

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Guideline scope

### Rehabilitation in adults with complex psychosis and related severe mental health conditions

NHS England has asked NICE to develop a new guideline on rehabilitation in adults with complex psychosis and related severe mental health conditions.

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. It has also been defined by NICE as an active process to restore or optimise physical, mental and social capability and full autonomy, and to 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'. This includes both inpatient and community components and involves supporting people to recover by helping them develop their own skills, functioning and autonomy to give them hope for the future and enable successful community living and social inclusion.

This guideline scope uses the term 'complex psychosis and related severe mental health conditions'. This group encompasses more than 1 primary diagnosis and refers to people who have complex problems that require a period of rehabilitation to make discharge to the community possible. This will include people with a primary diagnosis of psychoses, including schizophrenia, bipolar disorder, psychotic depression, delusional disorders and schizoaffective disorder. People with a primary diagnosis of personality disorders, obsessive compulsive disorders, eating disorders, anxiety disorders and substance misuse problems are not included in the scope.

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 lifetime prevalence of schizophrenia is 1 in 100 people, equating to 550,000 people in England. Around 25% of people newly diagnosed with a severe mental illness such as schizophrenia, schizoaffective disorder or bipolar affective disorder will go on to develop particularly complex problems and need mental health rehabilitation. People with other mental health disorders whose functioning is significantly affected by their illness or disorder may also need mental health rehabilitation.

Over 80% of people who are referred for mental health rehabilitation have a primary diagnosis of schizophrenia, schizoaffective disorder or other psychosis, around 8% have bipolar affective disorder, and the remaining 11% have other diagnoses. Around two-thirds are male. Although people who need mental health rehabilitation have varied primary diagnoses, a common feature is the complex problems they experience, which have a severe, negative impact on their day-to-day functioning, including managing everyday activities and social, interpersonal and occupational functioning. These problems make it impossible for people to be discharged from acute mental health inpatient care back to the community. Problems may include one or more of the following:

- treatment-resistant symptoms (for people with a primary diagnosis of psychosis this may include 'positive' symptoms such as delusions and hallucinations and/or severe 'negative' symptoms that lead to problems with motivation)
- specific cognitive impairments associated with severe psychosis that have a negative impact on organisational and social skills
- coexisting mental health problems, such as severe anxiety, depressive or obsessive compulsive symptoms or substance misuse

- coexisting physical health problems, such as diabetes, cardiovascular or pulmonary conditions
- pre-existing neurodevelopmental disorders, for example autism spectrum disorder.

Rehabilitation is essential to address these complex problems. For the vast majority of people, mental health rehabilitation leads to successful and sustained discharge from hospital and a meaningful, rewarding community life.

This scope does not include people with a primary diagnosis of personality disorder, obsessive compulsive disorder, eating disorder, anxiety disorder or substance misuse. While it is acknowledged that these conditions can be just as severe and disabling, the rehabilitation requirements of these groups are different and it would be difficult to cover all these varied requirements in a single guideline. Similarly, those people with a primary diagnosis of moderate to severe learning disabilities are not included in this scope, as these people will require specialist care delivered by learning disability services and it would be difficult to cover these specialist requirements in a single guideline.

Rehabilitation for people with complex psychosis and related severe mental health conditions is usually provided in a stepped 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 in a rehabilitation unit. Ongoing support to enable further recovery after discharge is provided by supported accommodation services, with clinical input from specialist rehabilitation mental health services, community rehabilitation teams (where they exist) or other statutory community mental health teams.

In 2009 the annual cost 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 complex psychosis 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 NHS rehabilitation services, people may receive treatment through the NHS or independent sector in the form of 'out of area treatments' (OATs). OATs often displace people with complex psychosis and related severe mental health conditions from their communities and families, although for some people being placed outside their local area is appropriate and may provide an opportunity to make a 'clean start' away from unhelpful environments or influences. However, OATs are twice as expensive as local placements. Overall, over £500 million is spent on inpatient rehabilitation beds in England per year (including NHS and independent sector provision).

Since 2012 there have been many closures of NHS inpatient rehabilitation units across England and only half of trusts have a community rehabilitation team. Given that the users of these services have complex psychosis and related severe mental health conditions as described above, this suggests that many people do not have access to the specialist rehabilitation services they need, either locally or elsewhere.

## **Policy, legislation, regulation and commissioning**

### **Legislation**

- The Mental Health Act 1983 (and its 2007 revision) describe what organisations may do to care for people with mental illness, including compulsory admission to inpatient care.
- 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 '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.
- The Equality Act 2010 legally protects people from discrimination in the workplace and wider society, and includes disability, which may be due to mental illness.

### **Commissioning**

In 2016, NHS England produced 'Commissioning Guidance for Rehabilitation' 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 and related severe mental health conditions. 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 conditions whose needs cannot be met by standard mental health services. 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:

- healthcare professionals in primary care, secondary care and specialist mental health services
- practitioners in social care and non-health sectors who may have direct contact with or are involved in providing public services for people with complex psychosis and related severe mental health conditions.
- those with responsibility for planning and developing rehabilitation services for people with complex psychosis and related severe mental health conditions, 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, employment and substance misuse services

- 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 and related severe mental health conditions in men. This means that services are often focused around men, and women can find it difficult to access rehabilitation services – for example, where local services are men-only. Black and minority ethnic groups, homeless people, refugees, people in poorer households, people with mild learning disabilities, and people who were in care as children may also find it more difficult to access mental health services.

## **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 and related severe mental health conditions. This includes people with a primary diagnosis of

psychoses, including schizophrenia, bipolar disorder, psychotic depression, delusional disorders and schizoaffective disorder.

### **Groups that will not be covered**

- People with a primary diagnosis of an eating disorder, obsessive compulsive disorder, personality disorder, neurodevelopmental disorder or anxiety disorder.
- 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 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 mental health 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 and related severe mental health conditions to help recovery and prevent relapse.
- 4 Collaborative care planning and service user experience.
- 5 Therapeutic programmes specific to rehabilitation including:



- activities of daily living, including
    - self-care
    - life skills, for example cooking, cleaning, shopping, budgeting, maintaining a tenancy
  - inter-personal functioning and social skills
  - vocational rehabilitation (including leisure, education and work)
  - healthy living (including diet, weight, activity, exercise, sleep, oral health, health monitoring, accessing health services, self-medication programmes, and cessation programmes for smoking and substance misuse).
- 6 Types of supported accommodation and housing.
  - 7 Transition from rehabilitation services to other parts of the mental health system or discharge to primary care.

### **Areas that will not be covered**

- 1 Comparative effectiveness of standard doses of individual pharmacological treatments for complex psychosis and related severe mental health conditions.
- 2 Rehabilitation for chronic neurological disorders including traumatic brain injury.
- 3 Specific rehabilitation programmes following other mental illnesses such as eating disorders.

### **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
- [Type 2 diabetes in adults: management](#) (2017) NICE guideline NG28
- [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) NICE guideline CG185
- [Psychosis and schizophrenia in adults: prevention and management](#) (2014) NICE guideline CG178
- [Smoking: acute, maternity and mental health services](#) (2013) NICE guideline PH48
- [Social anxiety disorder: recognition, assessment and treatment](#) (2013) NICE guideline CG159
- [Psychosis and schizophrenia in children and young people: recognition and management](#) (2013). NICE guideline CG155
- [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) NICE guideline 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***

- [Decision making and mental capacity](#). NICE guideline. Publication expected August 2018.
- [Post-traumatic stress disorder: management](#). Update to NICE guideline CG26. Publication expected December 2018
- [Rehabilitation after traumatic injury](#). NICE guideline. Publication date to be confirmed.
- [Depression in adults: recognition and management](#). Update to NICE guideline CG90. Publication date to be confirmed.

### **NICE guidance about the experience of people using NHS and adult social care services**

NICE has produced the following guidance on the experience of people using NHS and adult social care services. This guideline will not include additional recommendations on these topics unless there are specific issues related to rehabilitation in adults with complex psychosis and related severe mental health conditions.

- [People's experience in adult social care services](#) (2018) NICE guideline NG86
- [Medicines optimisation](#) (2015) NICE guideline NG5
- [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- [Service user experience in adult mental health](#) (2011) NICE guideline CG136

- [Medicines adherence](#) (2009) NICE guideline CG76.

### **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 What factors are associated with successful progress in rehabilitation services for people with complex psychosis and related severe mental health conditions?
  - 1.2 What coexisting medical, social (including family, cultural and ethnicity), communication, neurodevelopmental, cognitive or mental health problems pose barriers for people with complex psychosis and related severe mental health conditions 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 and related severe mental health conditions to help recovery and prevent relapse.
- 3.1 What principles should guide adjustments to standard pharmacological treatments in the management of the underlying psychosis in people using rehabilitation services?
- 4 Collaborative care planning and service user experience.
- 4.1 What is the best way of involving people with complex psychosis and related severe mental health conditions, and their families and carers, in planning their care collaboratively with practitioners and providers?
- 4.2 What approaches, care, support and treatment are valued by people with complex psychosis and related severe mental health conditions who are cared for by rehabilitation services, and are valued by their families?
- 5 Therapeutic programmes specific to rehabilitation including:
- activities of daily living, including
    - self-care
    - life skills, for example cooking, cleaning, shopping, budgeting, maintaining a tenancy
  - inter-personal functioning and social skills
  - vocational rehabilitation (including leisure, education and work)
  - healthy living (including diet, weight, activity, exercise, sleep, oral health, health monitoring, accessing health services, self-medication programmes, and cessation programmes for smoking and substance misuse).
- 5.1 What interventions specific to rehabilitation are effective for people with complex psychosis and related severe mental health conditions to improve their activities of daily living?
- 5.2 What interventions specific to rehabilitation are effective for people with complex psychosis and related severe mental health conditions to improve their inter-personal functioning and social skills?

- 5.3 What interventions specific to rehabilitation are effective for people with complex psychosis and related severe mental health conditions to improve their engagement in community activities (for example, leisure, education and work)?
- 5.4 What interventions specific to rehabilitation are effective in improving the engagement of people with complex psychosis and related severe mental health conditions in healthy living (diet, weight, activity, exercise, sleep, oral health, health monitoring, accessing health services, self-medication, smoking cessation)?
- 5.5 What interventions specific to rehabilitation are effective in improving the engagement of people with complex psychosis and related severe mental health conditions in addressing substance misuse?
- 6 Types of supported accommodation and housing.
- 6.1 What features of supported accommodation and housing promote successful community living in people with complex psychosis and related severe mental health conditions?
- 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?
- 7.2 What processes are needed to support successful transitions?

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 Morbidity.
- 14 Quality of life.
- 15 Capabilities.
- 16 Medication adherence.
- 17 Reduction or cessation of medication.

## **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**

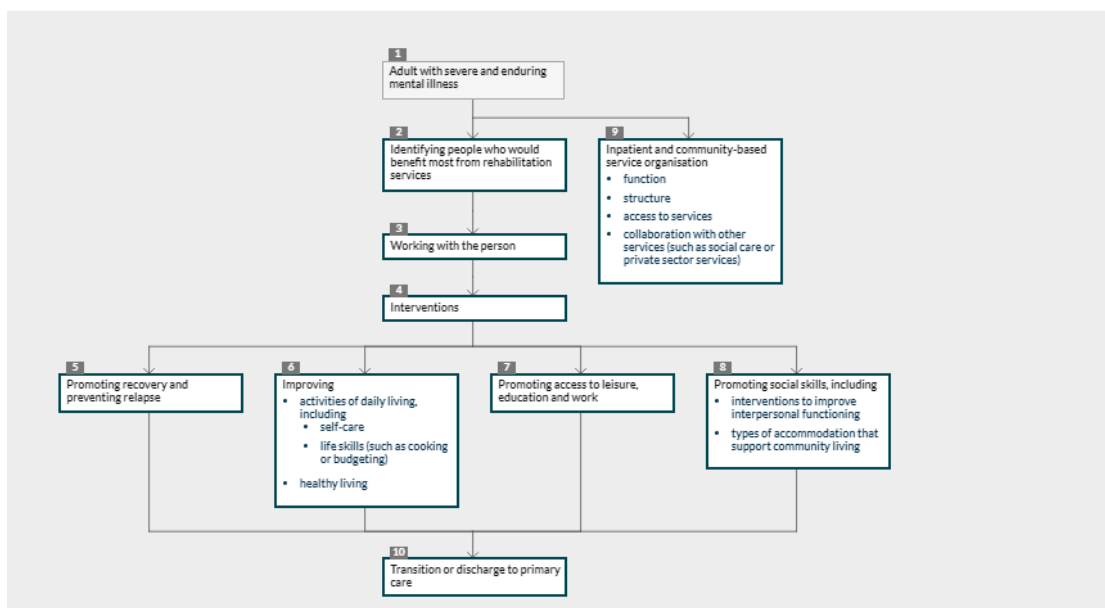
- [Psychosis and schizophrenia in adults](#) (2015) NICE quality standard QS80
- [Bipolar disorder in adults](#) (2015) NICE quality standard QS95
- [Bipolar disorder, psychosis and schizophrenia in children and young people](#) (2015) NICE quality standard QS102

### **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 rehabilitation for adults with complex psychosis and related severe mental health conditions (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 development. Links will be added to relevant NICE Pathways.

## Rehabilitation for adults with complex psychosis and other severe mental health conditions overview



## 5 Further information

This is the final scope, which takes into account comments from registered stakeholders during consultation.

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.

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