NICE Clinical Guideline: Rehabilitation in adults with severe and enduring mental illness

Stakeholder scoping workshop notes, 20 March 2018

Group 1

Presentations
• There were no comments on the presentations.
GC COMPOSITION
Included members
• The 'Registered Manager' role should be clarified. • Need to include social workers from multiple sites (units and community-based) in the main committee and one of these should be an approved mental health professional (AMHP). • There needs to be a greater balance between health and social care providers. • As the Topic Advisor is a psychiatrist, we could recruit one less psychiatrist for the main committee.
Members that should be included
• There should be more lay members – a carer, a service user, a peer supporter – and these people would ideally be diverse in age, gender, experience and setting. • A Senior Rehabilitation Services Manager could also be co-opted. • The manager of a social housing provider should be included. Job titles to look for could be 'Local Authority Commissioner, 'Social Landlord' or 'Director/Manager of a Social Housing Provider. This post could be co-opted.
SCOPE
General Comments
• The group suggested including a diagram of the care pathway in the introduction section of the guideline. • There needs to be a balance between the health and social care aspects of rehabilitation, with housing a crucial element. • Care needs to be patient-centred, so a one-size-fits-all approach is not going to work and the guideline should acknowledge this. Recommendations should be based on the needs of individuals, rather than a single recommended care plan.
SECTION 3
Groups that will be covered
• The scope should use a consistent phrase to describe the group being covered and include definitions of the terms used. • The group agreed that there should be guidance on the transfer from child to adult care, but that this could be through referencing existing guidelines. They agreed that the guideline should cover those aged 18 and over.

Groups that will not be covered
• The group wanted to know how the guideline would address the many comorbidities experienced by people with severe and enduring mental illness. They suggested that it should be clear that the severe and enduring mental illness is the primary diagnosis, with the comorbidity/ies a secondary diagnosis. • The group raised a concern that those with dual or triple diagnosis may slip through the cracks, as the conditions can fluctuate and an initial primary diagnosis may become a secondary diagnosis down the line. • Where do people with autism fit in? The group wanted to know whether there was a guideline addressing the needs of people with both autism and a severe mental illness.
Key areas that will be covered
• General: Support to stay in accommodation should be covered in the scope. • General: Where does advocacy fit in to this? The scope should consider the role of self-directed support, choice and control over services, and the availability of advocates. Independent mental health advocates are available if detained under the Care Act, but what about those who are not? • Area 3: Services need to be set up to be able to deliver rehabilitation – some services are thought of as 'care' rather than 'rehabilitation' so don't have the right resources or structures to support rehabilitation. • Area 4: Should include 'meaningful activities' such as picking up children from school, which don't necessarily fall under activities of daily living. General health promotion should be included in the scope. The group stressed that podiatry should be included as a vital element of health care that isn't easily accessed on the NHS. • Area 5: Suggestion to change this to 'accommodation and support', so that it covers the support that comes with accommodation. • Area 6: Replace 'private' with 'independent and voluntary sector' providers. This area should also include housing providers as they are key to rehabilitation, but are not considered rehabilitation or social care service providers. The group suggested changing the way the area to 'Integrated actors in the care pathway' with these actors then defined. They stressed that housing needs to be integrated in the care plan right from the beginning. • Area 8: When does rehabilitation officially stop? It is very important to include follow-up. It might be useful to focus more on the transition away from rehabilitation services and the outcomes that need to be achieved before this can happen.
Key areas that will not be covered
• No comments.
Equalities
• Need to consider the cultural context and experiences of people e.g. refugees, trauma survivors, and difference cultural attitudes towards mental illness. • While complex psychosis affects men more than women, this tends to mean services are men-centric. The group suggest that more services should be made available to women, particularly mixed-gender or women only wards. • Change 'male' to 'men' as this should refer to gender rather than sex, to include those who identify as men.

- Older people should be considered as they can feel vulnerable in mixed units or houses, often with a large proportion of young men. Also need to consider that older people often have specific needs and may be living in care or assisted living homes.
- Is the guideline going to look at the intersection of the different equalities considerations, for example a homeless man from a poor socio-economic background?
- Staff should be trained to handle people with autism spectrum disorder and consider their needs, with the understanding that there is a big difference between mild and severe ASD.
- Current services may not accommodate people with specific disabilities e.g. sensory loss.
- Services and housing should be accessible for those with mobility issues and the physical aspects of housing should be considered.
- Some people can be excluded from accessing services because they are considered too 'high risk'.

Care settings

- Need to ensure that this captures people being primarily cared for by their family.
- It is fine not to cover forensic units, but important to address the transition from forensic unit to community rehabilitation.
- The scope should also include the transition from the criminal justice system to rehabilitation.

Draft Review questions

Question 4.5:

- This question implies we want people to stop smoking and taking drugs and that this is essential to their rehabilitation. Some members of the group pointed out that smoking cessation, for example, is not always conducive to rehabilitation and shouldn't necessarily be seen as a barrier to rehabilitation.

No other comments on specific questions.

Group 2

Presentations

- There was discussion about the difference in definition of recovery and rehabilitation. Recovery is gaining full functions, and rehabilitation is reaching best possible functioning, but may not always lead to achieving all functions.

GC COMPOSITION

Included members

- Psychiatrist: It will be useful to have one Psychiatrist from the NHS and another from the independent sector. Independent practitioners could be either those working for charities or private providers; not necessarily only private practitioners e.g. Cygnet Healthcare, Priory Healthcare.

- Community Rehab Psychiatrist: The Royal College of Psychiatrists has a Faculty of Rehabilitation and Social Psychiatry. They can be contacted for this role. They also have a Faculty of Liaison Psychiatry, which deals with the interface between physical and psychological health. Consider including a Liaison Psychiatrist, who can cover aspects of both physical and mental health.

- Mental Health Nurse: One should be a community mental health nurse.

- Occupational therapist: One is sufficient.

- Regional Manager of Social Care Provider: This is too specific. In the job advert, ask for those with experience in supported living. It could be a Social Care/ Supported Living Provider/ Senior Rehab Mental Health Manager/ Rehab Services Director/ Locality Manager. Someone who works specifically in the homeless sector like a social care provider, employees of Shelter, or a manager of homeless accommodation under the Homeless Act. Another option would be to include someone who works for a homeless charity or Local Authority. It could be Social Housing Providers, not necessarily from the statutory sector, or Housing Tenancy Officers/Housing Association from third sector housing support providers. Need to distinguish between supported accommodation and housing, and ensure both are included. There should be a representative from the homeless and housing sectors separately.

- Commissioner: There are different pathways of commissioning. Some are commissioned by the NHS, some by Mental Health Commissioners, some by Local authorities and sometimes integrated. If one member has to be included, it might be useful to include an Integrated Commissioner.

- Lay members: A service user should be one of the lay members. Consider having two, as one may not be well enough to take part in all meetings.

- Social Worker: The social worker should be a main member of committee instead of co-opted member. It will be useful to have someone with broad experience across settings.

- GP: Maybe a GP with special interest in Mental Health should be included.

Members that should be included

- Include someone from IAPT (Improving access to psychological therapies). They support the management of employment or workplace stress. Their work mainly involves psychological therapies and CBT.

SCOPE

General Comments

- Social anxiety disorder and severe depression should be included in the scope.
- Autism is not mentioned separately, and people with autism and severe enduring illness must be included.
- The National Collaborating Centre for Mental Health (NCCMH) is working on Community Mental Health Pathway, and coming up with a document on Rehabilitation. It might be useful to link to that document.
- There should be consideration about post-engagement pathways. Issues like the remit for discharge/rehabilitation and inappropriate discharge must be considered.
- One suggestion is for individual contributions to healthcare funding. A care package could be developed and funded by raising £1/day per citizen x 365 days per year.

Main outcomes:

- Voluntary working (people not gaining employment but participate in community). This outcome is important, as many people may not gain employment but still may be able to participate in community.
- Health & Social care outcomes should be included. Risk reduction and Health promotion are important.

SECTION 3

Groups that will be covered

- People with depression/psychosis should be included.
- Homelessness with substance abuse and serious mental illness should be included.
- People with autism have not been mentioned separately.
- Age cut off of 18 years is reasonable. There are different pathways for rehabilitation in transition age group, and they should be covered separately.

Groups that will not be covered

- People with borderline personality disorder can have similar issues and needs. If they meet the criteria for rehabilitation, they should be considered and links can be provided to this guideline, but they should not necessarily be included in the scope of this guideline.

Key areas that will be covered

- Area 3: Personalised and individualised care should be provided
- Area 4: Therapeutic programmes specific to rehabilitation should be "Therapeutic individualised personalised programs".
- Area 4: Personalised therapeutic programmes should be offered. Need to look into the health economics of how this can be provided.

- "Psychosocial education" should replace social skills: includes diagnosis and management.
- Area 5: Housing should be separate from supported accommodation.
- Area 6: Change integrated to whole system working.
- Area 6: Integrated working: Public and individual health should be included.
- Area 7: Services can be only be valued if people are aware of them
- Area 8: Should include networking & public awareness

Key areas that will not be covered

- Personal trauma can spark schizophrenia or depressive illness. Borderline personality disorder can have similar presentation, but a different diagnosis. They should be mentioned, where relevant, but not necessarily included in guideline.

Equalities

- People in prisons who have enduring mental illness: Link them with Meet & Greet services

- BAME and refugees: There may be access issues due to:
  - Lack of education/awareness
  - Lack of support
  - Lack of access to public funds
  - Language barriers, as most of the therapy is delivered verbally
  - Religious and cultural beliefs may be barriers to access to care
  - They may not trust the services, or services may not be acceptable
  - Stigma also precludes people from accessing care

- Expats who return after a stay longer than 3 months don't have access to public funds
- Those engaging in substance use are not explicitly considered

Care settings

- If you don't include the criminal justice system, you can't include low secure settings. Active rehabilitation takes place in low secure settings. In medium to high secure settings, active rehabilitation takes place rarely. You could include low secure settings and exclude medium and high secure settings. Persons from criminal justice may present at rehabilitation services.
- Deprivation of limited safeguards (amendment to the Mental Health Capacity Act) should be taken into account while making considerations.

Draft Review questions

Question 1.1:

- First a referral is made, then the assessment takes place. Funding (e.g. panel funding) needs to be looked into, while referring. Speed of access also needs to be considered.

Question 2.1:

- Effectiveness could mean different things. It should relate to mental health outcomes. Regarding standard care, the comparison could be between areas which have rehabilitation services and those which don't.

Question 8.2:

- This question will pick up effective things from 8.1

Group 3

Presentations
• There were no comments on the presentations.
GC COMPOSITION
Included members
• The group felt that there was an imbalance between clinical and non-clinical members – need more non-clinical members.
Members that should be included
• Need at least 2 lay members with lived experience of rehabilitation services • Need a social worker • Need more diversity in the inpatient role • Need an allied worker in the co-opted members – e.g. a dietician
SCOPE
General Comments
• The group thought that treatment interventions are relevant to the guideline. • The group discussed the importance of having a 'recovery approach' in the guideline. This is a personalised approach in the way you work with a person and is key to rehabilitation. • The group discussed the importance of including the care pathway.
SECTION 3
Groups that will be covered
• The group suggested a new definition of the groups to cover: 'People with complex mental health needs who are unable to sustain successful appropriate community living without appropriate support'. • The current included and excluded groups are not mutually exclusive and the groups can overlap. • The group was concerned that some people may not be covered by this guideline and missed from services because they may meet the 'groups to be covered' definition but also fall into a group from the 'groups not to be covered' definition. They wanted clarity whether this would be the case. • The group would like some clarification as to what 'general adult mental health services' covered. • The group was happy that the guideline is for adults aged 18 and older. They discussed and agreed that those under 18, including transition groups, will be covered by CAMHS (child and adolescent mental health services).
Groups that will not be covered
• The group thought that people with personality disorders is an important group and should be covered as they are often referred by acute services. • The group thought that the 'groups not to be covered' list is too broad and that rehabilitation services can exclude many people based on this list. • The group thought that rather than focusing on peoples' disorders, they need to focus on their needs, and exclude them if these needs can be met elsewhere.

Key areas that will be covered

- Area 1: The group felt this was an important area and should remain in the scope.
- Area 2: The group felt that this is an important section and should remain in the scope. Something about the care pathway should be included in this section.
- Area 3: The group identified this area as one that needed more clarity in the scope. Is this about continuing the recommended treatments from recovery? The group felt that it is important to have continuation of care in this section, and that it may be more appropriate to reword this as 'maintenance of treatment'. The group felt that 'prevent relapse' should be removed, so that the section is more about living in the community.
- Area 4: The group felt that this section needs to include relationships or peer support. The group felt that maintaining accommodation/tenancy is also a key area and needs to be addressed. Include a collaborative care programme in this section. Include sexual health as part of healthy living. Include psychological support as part of therapeutic programme. The group suggested replacing 'diet and exercise' with 'Physical activity and healthy eating/nutrition' as these are less restrictive.
- Area 5: The group felt strongly that this was an important area. They felt this should read 'types of accommodation – including supported accommodation'.
- Area 6: The group felt this section needs to be more ambiguous to cover more. They felt there needs to be a term to include religious/cultural groups and services.
- Area 7: The group felt this was an important area and needs to be covered.
- Area 8: The group felt that this section needs to include monitoring of people whilst they are in rehabilitation and not just after they have been discharged.

Key areas that will not be covered

- Service user involvement should be covered somewhere in the scope.

Equalities

- No comments on equalities.

Care settings

- No comments on care settings.

Draft Review questions

Question 1.1:

- This question should be about assessment.

Groups 4 & 5 (combined)

Presentations

- There were no comments on the presentations.

GC COMPOSITION

Included members

- Suggestion to add someone in forensics to ensure a better mix of professionals
- Include a service user or carer from the BAME community with English as a second language
- Include someone who provides social housing, not just a manager of a service
- Include a local authority commissioner

Members that should be included

- Include a social worker with housing experience
- Include a speech and language therapist
- Include someone working in the voluntary or community sector

SCOPE

General Comments

- Complex psychosis has been deliberately left broad in order to cover a wide range of conditions that may fall under this criteria
- Remove the word “complex” from complex psychosis
- Transitioning from child services to adult services:
    - Can be cross-referenced
    - Should there be a separate or specific guideline on this?
    - Children have different needs from adults e.g. speech and language needs, so they would need separate guidance.

SECTION 3

Groups that will be covered

- Other serious mental health problems can include:
    - Any personality disorders – mostly unstable
    - People with psychosis associated with a co-morbidity
    - People with psychosis associated with other personality traits
    - People with severe depression, with or without psychosis should be covered
    - Schizophrenia and bipolar disorder
    - People with autism and mild learning disorder (can be considered as specific groups when measuring outcomes)
    - Consider including eating disorders
- The group raised the fact that a lot of people who are undergoing rehabilitation are in prisons, therefore prisons should possibly be included in the scope. People can access rehabilitation and then go back to prison.
- Should probably have people with enduring psychosis included in the scope

Groups that will not be covered

- Consider including people with moderate or severe learning disorders
- Consider including substance misuse with transient psychosis

- Should primary personality disorders be included?
    - Need to identify the population with these disorders and look at the evidence
    - This group should be kept separate from people with complex psychosis
    - The rehab principles for this group will be different

Key areas that will be covered

- Area 3: Are we considering psychological therapies?
- Area 3: Commissioners should structure psychotherapy services.
- Area 4: Include social skills such as communication needs e.g. speech and language
- Area 4: Important to include life skills such as money management and community living skills, access to community resources (e.g. use of transport)
- Area 4: Important to consider safeguarding and vulnerability

Key areas that will not be covered

- There were no comments.

Equalities

Consider:

- Anyone with communication needs (these people tend to be unidentified or go unnoticed because of misdiagnosis). Identify their communication needs and help them adopt rehabilitation
    - Need more on how to recognise or identify them
    - Recommend this is specifically mentioned in the review questions
- Women – do women get a good deal, as the population under this guideline topic tends to be more male
    - Complex psychosis is more prevalent in men than women
    - Women miss out because facilities are more focused on male units (this is area-specific)
    - Lack of provision of women-centred services
- Black and minority ethnic groups (BAME) – predominantly black African and Caribbean. Things to consider:
    - Cultural perceptions
    - Religious beliefs
    - Issues with access to services
    - Why are certain ethnic minorities not coming into units to seek help?
    - Is there any evidence that differentiates this group or their level of psychosis?
    - Exclusion criteria in studies/research e.g. language barriers
    - Is this area or region-specific?
    - Need to have an understanding of the issue
    - Need to understand the historical approach to people with psychosis
    - Need to know how to identify this population and engage with them
    - This group may have unconventional ways of getting into the system or not seek help on time

Care settings

- Locked rehabilitation – 50/50 proportion of them are NHS and private health funded
- Secure units with the forensic mental health services:
    - Offer long stay rehabilitation

- Are linked to funding
- May have to think about composition of this group differently
- Consider a shift in policy when defining this setting
- Forensic is more linked with risk in some circumstances

- Need a clearer definition for the term 'forensic' to avoid confusion for individual and their needs.
- The group recommends including the forensic mental health services setting.

Draft Review questions

Question 1.1:

- What do rehabilitation services have that others do not have?
- Who are rehabilitation services for?
- How are people discharged and who to?
- What can people expect from rehabilitation services?
- What are the core features patients need?

Question 1.2:

- Should be covered under its own section – expand:
  - Barriers – cultural and socio-economic factors
  - Should include all the topics under equalities
  - Include communication needs

Question 2.2:

- What is the definition of standard care?
  - this varies across the country and these variables are fast changing
  - people in community settings may not have the same level of care as those in rehabilitation
  - Change in configuration of services and teams - teams have been reduced to fit a smaller number of teams
  - specialist teams/skills have been lost over time
  - Too many gaps

- Are there any pharmacological interventions to consider?

Question 2.3:

- Does this refer to staffing or physical resources?
- Specify what is meant by "multidisciplinary rehabilitation team"

Question 3.1:

- Uptake should include treatment, adherence, better engagement

Question 4.1:

- Re-word vocational rehabilitation

Question 5:

- Need to consider the following:
  - Environment
  - Locality
  - Factors of successful community living
  - Staff
  - Need the view of commissioners for this question

Question 6:

- This is an important question – would we get to answer this via other questions above?
- Access issues – NHS vs. private
- Financial incentives – NHS vs. private

Question 7:

- Needs to be specific to rehabilitation, not general
- Not just about 'information standards'
- 'When' the information is delivered is key
- Must incorporate shared decision-making in care planning

Question 8:

- Not monitoring, more about communication
- Follow-up range of factors – increased function, not just relief of symptoms

Group 6

Presentations
• There were no comments on the presentations.
GC COMPOSITION
Included members
• The current composition is health professional heavy
Members that should be included
• More social care members needed • Lay members important • Include a social work perspective • Local Authority Commissioner (from Local Government Association) – this role is very important • A suggestion that a health professional (i.e. one of the nurses roles) could be replaced with an approved mental health professional as a full committee member • The committee composition should 'value' each part of the pathway and move from mental health to social care • It is vital to respect each experience and technical ability
SCOPE
General Comments
Overall impressions of the scope: • The current scope focuses largely on a medicalised approach to rehabilitation. • The scope is about the people involved in rehabilitation. • Topics 4, 5 and 6 are crucial to the guideline. • Risk management should be added to the scope.

- If there is a significant risk to life for the population, the scope does not cover what will happen.
- The guideline needs to be clear in terms of what should be in place for each area of rehabilitation.
- The guideline needs to respect each part of the system.
- Recalibration is needed in terms of committee composition and language used

Scope summary:

- The group felt that a social worker is essential to the committee.
- The committee composition should be better balanced between health and social care professionals.
- The guidance is needed to engage other health professionals to stop a relapse (cyclical), as this is one reason why people affected are stuck in hospitals.
- The group reiterated that a high level partnership between mental and social care is needed.

SECTION 3

Groups that will be covered

- Should include people whose needs cannot be met in mental health services
- The group suggests a change in phrasing of the scope– use 'people commissioned by adult services' instead of 'people in transition'.
- The group felt that there was no investment in community rehabilitation services and there is a need to focus on this.

Groups that will not be covered

- The group agreed that groups not covered in this scope were covered in other guidelines.
- The groups discussed that the scope does not cover transition from child to adult services.
- PTSD veterans was discussed. When this group ends up in a forensic setting, they get overlooked as a niche group in health based adult rehabilitation programmes.

Key areas that will be covered

- General: There seems to be an omission of digital services and blended care approaches which engage people in different ways. For example, online support planning, online apps, using digital solutions to become self-managing, help people prevent their own relapse.
- General: Outcomes should be included in the protocols.
- General: Overall the key areas are good.
- General: The group agreed that the wording needs to be tweaked to be brought up-to-date with the terms used in mental health.
- General: The list needs to take a person-centred approach.
- Area 1: Good, covers all aspects.
- Area 2: Add 'commissioning' to 'organisation and function'
- Area 2: It is a national guideline, therefore it sets precedence, so ensure the language used is person-centred
- Area 2: Ensure social care guideline refers to CCG's
- Area 2: Integrated commissioning is essential
- Area 2: Suggestion about including a question about commissioning services

- Area 2: Should commissioning be included as a separate question?
- Area 3: Consider rephrasing the wording in area 3, as 'recovery' can be a frame of mind.
- Area 3: For the delivery of treatments, include the best use of needs.
- Area 4: The phrasing should be more person-centred e.g. goals and aspirations for life
- Area 4: The group mentioned that there is a risk that some of the language used does not capture the aim of the guideline e.g. mental health issue vs mental illness.
- Area 5: This topic needs expansion to include types of accommodation and support
- Area 7: Contains good questions and format
- Area 8: Add 'managing risk' in monitoring and follow-up.
- Area 8: A question discussed was 'what range of interventions are effective/ available to individuals to prevent a relapse?' – The group considered that a question about relapse should be added in area 8.
- Area 8: The group suggested adding how the discharge is monitored sequentially to help clarify exactly what discharge means
- Area 8: the group considered that there should be clear guidance on the support that exists after discharge as most people in this group will need life-long care
- Area 8: Risk management should be added to this area
- Area 8: need to consider different types of discharge
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Key areas that will not be covered

- The group agreed that areas not covered are ok.

Equalities

- People who do not have moderate or severe learning disabilities – it is important to recognise some characteristics associated with these diagnoses.
- Groups of people with English not a first language should be an important consideration – ensure appropriate services for different cultural backgrounds.
- There is an over-representation of people who come from chaotic households with severe complex psychosis, so this should be addressed.
- No socio-economic factors are included.

The group also discussed:

- People with autism, Asperger's
- Quality of interventions
- Possibility of different recommendations for women
- The group agreed that women are 'bumped up the system' because of lack of lower end secure facilities
- There is a dominance of male services
- Appropriate housing for women needs to be taken into consideration
- For some women it is important to be supported by women (it is important to them to decide who supports them)
- Women sometimes do not use traditional methods to access care

Care settings

- The group felt that a recovery-oriented rehabilitation approach may be needed here.

Draft Review questions

Question 1.1:

- Might be best to lose the word 'referral' and use 'benefit from services'

Question 2.3

- Community based rehabilitation system – this is the over-arching goal of the guideline

Question 3.1

- There is a significant amount of evidence for personal budget of people in mental health and this is an important consideration.
- Overall this is a good question

Question 4.1

- Add examples in brackets and ensure it is clear the list is not exhaustive.

Question 4.2

- Change 'social functioning' to, for example, 'help people to develop relationships'

Question 4.3

- Add examples in brackets and ensure it is clear the list is not exhaustive.

Question 5.1

- People should have more choice and control over support, relapse and recovery
- Solid support will prevent the person to go back on the ward.
- NICE guidance on this question needs to tie with local authority policy, as well as government policies

Question 6.1:

- This should not be a separate topic, but integrated in all other sections
- This should be the guideline's guiding principle rather than a separate question
- Suggestion to remove this as a review question and make it an over-arching principle or add it to equality considerations

Question 7.1 and 7.2

- They are both person focused and specific, which is good
- The group suggested families and carers should be added to both questions

Questions 8.1 and 8.2:

- The group agreed that the word 'discharge' needs to be well defined and clarified based on interpretations that different disciplines use
- The discharge should be based on the support available i.e. monitoring and follow-up is tailored, depending on the type of intervention and how the intervention is reduced

Question 8.2

- There was a query on discharge services – should it be 'specialist services' instead of 'rehabilitation services'?