

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

29 personality disorder. The prevalence of severe mental illness is higher in men
30 than women, and in young adults than in older people. It is also higher among
31 black and ethnic minorities, people living in cities and people in poorer
32 neighbourhoods.

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

- 38 • treatment-resistant 'positive' symptoms (delusions and hallucinations) and
39 'negative' symptoms (loss of motivation and apathy)
- 40 • specific cognitive impairments that negatively affect the person's
41 organisational and social skills
- 42 • comorbidities including other mental health problems, for example anxiety
43 and depression
- 44 • physical health problems, such as diabetes and cardiovascular and
45 pulmonary conditions
- 46 • pre-existing developmental problems, for example autism spectrum
47 disorder
- 48 • co-existing problems such as substance misuse.

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

51 Rehabilitation for people with severe and enduring mental illness is usually
52 provided in a care pathway that includes inpatient and community
53 rehabilitation services. At any one time, around 1% (2,120 per year) of people
54 with psychosis are inpatients are in a rehabilitation unit. . Ongoing support to
55 enable further recovery after discharge is provided by specialist mental health
56 supported accommodation services, with clinical input from community
57 rehabilitation teams (where they exist) or other statutory community mental
58 health teams.

59 In 2009 the annual cost of all types of schizophrenia was estimated to be £8.8
60 billion. Of this, the greatest cost to society was from lost employment (£4.1
61 billion per year; 47%), emphasising the need for effective rehabilitation
62 services to enable people to return to work.

63 Treatment costs contributed £3.5 billion (40%) and informal care £1.2 billion
64 (13%), with psychiatric inpatient care representing the single largest service
65 cost (£1.7 billion). Although only 25% of people with schizophrenia go on to
66 develop severe and enduring mental illness and need rehabilitation services,
67 they will take up a significant proportion of this treatment cost. Therefore,
68 providing effective rehabilitation that allows people to be discharged from
69 inpatient care could lead to reduced costs.

70 **Current practice**

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

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

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

86 Since 2012 there have been closures of rehabilitation units in some areas,
87 and only 50% of trusts have community rehabilitation teams. Most people
88 affected by these changes have complex psychosis, which for the purposes of
89 this guideline is defined as enduring psychosis that has not responded to

90 treatment, may involve comorbidities and the effects of trauma, and impacts
91 on a person's social, interpersonal and occupational functioning.

92 **Policy, legislation, regulation and commissioning**

93 **Legislation**

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

103 **Commissioning**

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

109 The Five Year Forward View for Mental Health published by NHS England in
110 2016 sets out recommendations with the aim of achieving parity between
111 mental and physical health. However, understanding varies among
112 commissioners about the most clinical and cost effective way to structure
113 rehabilitation services for people with complex psychosis. This guideline will
114 provide a framework for commissioners to use.

115 The Joint Commissioning Panel for Mental Health (JCPMH), co-chaired by the
116 Royal College of Psychiatrists and the Royal College of General Practitioners,
117 provides specific guidance for commissioners of rehabilitation services for
118 people with complex mental health needs. This guideline will build on the
119 guidance produced by the JCPMH.

120 Education, Health and Care (EHC) plans are issued after a child or young
121 person is assessed, and set out the education and social care their local
122 authority must provide and the healthcare their local healthcare provider must
123 arrange. EHC plans last up to the age of 26 so there may be young people
124 needing rehabilitation whose care is still covered by an EHC plan.

125 **2 Who the guideline is for**

126 This guideline is for:

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

139 It may also be relevant for:

- 140 • charities and other non-statutory organisations who provide care and
141 support to people with mental health problems, particularly those who
142 provide supported accommodation
- 143 • private sector providers of mental health services
- 144 • further education services
- 145 • employers
- 146 • forensic mental health services.

147

148 NICE guidelines cover health and care in England. Decisions on how they
149 apply in other UK countries are made by ministers in the [Welsh Government](#),
150 [Scottish Government](#), and [Northern Ireland Executive](#).

151 ***Equality considerations***

152 NICE has carried out an equality impact assessment during scoping. The
153 assessment:

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

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

163 **3 What the guideline will cover**

164 **3.1 Who is the focus?**

165 **Groups that will be covered**

- 166 • Adults (aged 18 years and older) with complex psychosis.

167

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

172 **Groups that will not be covered**

- 173 • People with moderate or severe learning disabilities.

174 **3.2 Settings**

175 **Settings that will be covered**

- 176 • Any NHS or local authority funded service in which rehabilitation takes
- 177 place, or where people who would benefit from rehabilitation services can
- 178 be identified.

179 **Settings that will not be covered**

- 180 • Prisons.
- 181 • Secure units within the forensic mental health services.

182 **3.3 Activities, services or aspects of care**

183 **Key areas that will be covered**

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

- 186 1 Identifying people who would benefit most from rehabilitation services.
- 187 2 Organisation, function and structure of services, including inpatient and
- 188 community-based rehabilitation units and teams.
- 189 3 Delivering optimised treatments for people with complex psychosis to
- 190 help recovery and prevent relapse.
- 191 4 Therapeutic programmes specific to rehabilitation including:
 - 192 – activities of daily living
 - 193 ○ self-care
 - 194 ○ life skills, for example cooking, cleaning, shopping, budgeting,
 - 195 maintaining a tenancy
 - 196 ○ social skills
 - 197 – vocational rehabilitation (including leisure, education and work)
 - 198 – healthy living (diet, exercise, oral health, health monitoring and
 - 199 accessing health services, and cessation programmes for smoking and
 - 200 alcohol/drug).
- 201 5 Types of supported accommodation and housing.
- 202 6 Collaborative care planning and service user experience.

203 7 Transition from rehabilitation services to other parts of the mental health
204 system or discharge to primary care.

205 **Areas that will not be covered**

- 206 8 Effectiveness of individual treatments for complex psychosis.
207 9 Rehabilitation for chronic neurological disorders including traumatic brain
208 injury.
209 10 Specific rehabilitation programmes following other mental illnesses.

210 **Related NICE guidance**

211 ***Published***

- 212 • [Attention deficit hyperactivity disorder: diagnosis and management](#) (2018)
213 NICE guideline NG87
214 • [Mental health of adults in contact with the criminal justice system](#) (2017)
215 NICE guideline NG66
216 • [Coexisting severe mental illness and substance misuse: community health
217 and social care services](#) (2016) NICE guideline NG58
218 • [Transition from children's to adults' services for young people using health
219 or social care services](#) (2016) NICE guideline NG43
220 • [Mental health problems in people with learning disabilities: prevention,
221 assessment and management](#) (2016) NICE guideline NG54
222 • [Transition between inpatient mental health settings and community or care
223 home settings](#) (2016) NICE guideline NG53
224 • [Bipolar disorder: assessment and management](#) (2014) CG185
225 • [Psychosis and schizophrenia in adults: prevention and management](#) (2014)
226 NICE guideline CG178
227 • [Social anxiety disorder: recognition, assessment and treatment](#) (2013)
228 NICE guideline CG159
229 • [Autism spectrum disorder in adults: diagnosis and management](#) (2012)
230 NICE guideline CG142
231 • [Service user experience in adult mental health](#) (2011) NICE guideline
232 CG136

- 233 • [Self-harm in over 8s: Long-term management](#) (2011) NICE guideline
234 CG133
- 235 • [Common mental health problems: identification and pathways to care](#)
236 (2011) NICE guideline CG123
- 237 • [Coexisting severe mental illness \(psychosis\) and substance misuse:
238 assessment and management in healthcare settings](#) (2011) NICE guideline
239 CG120
- 240 • [Alcohol-use disorders: diagnosis, assessment and management of harmful
241 drinking and alcohol dependence](#) (2011) NICE guideline CG115
- 242 • [Alcohol-use disorders: diagnosis and management of physical
243 complications](#) (2010) NICE guideline CG100
- 244 • [Borderline personality disorder: recognition and management](#) (2009) NICE
245 guideline CG78
- 246 • [Antisocial personality disorder: prevention and management](#) (2009) CG77
- 247 • [Depression in adults: recognition and management](#) (2009) NICE guideline
248 CG90
- 249 • [Depression in adults with a chronic physical health problem: recognition
250 and management](#) (2009) NICE guideline CG91
- 251 • [Obsessive-compulsive disorder and body dysmorphic disorder: treatment](#)
252 (2005) NICE guideline CG31
- 253 • [Post-traumatic stress disorder: management](#) (2005) NICE guideline CG26

254 ***In development***

- 255 • Rehabilitation for chronic neurological disorders including traumatic brain
256 injury. NICE guideline. Publication date to be confirmed
- 257 • Update to: Depression in adults: recognition and management (2009) NICE
258 guideline CG90. Publication date to be confirmed

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

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

- 264 • [People's experience in adult social care services](#) (2018) NICE guideline
265 NG86
- 266 • [Medicines optimisation](#) (2015) NICE guideline NG5
- 267 • [Patient experience in adult NHS services](#) (2012) NICE guideline CG138
- 268 • [Service user experience in adult mental health](#) (2011) NICE guideline
269 CG136
- 270 • [Medicines adherence](#) (2009) NICE guideline CG76

271 **3.4 Economic aspects**

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

280 **3.5 Key issues and draft questions**

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

- 283 1 Identifying people who would benefit most from mental health
284 rehabilitation services.
- 285 1.1 Which people with complex psychosis are likely to benefit most from
286 referral to rehabilitation services?
- 287 1.2 What co-existing medical, social (including family, cultural and
288 ethnicity), communication, neurodevelopmental, cognitive or mental
289 health problems pose barriers for people with complex psychosis in
290 accessing rehabilitation services?
- 291 2 Organisation, function and structure of services, including inpatient and
292 community-based rehabilitation units and teams.
- 293 2.1 What is the effectiveness of rehabilitation services compared with
294 standard care?

- 295 2.2 What is the effectiveness of inpatient rehabilitation services
296 compared with community-based rehabilitation services?
- 297 2.3 What are the required components of an effective rehabilitation
298 pathway?
- 299 2.4 What are the barriers and facilitators to integrated rehabilitation care
300 pathways involving multiple providers (including health, social care, non-
301 statutory, independent and voluntary services)?
- 302 3 Delivering optimised treatments for people with complex psychosis to
303 help recovery and prevent relapse.
- 304 3.1 What principles should guide adjustments to standard treatments in
305 the management of the underlying psychosis in people using
306 rehabilitation services?
- 307 4 Therapeutic programmes specific to rehabilitation including:
308 – activities of daily living
309 ○ self-care
310 ○ life skills, for example cooking, cleaning, shopping, budgeting,
311 maintaining a tenancy
312 ○ social skills
313 – vocational rehabilitation (including leisure, education and work)
314 – healthy living (including diet, exercise, oral health, health monitoring and
315 accessing health services, and cessation programmes for smoking and
316 alcohol/drug).
- 317 4.1 What interventions specific to rehabilitation are effective for people
318 with complex psychosis to improve their activities of daily living?
- 319 4.2 What interventions specific to rehabilitation are effective for people
320 with complex psychosis to improve their inter-personal functioning?
- 321 4.3 What interventions specific to rehabilitation are effective for people
322 with complex psychosis to improve their engagement in community
323 activities (leisure, education and work)?
- 324 4.4 What interventions specific to rehabilitation are effective in improving
325 the engagement of people with complex psychosis in healthy living (diet,
326 exercise, oral health, accessing health services, health monitoring)?

327 4.5 What interventions specific to rehabilitation are effective in improving
328 the engagement of people with complex psychosis in smoking
329 cessation?

330 4.6 What interventions specific to rehabilitation are effective in improving
331 the engagement of people with complex psychosis in addressing
332 substance misuse?

333 5 Types of supported accommodation and housing.

334 5.1 What features of supported accommodation and housing promote
335 successful community living in people with complex psychosis?

336 6 Collaborative care planning and service user experience.

337 6.1 What is the best way of facilitating collaborative care planning
338 between people with complex psychosis, practitioners and providers?

339 6.2 What interventions are valued by people with complex psychosis
340 who are cared for by rehabilitation services, and valued by their families?

341 7 Transition from rehabilitation services to other parts of the mental health
342 system or discharge to primary care.

343 7.1 What are the criteria for transition from rehabilitation services to
344 other parts of the mental health, social care and primary care systems?

345

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

348 **3.6 Main outcomes**

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

351 1 Social functioning.

352 2 Activities of daily living.

353 3 Successful discharge from inpatient rehabilitation unit to community.

354 4 Independent or successful community living.

355 5 Gaining or maintaining employment.

356 6 Participation in education.

357 7 Service user experience.

358 8 Carer experience.

- 359 9 Readmission to hospital.
360 10 Rate of relapse.
361 11 Duration of stay in rehabilitation unit.
362 12 Mortality.
363 13 Quality of life.
364 14 Capabilities.

365 **4 NICE quality standards and NICE Pathways**

366 **4.1 NICE quality standards**

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

- 369 • [Psychosis and schizophrenia in adults](#) (2015) NICE quality standard QS80
370 • [Learning disabilities: identifying and managing mental health problems](#)
371 (2017) NICE quality standard QS142
372

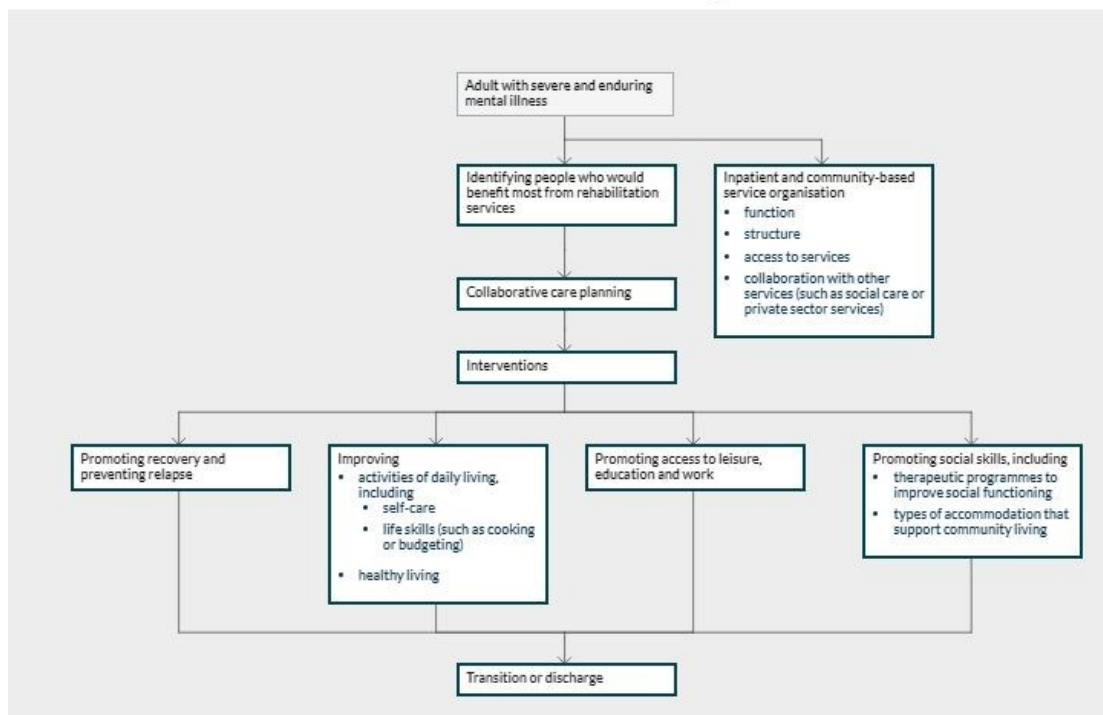
373 **4.2 NICE Pathways**

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

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

379 development. Links will be added to relevant NICE Pathways.

Rehabilitation for adults with severe and enduring mental illness overview



380

381 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.

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