NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Rehabilitation in adults with severe and enduring mental illness

NHS England has asked NICE to develop a new clinical guideline on rehabilitation in adults with severe and enduring mental illness.

For the purposes of this guideline, rehabilitation has been defined by NHS England as a personalised, interactive and collaborative process which aims to enable a person to maximise their potential to live a full and active life within their family, community, and education or workplace as appropriate. It has also been defined by NICE as an active process to restore or optimise physical, mental and social capability and full autonomy and prevent avoidable functional regression. The rehabilitation process has short-, medium- and long-term goals. In mental health rehabilitation, there is also an emphasis on the ‘whole system approach’ which includes inpatient and community components and supports individuals to progress in their recovery by encouraging their skills, functioning and autonomy, in order to give them hope for the future, and which leads to successful community living and social inclusion.

The guideline will be developed using the methods and processes outlined in developing NICE guidelines: the manual.

1 Why the guideline is needed

Key facts and figures

The prevalence of severe mental illness is estimated to be about 1 in 100 people, equating to 550,000 people in England. About 75% have a diagnosis of psychosis, around 10% have bipolar disorder, and the remaining 15% have other diagnoses such as neurodevelopmental disorders, severe depression or
The prevalence of severe mental illness is higher in men than women, and in young adults than in older people. It is also higher among black and ethnic minorities, people living in cities and people in poorer neighbourhoods.

Around 25% of people who are newly diagnosed with psychosis go on to develop particularly complex problems that need mental health rehabilitation. These problems can have a severe impact on the person’s day to day function and often make it impossible for them to be discharged from acute mental health inpatient care back to the community. Complex problems include:

- treatment-resistant ‘positive’ symptoms (delusions and hallucinations) and ‘negative’ symptoms (loss of motivation and apathy)
- specific cognitive impairments that negatively affect the person’s organisational and social skills
- comorbidities including other mental health problems, for example anxiety and depression
- physical health problems, such as diabetes and cardiovascular and pulmonary conditions
- pre-existing developmental problems, for example autism spectrum disorder
- co-existing problems such as substance misuse.

Rehabilitation is essential to address these complex problems and can lead to successful and sustained community discharge for many people in this group.

Rehabilitation for people with severe and enduring mental illness is usually provided in a care pathway that includes inpatient and community rehabilitation services. At any one time, around 1% (2,120 per year) of people with psychosis are inpatients are in a rehabilitation unit. Ongoing support to enable further recovery after discharge is provided by specialist mental health supported accommodation services, with clinical input from community rehabilitation teams (where they exist) or other statutory community mental health teams.
In 2009 the annual cost of all types of schizophrenia was estimated to be £8.8 billion. Of this, the greatest cost to society was from lost employment (£4.1 billion per year; 47%), emphasising the need for effective rehabilitation services to enable people to return to work.

Treatment costs contributed £3.5 billion (40%) and informal care £1.2 billion (13%), with psychiatric inpatient care representing the single largest service cost (£1.7 billion). Although only 25% of people with schizophrenia go on to develop severe and enduring mental illness and need rehabilitation services, they will take up a significant proportion of this treatment cost. Therefore, providing effective rehabilitation that allows people to be discharged from inpatient care could lead to reduced costs.

**Current practice**

Although the mental health rehabilitation care pathway includes both inpatient and community services, there is significant national variation in how they are provided.

A national survey in 2012 found that almost all NHS trusts in England that provide mental health services have at least 1 type of inpatient rehabilitation unit accepting referrals from acute admission wards and secure mental health services. Most of these (59%) are stand-alone, community-based rehabilitation units, 29% are separate units within the mental health unit's grounds and 11% are wards within a mental health unit.

In areas where there is a lack of local rehabilitation services, people may only be able to have treatment through the independent sector in the form of 'out of area treatments' (OATs). OATs displace people with severe and enduring mental illness from their communities and families and are 65% more expensive than local placements. Around £350 million each year is spent on OATs for people with severe and enduring mental illness.

Since 2012 there have been closures of rehabilitation units in some areas, and only 50% of trusts have community rehabilitation teams. Most people affected by these changes have complex psychosis, which for the purposes of this guideline is defined as enduring psychosis that has not responded to
treatment, may involve comorbidities and the effects of trauma, and impacts on a person's social, interpersonal and occupational functioning.

Policy, legislation, regulation and commissioning

Legislation

- The Mental Capacity Act 2005 describes how decisions should be made for people who are unable to make decisions themselves.
- The Care Act 2014 describes the care and support to be provided for adults, including safeguarding adults from abuse or neglect, and the support to be provided to carers.
- The Department of Health guidance on Refocusing the Care Programme Approach sets out details of this approach, including the formation of a care plan which identifies people's health and social care needs and the appointment of a key worker.

Commissioning

NHS England has produced rehabilitation commissioning guidance for clinical commissioning groups which covers both physical and mental illness, and sets out the definitions, principles and expectations and proposed models for rehabilitation services. This guideline will follow these principles when recommending how rehabilitation services should be provided.

The Five Year Forward View for Mental Health published by NHS England in 2016 sets out recommendations with the aim of achieving parity between mental and physical health. However, understanding varies among commissioners about the most clinical and cost effective way to structure rehabilitation services for people with complex psychosis. This guideline will provide a framework for commissioners to use.

The Joint Commissioning Panel for Mental Health (JCPMH), co-chaired by the Royal College of Psychiatrists and the Royal College of General Practitioners, provides specific guidance for commissioners of rehabilitation services for people with complex mental health needs. This guideline will build on the guidance produced by the JCPMH.
Education, Health and Care (EHC) plans are issued after a child or young person is assessed, and set out the education and social care their local authority must provide and the healthcare their local healthcare provider must arrange. EHC plans last up to the age of 26 so there may be young people needing rehabilitation whose care is still covered by an EHC plan.

2 Who the guideline is for

This guideline is for:

- health and social care practitioners in primary care, secondary care and specialist mental health services
- practitioners in other health, social care and non-health sectors who may have direct contact with or are involved in providing health and other public services for people with complex psychosis
- those with responsibility for planning and developing rehabilitation services for people with complex psychosis, including health and social care commissioners (including those commissioning private services), local authorities and directors of public health and NHS trust managers
- public sector providers of mental health services
- people using mental health services, their families and carers and the public.

It may also be relevant for:

- charities and other non-statutory organisations who provide care and support to people with mental health problems, particularly those who provide supported accommodation
- private sector providers of mental health services
- further education services
- employers
- forensic mental health services.
NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive.

Equality considerations
NICE has carried out an equality impact assessment during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will look at inequalities relating to the higher prevalence of complex psychosis in men (70%) as well as higher rates in young adults, black and minority ethnic groups, people in poorer households, people with mild learning disabilities, and people who were in care as children. People in these groups may also find it more difficult to access mental health services. Women may also find it difficult to access rehabilitation services where local services are men-only.

3 What the guideline will cover

3.1 Who is the focus?

Groups that will be covered
- Adults (aged 18 years and older) with complex psychosis.

For the purposes of this guideline, complex psychosis is defined as enduring psychosis that has not responded to treatment, may involve comorbidities and the effects of trauma, and impacts on a person’s social, interpersonal and occupational functioning.

Groups that will not be covered
- People with moderate or severe learning disabilities.
3.2 Settings

Settings that will be covered
- Any NHS or local authority funded service in which rehabilitation takes place, or where people who would benefit from rehabilitation services can be identified.

Settings that will not be covered
- Prisons.
- Secure units within the forensic mental health services.

3.3 Activities, services or aspects of care

Key areas that will be covered
We will look at evidence in the areas below when developing the guideline, but it may not be possible to make recommendations in all the areas.

1 Identifying people who would benefit most from rehabilitation services.
2 Organisation, function and structure of services, including inpatient and community-based rehabilitation units and teams.
3 Delivering optimised treatments for people with complex psychosis to help recovery and prevent relapse.
4 Therapeutic programmes specific to rehabilitation including:
   - activities of daily living
     - self-care
     - life skills, for example cooking, cleaning, shopping, budgeting, maintaining a tenancy
     - social skills
   - vocational rehabilitation (including leisure, education and work)
   - healthy living (diet, exercise, oral health, health monitoring and accessing health services, and cessation programmes for smoking and alcohol/drug).
5 Types of supported accommodation and housing.
6 Collaborative care planning and service user experience.
7. Transition from rehabilitation services to other parts of the mental health system or discharge to primary care.

**Areas that will not be covered**

8. Effectiveness of individual treatments for complex psychosis.


10. Specific rehabilitation programmes following other mental illnesses.

**Related NICE guidance**

*Published*

- **Attention deficit hyperactivity disorder: diagnosis and management** (2018) NICE guideline NG87
- **Mental health of adults in contact with the criminal justice system** (2017) NICE guideline NG66
- **Coexisting severe mental illness and substance misuse: community health and social care services** (2016) NICE guideline NG58
- **Transition from children’s to adults’ services for young people using health or social care services** (2016) NICE guideline NG43
- **Mental health problems in people with learning disabilities: prevention, assessment and management** (2016) NICE guideline NG54
- **Transition between inpatient mental health settings and community or care home settings** (2016) NICE guideline NG53
- **Bipolar disorder: assessment and management** (2014) CG185
- **Psychosis and schizophrenia in adults: prevention and management** (2014) NICE guideline CG178
- **Social anxiety disorder: recognition, assessment and treatment** (2013) NICE guideline CG159
- **Autism spectrum disorder in adults: diagnosis and management** (2012) NICE guideline CG142
- **Service user experience in adult mental health** (2011) NICE guideline CG136
• **Self-harm in over 8s: Long-term management** (2011) NICE guideline CG133

• **Common mental health problems: identification and pathways to care** (2011) NICE guideline CG123

• **Coexisting severe mental illness (psychosis) and substance misuse:** assessment and management in healthcare settings (2011) NICE guideline CG120

• **Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence** (2011) NICE guideline CG115

• **Alcohol-use disorders: diagnosis and management of physical complications** (2010) NICE guideline CG100

• **Borderline personality disorder: recognition and management** (2009) NICE guideline CG78

• **Antisocial personality disorder: prevention and management** (2009) CG77

• **Depression in adults: recognition and management** (2009) NICE guideline CG90

• **Depression in adults with a chronic physical health problem: recognition and management** (2009) NICE guideline CG91

• **Obsessive-compulsive disorder and body dysmorphic disorder: treatment** (2005) NICE guideline CG31

• **Post-traumatic stress disorder: management** (2005) NICE guideline CG26

**In development**

• Rehabilitation for chronic neurological disorders including traumatic brain injury. NICE guideline. Publication date to be confirmed

• Update to: Depression in adults: recognition and management (2009) NICE guideline CG90. Publication date to be confirmed

**NICE guidance about the experience of people using NHS services**

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to rehabilitation in adults with complex psychosis.
3.4 Economic aspects

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using an NHS and personal social services (PSS) perspective, although wider perspectives will be considered if it is appropriate and feasible to do so.

3.5 Key issues and draft questions

While writing this scope, we have identified the following key issues and draft questions related to them:

1. Identifying people who would benefit most from mental health rehabilitation services.
   1.1 Which people with complex psychosis are likely to benefit most from referral to rehabilitation services?
   1.2 What co-existing medical, social (including family, cultural and ethnicity), communication, neurodevelopmental, cognitive or mental health problems pose barriers for people with complex psychosis in accessing rehabilitation services?

2. Organisation, function and structure of services, including inpatient and community-based rehabilitation units and teams.
   2.1 What is the effectiveness of rehabilitation services compared with standard care?
2.2 What is the effectiveness of inpatient rehabilitation services compared with community-based rehabilitation services?

2.3 What are the required components of an effective rehabilitation pathway?

2.4 What are the barriers and facilitators to integrated rehabilitation care pathways involving multiple providers (including health, social care, non-statutory, independent and voluntary services)?

3 Delivering optimised treatments for people with complex psychosis to help recovery and prevent relapse.

3.1 What principles should guide adjustments to standard treatments in the management of the underlying psychosis in people using rehabilitation services?

4 Therapeutic programmes specific to rehabilitation including:

- activities of daily living
  - self-care
  - life skills, for example cooking, cleaning, shopping, budgeting, maintaining a tenancy
  - social skills
- vocational rehabilitation (including leisure, education and work)
- healthy living (including diet, exercise, oral health, health monitoring and accessing health services, and cessation programmes for smoking and alcohol/drug).

4.1 What interventions specific to rehabilitation are effective for people with complex psychosis to improve their activities of daily living?

4.2 What interventions specific to rehabilitation are effective for people with complex psychosis to improve their inter-personal functioning?

4.3 What interventions specific to rehabilitation are effective for people with complex psychosis to improve their engagement in community activities (leisure, education and work)?

4.4 What interventions specific to rehabilitation are effective in improving the engagement of people with complex psychosis in healthy living (diet, exercise, oral health, accessing health services, health monitoring)?
4.5 What interventions specific to rehabilitation are effective in improving the engagement of people with complex psychosis in smoking cessation?

4.6 What interventions specific to rehabilitation are effective in improving the engagement of people with complex psychosis in addressing substance misuse?

5 Types of supported accommodation and housing.

5.1 What features of supported accommodation and housing promote successful community living in people with complex psychosis?

6 Collaborative care planning and service user experience.

6.1 What is the best way of facilitating collaborative care planning between people with complex psychosis, practitioners and providers?

6.2 What interventions are valued by people with complex psychosis who are cared for by rehabilitation services, and valued by their families?

7 Transition from rehabilitation services to other parts of the mental health system or discharge to primary care.

7.1 What are the criteria for transition from rehabilitation services to other parts of the mental health, social care and primary care systems?

The key issues and draft questions will be used to develop more detailed review questions, which guide the systematic review of the literature.

3.6 Main outcomes

The main short-, medium- and long-term outcomes that may be considered when assessing the evidence are:

1 Social functioning.

2 Activities of daily living.

3 Successful discharge from inpatient rehabilitation unit to community.

4 Independent or successful community living.

5 Gaining or maintaining employment.

6 Participation in education.

7 Service user experience.

8 Carer experience.
9 Readmission to hospital.
10 Rate of relapse.
11 Duration of stay in rehabilitation unit.
12 Mortality.
13 Quality of life.
14 Capabilities.

4 NICE quality standards and NICE Pathways

4.1 NICE quality standards

NICE quality standards that may need to be revised or updated when this guideline is published

- Psychosis and schizophrenia in adults (2015) NICE quality standard QS80
- Learning disabilities: identifying and managing mental health problems (2017) NICE quality standard QS142

4.2 NICE Pathways

NICE Pathways bring together everything we have said on a topic in an interactive flowchart. When this guideline is published, the recommendations will be included in the NICE Pathway on [X] (in development).

An outline based on this scope is included below. It will be adapted and more detail added as the recommendations are written during guideline.
5 Further information

This is the draft scope for consultation with registered stakeholders. The consultation dates are 17 April to 15 May 2018.

The guideline is expected to be published in June 2020.

You can follow progress of the guideline here.

Our website has information about how NICE guidelines are developed.