge, or when a person transfers to another service (in consultation with other providers), was included in the recommendation.

The committee agreed that encouraging practitioners to meet at multidisciplinary and multi-agency meetings is likely to improve physical health, social care and support outcomes and potentially reduce admissions for crisis care. But it also noted that this may be a new approach for the non-mental health sectors and that releasing staff for these meetings could be problematic without additional resources.

## **Section 1.4 Partnership working between specialist services, health, social care and support services and commissioners**

### **Recommendations 1.4.1 to 1.4.5**

The discussion below explains how we made recommendations 1.4.1 to 1.4.5.

## Current practice

The committee noted that although a policy guide in 2002 (the [Department of Health's dual diagnosis good practice guide](#)) had set out the vision for how services and care could be delivered, it was not being implemented. The committee was aware of [Public Health England's guidance on co-existing alcohol and drug misuse with mental health issues: guidance to support local commissioning and delivery of care](#) [to be published December 2016] which sets out the importance of joint working.

The committee discussed the fact that since April 2013 there have been separate funding streams for mental health and substance misuse services, with mental health services funded by clinical commissioning groups and substance misuse services by local authorities. The committee felt this exacerbated a longstanding division between the mental health and substance misuse sectors. It has also led to 2 different sets of organising paradigms for commissioners, which does not serve people with coexisting severe mental illness and substance misuse.

Members also noted that funding for addiction services comes from local authority budgets and is subject to commissioning contracts (which may exclude provision of mental health assessment or prescribing) and competitive tendering.

## Evidence

The committee decided to recommend partnership working because there is a lack of provision of health and social care services for people with coexisting severe mental illness and substance misuse. Where it exists, it is often fragmented and inconsistent and this can affect continuity of care. This was based on members' experience and the evidence previously noted in the [discussion for section 1.2](#) [ES2.2.4].

The committee noted from the qualitative evidence previously described in the [discussion for section 1.3](#) that different disciplines working together to support people with coexisting severe mental illness and substance misuse could help with coordinating care. If they work together and share responsibility for this group, the evidence showed it could improve the quality of health and social care services offered [ES2.1.7]. The evidence showed this could be done by joint management of cases and regular communication.

The committee also heard from an expert in local partnership working who described a framework designed to help local areas design and deliver flexible and coordinated services for people with multiple needs [EP1].

The committee noted that there needs to be a strategic framework for services that work with people with coexisting severe mental illness and substance misuse. And that commitment from providers and commissioners is essential for services to collaborate locally.

Based on the evidence, the expert testimony and their own experience, committee members agreed that a cross-sector partnership, with a shared understanding of the problem (based on assessment of local needs) and a shared vision for the future were important factors [ES2.1.7, EP1]. Based on their expertise and expert testimony, they developed a recommendation on how services need to work together. They also noted the lack of evidence from review question 1.2 on existing care pathways and agreed further research is needed (see the [recommendation for research on care pathway](#)).

The committee was aware of evidence from review 2 that a lack of policy on referrals has an effect on the organisation and continuity of care. Evidence from 4 qualitative studies conducted in different settings (including 1 UK study set in the voluntary sector) noted that uncertainty on who should make referrals can also have an impact [ES2.1.11].

Committee members noted that the evidence from qualitative studies (previously noted in sections 1.1 and 1.2) was consistent with their experience [ES2.1.10, ES2.1.11]. This showed that pathways were inadequately planned and supported and that movement across a care pathway was often restricted because none of the specialist services took responsibility for this group. They also noted that continuity of care can be interrupted because of changes in the commissioning process or cycle. For example, re-tendering for services can lead to disruption and the need to build new care pathways.

One UK low-quality qualitative study exploring the views of commissioners provided evidence of a facilitator associated with organisation and continuity of care. The study noted that good links between the statutory and voluntary sectors improved outcomes, such as reduced waiting times and delivery of care [ES2.1.11]. This could also help with organisation and continuity of care.

The same study also highlighted that existing resources were stretched and that investment in the non-statutory sector could lead to provision of services not available in the statutory sector [ES2.1.5; ES2.1.6]. But the committee noted that this study was published in 2006. It also noted that commissioning and service provision for addiction services, the demography of people who use the services, treatment and the types of substances used have all changed markedly since 2002.

The committee noted from the evidence that there is no national service configuration in place (review question 1.2). Members acknowledged the importance of including the needs of people with coexisting severe mental illness and substance misuse in the joint strategic needs assessment. They agreed the needs of this group could be included in local strategies (for example, housing, alcohol or drug services and crime prevention). The committee noted that referral processes and pathways need to be in place to ensure this happens – and that a joined-up approach would help because this group often falls through the gaps in services.

Committee members also highlighted the importance of prompt access to services, based on their own experience and evidence. This was based on 1 high-, 2 moderate- and 3 low-quality qualitative studies (3 set in the UK) reporting on barriers and facilitators when seeking access to health advice. Barriers included long waiting lists, and 1 low-quality UK study indicated that direct referrals by alcohol and addictions teams could act as a facilitator [ES2.2.8]. Members agreed that direct referrals may be useful. They noted that direct access to services may be beneficial (compared with, for example, open access drop-in clinics) because this would give the person a sense of continuity of care. In turn, this may also enhance feelings of trust [ES2.2.4].

## **Cost effectiveness**

There was no evidence for cost effectiveness for this recommendation.

## **Information sharing**

The discussion below explains how we made [recommendations 1.4.6 and 1.4.7](#).

## **Evidence**

The committee made recommendations to highlight the importance of information sharing. The committee noted an expert testimony that highlighted that confidentiality is a barrier often faced by voluntary sector as an excuse not to share information [EP2]. The committee also noted the importance of services knowing about other local services and being able to tell people with coexisting severe mental illness and substance misuse or their families or carers about them [ES2.2.3, ES2.2.10]. For example, 1 UK low-quality study set in the voluntary sector noted that GPs were unaware of local community groups that people with coexisting severe mental illness and substance misuse could use [ES2.2.3].

## Cost effectiveness

There was no evidence for cost effectiveness for this recommendation.

# Section 1.5 Improving service delivery

## Making health, social care and other support services more inclusive

The discussion below explains how we made [recommendations 1.5.1 to 1.5.5](#).

### Current practice

The committee observed what appears to be an inequity in the way that people with coexisting severe mental illness and substance misuse are treated by services compared with other groups. It noted that the needs of this group are often not taken into account and they risk being excluded from mainstream services. Therefore the committee made a strong recommendation on improving delivery of existing services to make them more inclusive.

### Evidence

Committee members were aware, from their own experience, the evidence and expert testimonies of the benefits of supporting people to participate in improving services [review 1, EP1, EP2]. The committee also noted from the evidence (previously described in the [discussion for section 1.2](#)) the importance of involving people with coexisting severe mental illness and substance misuse (and their family or carers), and providing them with information and support [ES2.2.9, ES2.2.10]. The ways in which people with coexisting severe mental illness and substance misuse, and their family or carers, could be involved in design and delivery of services were based on the findings from the review on epidemiology and current configuration [review 1].

The committee noted from its expertise and evidence (previously noted in the [discussion for section 1.1](#)) that people are often passed between services without being provided with appropriate care and support and that this may be because of negative attitudes or stereotyping by staff or services [ES2.1.3, ES2.2.5].

The committee also noted from its experience and the evidence that these factors can lead to a mistrust of professionals, resulting in poor engagement with services [ES2.2.5]. This was based on evidence from 3 (1 high and 2 moderate quality) of the 9 qualitative studies (1 high, 4 moderate and 4 low quality) reporting on barriers associated with access to effective care by trusted professionals. In addition, members agreed that a pessimistic attitude among professionals, about the likelihood of the person staying in the service may also be a contributing factor to the poor service.

The committee was aware from the evidence review on epidemiology that the prevalence of coexisting severe mental illness and substance misuse varied across regions. The evidence showed that semi-rural areas seem to have the highest need [ES1.1.2]. This was based on moderate evidence from 9 cohort studies (4 high, 1 moderate and 4 low quality) and 7 case-control studies (2 high, 2 moderate and 3 low quality) reporting on the prevalence of coexisting severe mental illness and substance misuse among those in contact with secondary mental health services.

Expert testimony suggested there is a high incidence of early psychosis in rural areas, but the committee noted from the evidence that specialist services are mostly in urban areas [review 1, EP3]. The committee agreed not to make a recommendation specifying content or configuration of service delivery by geographical settings. Instead it felt that the most important message was to ensure that any services needed (as identified by the joint strategic needs assessment) are delivered locally.

The committee made a strong recommendation on locating services in places that are safe and where there is minimal stigma attached to attending. It acknowledged the evidence (1 moderate- and 1 low-quality study) on co-location of services (for example, services based in the same facility) was mixed but recognised that there may be stigma in accessing certain services [ES2.1.12]. Committee members were aware from their experience and from expert testimony that people with coexisting severe mental illness and substance misuse are particularly vulnerable. They may be at risk of exploitation (for example, being forced to become sex workers or being taken advantage of in relation to their housing or financial situation). Or they may have experienced trauma (for example, women may have experienced rape) [EP1, EP2]. It agreed that a 'trauma-informed' approach would provide the best support for this group.

Members were also aware from the evidence that even if people knew about services, barriers to access included difficulty in contacting or gaining admission to services outside hours, long waiting lists and services not being local [review 2]. The committee considered

the evidence review (review question 1.2) on current configuration of services and developed a recommendation highlighting the importance of safety of location, low stigma and flexibility in opening times as factors that can help make services more accessible.

## **Cost effectiveness**

See the end of this section for details on cost effectiveness.

## **Adapting existing secondary care mental health services**

The discussion below explains how we made [recommendations 1.5.6 to 1.5.9](#).

### **Current practice**

The committee was aware of moderate evidence from 13 UK studies (2 high, 9 moderate and 2 low quality) that there were inconsistencies in the current configuration of 'dual diagnosis' services in NHS trusts across the UK [ES1.2.1]. These inconsistencies lie in several areas, including sources of funding, structure of services, type of staff members, services delivered and coordination of care. The committee considered the evidence on configuration of services and observed there were few specialist services for adults [ES1.2.1].

The committee agreed that the recommendations for specialist services (secondary care mental health services and 'dual diagnosis' services) need to focus on improving existing services using the expertise that is available instead of creating a specialist 'dual diagnosis' service. It felt that the standard care delivered in the UK could be improved by increasing the level of engagement people with severe mental illness and substance misuse have with existing services and that existing capacity and resources could be used to deliver this.

### **Evidence**

The committee made recommendations about the design, delivery and content of the service model, based on the evidence, economic model, expert testimony and members' expertise.

The committee considered the evidence for the effectiveness and efficiency of service delivery models, which included randomised controlled trials (RCTs) and observational

studies [ES3.1, ES3.2, ES3.3, ES3.4, ES3.5, ES3.6, ES3.7, ES3.8, ES3.9, ES3.10]. The evidence covered a range of service delivery interventions, showing some positive outcomes and that there was value in what the models were aiming to achieve. However, the members agreed that there was no overwhelming evidence of benefit to indicate a particular model should be recommended.

The committee agreed that there was limited evidence of effect for assertive community treatment and integrated treatment interventions in relation to mental health and substance misuse outcomes [ES3.1, ES3.2, ES3.3]. The committee noted that fidelity to delivery of interventions (whether the intervention was delivered as designed) in the service models was reported for only 5 studies. Where reported, the fidelity was considered to be good.

There was weak evidence for assertive community treatment based on 5 US RCTs [ES3.1]. The committee noted that the assertive community treatment intervention model is no longer used in the US and is rare in the UK. There was moderate evidence from 6 RCTs and 1 observational study (3 studies based in the UK) for integrated treatment interventions compared with treatment as usual [ES3.2]. There was weak evidence from 1 RCT for integrated treatment intervention compared with enhanced assessment and monitoring. The RCTs did not all show a clear evidence of benefit [ES3.3].

There was some improvement in service use outcomes (increase in physical and telephone contact) but members noted that it was debatable whether this was necessarily an evidence of benefit, because the reasons for contacts were not reported [ES3.1]. There was some evidence of effect on social care outcomes such as housing, employment and social functioning [ES3.1].

The committee felt that although the follow-up in the studies ranged from 24 weeks to 3 years, the length of time needed to observe small improvements can sometimes be 5 to 10 years [ES3.1, ES3.2].

There was moderate to weak evidence from 8 RCTs and 1 non-randomised controlled trial evaluating a range of interventions. The intervention included:

- brokerage case management [ES3.4]
- contingency management [ES3.5]
- time-limited care coordination [ES3.6]

- shelter-based psychiatric clinic [ES3.7]
- staff training [ES3.8]
- supportive housing [ES3.9]
- supportive text messaging. [ES3.10]

The comparator arms were no intervention, treatment as usual or an active comparator.

The committee noted that there was mainly weak evidence from small studies, with short follow-up (ranging from 16 to 78 weeks). Three studies were based in UK and Ireland but most of the evidence was from US. It noted that fidelity to delivery of the intervention was reported in only 2 studies (1 reported as low and 1 as high fidelity). Members discussed the potential value of service models incorporating contingency management, peer support (delivered as part of a care coordination intervention in 1 US study) or text messaging, and considered these further under research recommendations [ES3.5, ES3.6, ES3.10] (see the [recommendation for research on what works](#)).

The committee agreed that there was weak evidence for a staff training intervention considered in the review of effectiveness of service delivery models [ES3.8]. It noted that the 2 UK studies were of low quality, the evidence was inconsistent and did not appear to show an overall benefit. In addition, a committee member reflected on their own involvement in delivery of the intervention in 1 of the studies. The committee member noted that there were a number of challenges: staff often moved between services, there was a high turnover of staff, and low fidelity to delivery of the intervention.

The committee agreed not make a recommendation on training because the evidence did not show an overall benefit.

The committee agreed there were several gaps in the evidence from review 3 including:

- population (limited evidence on young people and vulnerable groups)
- interventions or measures – for example, measures looking at improving accessibility and availability of services
- outcomes (no evidence on physical health outcomes)
- efficiency of service delivery models – for example outcomes on accessibility of services (waiting times).

## Cost effectiveness

See the end of this section for details on cost effectiveness.

## Additional factors taken into account

The committee was aware of evidence from 4 qualitative studies (1 moderate- and 3 low-quality studies) of barriers or facilitators associated with integrated services. One low-quality UK study, for example, described mixed views among staff in a specialist 'dual diagnosis' service on whether services should be separate or integrated with mental health or substance misuse services [ES2.1.13]. It noted that there was evidence from the same study indicating that most commissioners felt that integrating services is essential for the effective and efficient delivery of care for people with complex needs. Some commissioners also noted that relationships between different services could be expected to improve if they were required to share budgets and resources.

Committee members felt this finding (published in 2006) should be treated with caution because the funding landscape has changed considerably since 2002. Based on their experience they noted that:

- a third tier of provision may not necessarily meet the needs of people with coexisting severe mental illness and substance misuse, and
- 'integration' in this context should be about joint working and coordinated care rather than developing a specialist service.

The committee noted that there was limited description of the comparator arms (often described as 'treatment as usual') in the studies included in review 3 and that most of the studies were conducted in the US. The committee's view was that 'usual care' in the US is likely to differ from that in the UK and the level of 'usual care' in the UK was considered to be of a better standard.

The committee used members' expert knowledge and the evidence to develop a recommendation on aspects that could be included in a service. This includes interventions that have shown to be effective in NICE guidelines for either severe mental illness or substance misuse. The committee was aware of the [study by Wenze \(2015; adjunctive psychosocial intervention following Hospital discharge for Patients with bipolar disorder and comorbid substance use: a pilot randomized controlled trial\)](#) included in the economic model. It reflected on the components of the 'treatment-engagement' sessions

in the Wenze (2015) study as well as members' own experience to develop a recommendation on ways to improve engagement.

The committee noted that any recommendation on improving service delivery needs to take into account the needs of those who reach crisis and those who experience a relapse after discharge. This recommendation was based on members' expertise. Members were aware from the evidence and their experience that people's care is often fragmented and that plans need to be in place to allow people to return for additional support after being discharged or losing touch with the system. They noted the evidence on facilitators for consistent care, including from 1 low-quality UK study that highlighted that good aftercare is an important means of preventing relapse [ES2.2.4]. They also noted that the [Department of Health's Mental Health Crisis Care Concordat](#) has information on developing an action plan for people in a crisis.

## Support for staff

The discussion below explains how we made [recommendations 1.5.10 to 1.5.12](#).

## Current practice

It is good practice for care coordinators working with people with severe mental illness who misuse substances to be offered support and supervision in secondary care mental health services. But practice may vary.

## Evidence

The committee noted the importance of support and supervision from their experience and the evidence from 2 high-, 1 moderate- and 2 low-quality qualitative studies (3 set in the UK) [ES2.1.15]. Because of the complexity of the care coordinator's role, the committee felt it was important to highlight in the recommendation the importance of a support structure for this role.

Committee members were also aware from the evidence that lack of training may act as a barrier to the effective delivery of care [ES2.1.16]. This was based on 10 qualitative studies (2 high, 3 moderate and 5 low quality), with 5 studies set in the UK. They also noted from the evidence and their experience that addressing gaps in practitioners' knowledge on substance misuse and mental health can encourage them to establish links with other services and help improve delivery of services.

Evidence from 1 high-, 3 moderate-, and 1 low-quality qualitative studies (2 set in the UK) found that staff having different perceptions of people with drug and alcohol problems, depending on the focus of the service they work in, is a barrier to service delivery and partnerships. This view was consistent among providers and commissioners across various settings [ES2.1.14].

Providers' views across 6 qualitative studies highlighted services not taking responsibility for people with coexisting severe mental illness and substance misuse, and the potential impact of this on meeting people's wider health, social care or support needs [ES2.1.10]. Three of the studies were set in the UK, 1 was of moderate quality and 2 were low quality. The committee noted that although 1 of the UK studies was of low quality it was recent and reflected voluntary sector providers' views. Members drew on the evidence and their own expertise and noted that helping overcome negative attitudes in staff will help make sure people with coexisting severe mental illness and substance misuse are not excluded from services.

Committee members were aware from the evidence from 5 qualitative studies (2 high-, 2 moderate- and 1 low-quality studies) of the importance of establishing good relationships between practitioners and people with coexisting severe mental illness and substance misuse and its impact on delivery of care [ES2.1.4]. They also noted there was high-quality UK evidence from 1 study to show that practitioners perceived that behaviours such as misusing drugs could affect relationships and act as a barrier to delivering care [ES2.1.4].

Based on the evidence and their experience, the committee made a strong recommendation on the need to build services that are tolerant and resilient. It agreed that services need to be able to help people work through relapse, poor attendance or a crisis to ensure they are not discharged too soon.

The committee heard from an expert on a service delivery model in early intervention services [EP3]. It noted that these services offer a more consistent and coordinated approach. That is because the staff working in them have lower caseloads, so can have more contact with the people they work with and provide stability. The committee noted a similar approach needs to be considered for staff who work with people with severe mental illness and substance misuse.

Taking into account the evidence, members' experience and expert testimony, the committee made strong recommendations on providing the right kind of support for staff.

## Cost effectiveness

The committee discussed the evidence from the cost effectiveness studies and the economic model when developing the recommendations on improving service delivery.

An economic analysis was undertaken. This comprised a review of existing cost effectiveness studies and a bespoke economic model.

The findings from the review of evidence (from 1 UK and 7 US studies) were inconsistent [ES4.1, ES4.2, ES4.3, ES4.4, ES4.5]. The US studies found that integrated treatment leads to minor cost savings but the UK study found that the intervention resulted in an increase in public sector costs.

In all studies, integrated treatment appears to result in improvement in some outcomes. But economic analyses used different outcome measures, reported as changes on various scales, making comparisons challenging. Three studies adopted before-and-after design, studies used different perspectives and time horizons, only 1 included economic study was judged to be directly applicable, 3 studies were judged to be characterised by minor limitations [++], 4 by potentially serious limitations [+], and 1 by very serious limitations [-]. Overall, there is little evidence to support one service delivery model over another, based on existing economic evidence.

The model was based on 3 studies. The first study, conducted in the US, comprised a treatment–engagement intervention (using resources more intensively than in standard care) for people with bipolar disorder and substance misuse. It was a small study whose health outcome was inconclusive, but yielded resource use data. The remaining 2 studies, both from the UK, were used to estimate baseline admissions rates for people with dual diagnosis.

The model's time-horizon was 1 year only. So increases in life expectancy that might have occurred as a result of an intervention were not included as benefits in the model. Because of the lack of data, a further conservative assumption was that wider costs, particularly those falling on the criminal justice system, were not included. Further, the model's measured outcome might not have measured all of the health outcome benefits.

The model showed that an intervention that combined enhanced engagement with standard care would need to reduce relapses by about 12% for the intervention to become cost saving.

The committee members had differing views about whether UK standard care is better than that reported in the US studies. It was felt that standard care in the UK may be more similar to the enhanced intervention modelled.

Assuming standard care in the UK is equivalent to the enhanced intervention modelled, it would be offering better outcomes at the same cost. By definition, that would be a cost-effective approach. However, assuming standard care in the UK would need to be enhanced and therefore need additional resources, at a cost of £226 per person and assuming an effect size of 10% the intervention would need to result in a small quality-adjusted life year (QALY) gain of 0.002 (equivalent to 0.73 days in full health) to be considered cost effective at an incremental cost effectiveness ratio threshold of £20,000 per QALY [ES4.6].

Given the results that were obtained even though a number of potential benefits were not considered because of the lack of data (for example on a person's life expectancy, improvement in the substance misuse problem, improvement in the mental health of service users the reduction in health and social care and the criminal justice system costs) the treatment–engagement intervention is very likely to be a cost-effective option.

## **Section 1.6 Maintaining contact between services and people with coexisting severe mental illness and substance misuse who use them**

The discussion below outlines how we made [recommendations 1.6.1 to 1.6.5](#).

Committee members decided to make recommendations on encouraging people to stay in contact with services and making services accessible. That is because they were aware, from the evidence and their own experience, that this group may find it hard to start or maintain contact with services [evidence review 2, EP2]. Also, their physical health, social care, housing or support needs are not being met.

### **Evidence**

The committee noted from its experience that it is important to take a long-term, realistic view in relation to involving the person in their care plan and coordinating their care. It noted from experience and evidence (previously noted in the [discussion for section 1.3](#)) that this is particularly true in light of the challenging nature of working with this group

[ES2.1.8].

Committee members were aware – from the evidence, expert testimony and their own experience – of the importance of providing continuity and adopting a flexible approach. The committee heard from experts working with people who are homeless about a range of methods that could be used to engage and stay in touch with this group [EP2]. The committee also considered evidence from 4 qualitative studies (1 high, 1 moderate, 2 low quality), of which 2 were UK studies [ES2.2.4]. This highlighted that a lack of continuity of care, along with changes in staff, can result in a lack of trust or reluctance to engage with services. It also highlighted that good aftercare was an important aspect of preventing relapse.

Committee members reflected on their experience and the evidence from 8 qualitative studies of mixed quality (2 high, 3 moderate and 3 low). Three of the studies (low quality) were set in the UK. The studies showed that a non-judgemental empathetic approach was needed when encouraging a person to stay in contact [ES2.2.7].

The committee noted barriers to access or uptake of social care or physical health services as highlighted in review 2 [ES2.1.3, ES2.2.1, ES2.2.2, ES2.2.4, ES2.2.5, ES2.1.12]. These included:

- fragmented care
- lack of support during a transition period (for those who had criminal convictions)
- failure to recognise cultural differences
- mistrust of healthcare professionals
- poor links to services
- negative connotations of being labelled as having problems with both mental health and substance misuse
- negative attitudes
- stereotyping or stigma about mental health diagnoses in substance misuse settings or about substance misuse in mental health settings.

The committee was aware from evidence review 2 and members' experience that having continuity of contact encourages people to keep in touch with services. The committee

made a weak recommendation on a range of approaches based on members' experience and expert testimony [EP2, EP4].

The committee recognised that everyone with coexisting severe mental illness and substance misuse faces difficulties in receiving care, but it wanted to highlight that some groups are particularly vulnerable. It acknowledged that factors contributing to this include not being able to get to, or stay in contact with, the services they need [ES2.1.10].

The committee noted moderate to strong evidence from 11 cohort studies and 7 case-control studies on the characteristics of the coexisting severe mental illness and substance misuse population [ES1.1.5]. It noted that it is more common in younger people and men [ES1.1.5]. It also noted that homelessness is a frequent outcome for this group [ES1.1.9]. Members also acknowledged that pregnant women or women who have recently given birth are particularly vulnerable. This was based on their experience and evidence review 2. The committee noted from its experience that people with coexisting severe mental illness and substance misuse frequently have a history of trauma and that this can lead to disruptive attachments and challenging behaviour. It also noted that, from a 'life course' perspective, older people may be a particularly vulnerable group.

The committee noted that the evidence linking ethnicity with coexisting severe mental illness and substance misuse was inconsistent [ES1.1.5]. Apart from age, gender and ethnicity, there was a lack of evidence to show that groups identified in the equality impact assessment are more likely to have a coexisting severe mental illness and substance misuse. This includes, for example: people with a learning disability; teenage parents; Gypsies and Travellers; asylum seekers or refugees; lesbian, gay, bisexual, transsexual or transgender people; and sex workers [ES1.1.5].

The committee was aware from its experience that everyone has a range of social care needs, but noted that the evidence did not identify particular social care needs for groups identified in the equality impact assessment. That includes, for example, those who are socially isolated, on low income, have a history of being 'looked after' or are adopted or have a history of experiencing or witnessing domestic violence and abuse [ES1.1.9].

Although no evidence was identified, the committee was aware from its experience that some groups may be reluctant to engage with, or may encounter difficulties when engaging with, services for people with coexisting severe mental illness and substance misuse. This includes people who are recent migrants, have language difficulties or are from specific religious communities. From an equality perspective, committee members

recommended including people with language difficulties.

Although it is not an exhaustive list, the committee highlighted the groups identified in recommendation 1.6.4 based on the evidence, their expertise and expert testimony [ES1.1.5, ES1.1.9, review 2, EP2].

The committee noted that, although the evidence from review 2 provided insight into barriers and facilitators to delivery of care, it agreed that research was needed to understand the experience of people at different stages of recovery (see the [recommendation for research on barriers and facilitators](#)).

Committee members were aware, from the evidence and their experience, that lack of emotional support and empathy can be a contributing factor to non-attendance at appointments or loss of contact [ES2.2.7]. They were also aware that non-attendance can often lead to discharge [review 2]. Based on the evidence, their expertise and expert testimony, they made a strong recommendation on actions services can take to ensure that non-attendance or loss of contact is treated as a matter of concern [review 2, EP2].

Committee members reflected on their experience and expert testimony and noted the importance of maintaining contact and reaching out to people to help them remain engaged with services [EP2]. Based on their experience, they made a weak recommendation on the follow-up actions to address non-attendance.

### **Additional factors taken into account**

The committee noted that maintaining engagement can lead to improved outcomes and may place less burden on crisis care or inpatient admissions.

## **Other points the committee discussed**

The committee discussed the exclusion criteria in the scope and noted that exclusion of mental health disorders such as eating disorders was a major gap.

The committee noted that criminal justice system settings were excluded from the scope, but was aware of [NICE guidelines currently in development on the mental health of adults in contact with criminal justice system](#) and the [physical health of people in prison](#). It also recognised that young people and adults with coexisting severe mental illness and substance misuse who need a safe place to stay may come into contact with people within

this setting, for example, the police. The committee noted that resources for helping the police to support people with vulnerabilities are available in the [Home Office's Crisis Care Concordat](#).

The committee considered a range of expertise that would be helpful to inform the development of the guideline and invited expert testimony in early intervention services, primary care, homeless, and local partnership working. The committee also acknowledged other groups (refugees, veterans) but recognised that there is a general set of needs that would subsume the specific needs of particular populations.

The committee considered all the evidence available in developing this guideline. However, some evidence statements provided background information and could not be explicitly linked to recommendations [ES1.1.1, ES1.1.3, ES1.1.4, ES1.1.6, ES1.1.7]. The committee heard from an expert in early intervention services who described a study on contingency management (see the [CIRCLE study](#)) that provided background information and was not linked to a specific recommendation [EP5].

The committee discussed the various forms of support groups or mechanisms for peer support. It was aware of mutual aid organisations including Alcoholics Anonymous (AA), Narcotics Anonymous (NA), Dual Recovery Anonymous (DRA) and SMART recovery and discussed the merit of adding a reference to such forms of support as examples in the guideline recommendations.

It was also aware of [Public Health England's briefing on the evidence-based drug and alcohol treatment guidance recommendations on mutual aid](#) but noted it was not aware of evidence establishing use of mutual aid in people with coexisting severe mental illness and substance misuse. In addition, because peer support and mutual aid were areas identified for a research recommendation, the committee did not recommend specifying examples of mutual aid groups in the guideline recommendations.

The committee also noted that there is a stigma attached to the term substance 'misuse' but recognised that this term is used in other NICE guidelines.

## Evidence reviews

Details of the evidence discussed are in [evidence reviews, reports and papers from experts in the area](#).

Studies reported in evidence review 1 were all based in the UK. For evidence statements derived from evidence reviews 2, 3 and 4 we have noted the number of studies based in the UK in the committee's discussion section. Please refer to the full evidence statements in the evidence reviews on the applicability of the evidence base to the UK.

The evidence statements are short summaries of evidence. Each statement has a short code indicating which document the evidence has come from.

**Evidence statement (ES) number 1.1.1** indicates that the linked statement is numbered 1 in review question 1.1 of review 1. **ES1.2.1** indicates that the linked statement is numbered 1 in review question 1.2 of review 1. **ES2.1.1** indicates that the linked statement is numbered 1 in review question 2.1 of review 2. **ES3.1** indicates the linked statement is numbered 1 in review 3 and **ES4.1** indicates the linked statement is numbered 1 in review 4. **EP1** indicates that expert paper 1: 'Local partnership working: examples drawn from the work of the Making Every Adult Matter coalition' is linked to a recommendation. **EP2** indicates that expert paper 2: 'St Mungo's: people who have a dual diagnosis and are homeless' is linked. **EP3** indicates that expert paper 3: 'Early Intervention in psychosis services' is linked. **EP4** indicates that expert paper 4: 'Dual diagnosis among homeless people: primary care perspective' is linked.

If a recommendation is not directly taken from the evidence statements, but is inferred from the evidence, this is indicated by **IDE** (inference derived from the evidence).

**Section 1.1:** ES1.1.8, ES1.1.9, ES2.1.2, ES2.1.3, ES2.1.10, ES2.2.1, ES2.2.4; EP2, EP4; IDE

**Section 1.2:** ES2.1.1, ES2.1.4, ES2.1.9, ES2.1.11, ES2.2.4, ES2.2.7, ES2.2.9, ES2.2.10; EP2; IDE

**Section 1.3:** ES1.1.8, ES1.1.9, ES2.1.7, ES2.1.8, ES2.2.1, ES2.2.2, ES2.2.3, ES2.2.4, ES2.2.6; EP1, EP2, EP3, EP4; IDE

**Section 1.4:** ES2.1.5, ES2.1.6, ES2.1.7, ES2.1.10, ES2.1.11, ES2.2.3, ES2.2.4, ES2.2.8, ES2.2.10; EP1, EP2; IDE

**Section 1.5:** ES1.1.2, ES1.2.1, ES2.1.3, ES2.1.4, ES2.1.10, ES2.1.12, ES2.1.13, ES2.1.14, ES2.1.15, ES2.1.16, ES2.2.4, ES2.2.5, ES2.2.9, ES2.2.10, ES3.1, ES3.2, ES3.3, ES3.4, ES3.5, ES3.6, ES3.7, ES3.8, ES3.9, ES3.10, ES4.1, ES4.2, ES4.3, ES4.4, ES4.5, ES4.6; EP1, EP2, EP3; IDE

**Section 1.6:** ES1.1.5, ES1.1.9, ES2.1.3, ES2.1.8, ES2.1.10, ES2.1.12, ES2.2.1, ES2.2.2, ES2.2.4,

ES2.2.5, ES2.2.7; EP2, EP4; IDE

## Gaps in the evidence

The committee's assessment of the evidence on coexisting severe mental illness and substance misuse identified a number of gaps. These gaps are set out below.

1. Evidence on the characteristics of people with coexisting severe mental illness and substance misuse in the groups identified in the equity impact assessment. This includes: people with a learning disability; teenage parents; Gypsies and Travellers; asylum seekers or refugees; lesbian, gay, bisexual, transsexual or transgender people; and sex workers.

(Source review 1)

2. Social care needs of people identified in the equity impact assessment. This includes those who are socially isolated, are on a low income, have a history of being 'looked after' or are adopted, or have a history of experiencing or witnessing domestic violence and abuse.

(Source review 1)

3. Views and experiences of:

a) commissioners

b) primary care practitioners who work with vulnerable groups

c) groups identified in the equity impact assessment (with the exception of young people and ex-offenders).

(Source review 2)

4. Interventions or measures assessing efficiency of services (for example, measures looking at improving accessibility and availability of services).

(Source review 3)

5. Different models of service delivery (for example, a comparison of specialist, integrated

or separate services) and efficiency of service delivery models.

(Source review 3)

# Recommendations for research

The guideline committee has made the following recommendations for research.

## 1 Needs assessment

In the UK, how prevalent is coexisting severe mental illness with substance misuse and what are the physical health, social care, housing or other support needs of people with this diagnosis?

### Why this is important

There is limited evidence on the physical health, social care, housing or other support needs of people with coexisting severe mental illness and substance misuse. This includes prevalence of coexisting physical conditions such as cardiovascular, respiratory or infectious diseases and social care needs such as social isolation or poor housing.

Evidence on the differential impact on physical health of the type of substance used and the mental health condition would also be useful. Longitudinal evidence is needed.

This will help design coordinated evidence-based services to meet the wider health and social care needs of this group of people and provide a good standard of care.

People with coexisting severe mental illness and substance misuse may present in a variety of settings. Research on the needs that this group present with in specific settings (for example, primary care) would be beneficial. So would research evaluating the needs of particularly vulnerable groups (for example, those identified in the equality impact assessment).

## 2 What works?

In the UK, how effective and cost effective are service delivery interventions such as peer support, contingency management or text messaging delivered alone or in combination (in conjunction with standard care) compared with standard care alone for young people and adults with coexisting severe mental illness and substance misuse?

## Why this is important

There is limited evidence on the optimal service delivery model for young people and adults with coexisting severe mental illness and substance misuse. There is increasing use of contingency management, peer support (including mutual aid) or text messaging as part of a service delivery model to help people access services.

More research is needed to assess the use, benefit and whether these methods improve this group's engagement with services.

There is limited evidence on the cost effectiveness of interventions and services with this group. Further research is also needed on whether particular services or elements of standard care for this group give better value for money. A mixed methods approach could identify which of the different elements delivered in a service model are optimal for the person.

Research in particularly vulnerable groups (for example those identified in the equality impact assessment) is needed.

## 3 Costing tool

Which elements of health, social care or other support services work best at a local level and provide the best 'value for money' to address the needs of young people and adults with coexisting severe mental illness and substance misuse?

## Why this is important

There is a lack of agreed service models that address the range of health, social care and other support needs of people with coexisting severe mental illness and substance misuse. Information on the value these may provide are also limited.

A costing tool will help decision makers 'mix and match' interventions and services to see which package provides the best outcome. It will also help identify cost savings and determine whether the additional benefits (in terms of health, social care or criminal justice outcomes) are worth the extra costs. It may also help to demonstrate whether better functioning mainstream services are effective and provide value for money.

## 4 Barriers and facilitators

What are the barriers and facilitators for young people and adults with coexisting severe mental illness and substance misuse to obtain an optimal service (including optimal time frame for delivering interventions) to meet their needs and enable their recovery?

### Why this is important

There is limited evidence that identifies the triggers for deterioration and the turning points for recovery for people with coexisting severe mental illness and substance misuse.

Although review 2 contains evidence on the views and experiences of this group, their family or carers, it is not always clear which point in the care pathway the views and experiences expressed relate to. As such, it is difficult to fully break down the experience of care received at various intervals along the care pathway. Understanding the experience of people who are at different stages of recovery and how they have maintained their progress and success (1 year, 3 years, 5 years, 10 years+) will help with designing more effective services and planning services that deliver interventions at the right time.

## 5 Care pathway

In the UK, what is the optimal care pathway for young people and adults with coexisting severe mental illness and substance misuse?

### Why this is important

There is a lack of published evidence on care pathways on treatment, management and follow-up of people with coexisting severe mental illness and substance misuse. In the UK, service configurations, treatment philosophies and funding streams act as barriers to providing coordinated care. Separate mental health and substance misuse services are usually provided by different organisations, have different organisational and managerial structures, and staff within each service often lack the knowledge and skills needed to work effectively with people from another organisation.

A review of what has worked or not in areas that have implemented changes to practice will help services develop optimal care pathways.

## Update information

### Minor changes since publication

**March 2020:** Cross reference to NICE's guideline on supporting adult carers added to recommendations 1.27 and 1.2.8.

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## Accreditation

