Rehabilitation in adults with complex psychosis and other severe mental health conditions

Consultation on draft scope
Stakeholder comments table

17/04/2018 to 15/05/2018

Stakeholder	Page no.	Line no.	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
Action on Smoking and Health (ASH)	General	General	**ASH welcomes the inclusion of smoking cessation programmes** The scope document defines rehabilitation as the maximising of "potential to live a full and active life" and specifically mentions physical health. It also presents reducing mortality as one of the main objectives of the consultation. ASH therefore welcomes the scope's recognition of smoking cessation programmes as central to the achievement of this aim. Firstly, smoking rates amongst people with a mental health condition are significantly higher than in the general population, [1] and the highest levels of smoking are found in psychiatric inpatients. [2] Moreover, people with a mental health condition have increased levels of nicotine dependency, smoke significantly more and are therefore at even greater risk of smoking-related harm. [3] Indeed, smoking is the largest contributor to the 10-20 year difference in life expectancy suffered by those with a mental health condition. [4] Secondly, cessation would contribute to a reduction in diabetes and cardiovascular and pulmonary conditions, which the draft scope specifically highlights as an objective. Smoking is by far the leading behavioural risk factor of CVD, accounting for 14% of deaths from heart and circulatory disease. [5] Indeed, there is a 62% increased rate of death from heart attacks among smokers compared to lifelong non-smokers, and a 32% increased	Thank you for your comment and for providing this information on the value of smoking cessation. We have addressed your three specific comments, below.

			risk of death compared to former smokers. [6] However, within a year of giving up smoking, the risk of a heart attack halves compared to that of an active smoker and declines gradually thereafter. [7] Similarly, a 2014 US Surgeon General report concluded that cigarette smoking is a cause of diabetes, that the risk of developing diabetes is 30-40% higher for active smokers than non-smokers, and that there is a positive dose-response relationship between the number of cigarettes smoked and the risk of developing diabetes. [8] Effective smoking cessation programmes could therefore help to prevent the onset of these diseases, which can make it impossible for patients to be discharged from acute mental health impatient care. Finally, effective smoking cessation programmes make economic sense. The NHS currently spends approximately £720m per year in primary and secondary care treating smoking-related diseases in people with mental health conditions. [9] These costs come from an annual estimated 2.6 million avoidable hospital admissions, 3.1 million GP consultations and 18.8 million prescriptions. However, whilst ASH is supportive of the inclusion of smoking cessation services in the draft scope, we believe it would be improved by: (1) Including people with severe and enduring mental health conditions other than psychosis	

			(2) Explicitly referencing reducing incidence of morbidity as a key outcome (3) Including the need for continuity of care	
Action on Smoking and Health (ASH)	6	163-173	**1. Including people with severe and enduring mental health conditions other than psychosis** The scope will cover adults with complex psychosis, defined as enduring psychosis that has not responded to treatment, may involve comorbidity and the effects of trauma, and impacts on a person's social, interpersonal and occupational functioning. ASH supports the inclusion of people with complex psychosis, with smoking rates at around 60% in those with probable psychosis. [10] However, ASH does not believe the scope should be limited to this population alone, since 70% of all people in psychiatric units smoke. [11] In other words, there is still a high prevalence of smoking in those with other types of severe and enduring mental health conditions, with the average smoking rate among people with a serious mental illness currently 40%. [12] ASH therefore recommends the draft scope be revised to include people who do not have psychosis but who have other forms of severe and enduring mental illness, to ensure they are not denied access to beneficial programmes.	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.

Action on Smoking and Health (ASH)	12	327-329	**4. Including the need for continuity of care** Finally, the scope should account for continuity of care (both within and between impatient and community services and also before and during the rehabilitation phase). Therefore NICE should be cautious that the phrase “specific to rehabilitation” does not perpetuate the misunderstanding that people receiving treatment for a mental health condition cannot also undergo smoking cessation programs. The common misconception that (1) people with enduring and severe mental health conditions do not want to quit smoking and (2) smoking cessation exacerbates mental health conditions, means practitioners are often reluctant to engage with patients about smoking. [16] [17] [18] Since advice from health professionals has been shown to be an important driver in quit attempts among all smokers, this lack of awareness can limit the support given to patients with severe and enduring mental health conditions who smoke. [19] This means many people with mental health conditions do not get the same smoking cessation support, even though evidence shows smokers with mental illness are frequently motivated to quit and are generally able to do so (provided they are given evidence-based support). [20] [21] [22] [23] Moreover, quitting can actually lower levels of anxiety, depression and stress in former smokers. [24]	Thank you for your comment. We agree that smoking cessation services should not just be a focus during the rehabilitation phase, nor need to be rehabilitation-specific and have therefore now included smoking cessation in the healthy living question.

			Patients can and should be receiving a suite of support to quit smoking before and during the rehabilitation stage, with this ideally occurring when patients first enter the system and continuing throughout their care pathway. This may involve referral to stop smoking services, support through pharmacotherapy, or prompting quit attempts through the delivery of brief advice. Part of this vision of continuity also means both impatient settings and community settings must provide support and advice around quitting smoking, to ensure consistency throughout the patient's service engagement. In order to support this, concrete social and financial incentives in these settings should be mobilised in order to change deeply ingrained behaviour and attitudes towards smoking and mental health.	
Action on Smoking and Health (ASH)	12	348-364	**2. Explicitly referencing reducing incidence of morbidity as a key outcome** Effective smoking cessation programmes would contribute to the scope's objective of enhancing quality of life. Stopping smoking can mean psychiatric medication can be reduced, since nicotine increases the metabolism of drugs, [13] and quitting is also associated with reduced depression, anxiety and stress, and improved positive mood compared with continuing to smoke. [14] However, one of the most significant contributions effective stop smoking services could make to quality of life within this population is a reduction of morbidity, since for every	Thank you for your comment. We have added morbidity to the list of outcomes that may be used. The outcomes for each review question will be decided by the committee.

			death caused by smoking, approximately 20 smokers are suffering from a smoking related disease. [15] ASH therefore believes the draft scope should explicitly outline a reduction in morbidity as one of the "main short-, medium-, and long-term outcomes that may be considered when assessing the evidence."	
Association for Family Therapy and Systemic practice (UK)	General		**Question 1** Cost-saving: It seems from the evidence you present in the document that independent out of area placements increase both financial and social costs. It would therefore seem prudent to invest in NHS resources in accordance with local need.	Thank you for your comment. This aspect is likely to be considered when developing recommendations.
Association for Family Therapy and Systemic practice (UK)	General		**Question 2** Whether the guidance should relate only to those with complex psychosis: Those with severe and enduring symptoms which impact equally on social, emotional and occupational domains should not be excluded because they may not have received a diagnosis of complex psychosis, unless there is an important difference in what would be recommended. The issues of separation from family, friends, supports and geographical areas which people know would appear to be the same for any person having to be placed out of area. Similarly, if similar interventions would be recommended to enhance quality of life and rehabilitation, then it makes little sense to	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.

			exclude people with need, on the basis of a diagnostic category.	
Association for Family Therapy and Systemic practice (UK)	1	8-20	The draft guideline sets out NHS England's definition of the rehabilitation laying emphasis on an interactive and collaborative process, and the need to address physical, mental, and social capability. Further in line 16 mention is made of a whole system approach. . However, it does not appear to offer a framework within which this might be developed. Currently services for people with severe and enduring mental illness continue to be offered a on silo basis. Whilst there appears to be in initiatives such as the Vanguard project, attempts to develop collaborative integrated working. The prevailing advocated model of collaborative working seems to be the 'triangle of care' which locates the patient on one point, the carer on the other and the professional on the other. In doing this it does not address the need for collaboration between mental and physical health professionals. An alternative developed in the US model which is more 'systemic' is the Tri Optic Fogarty, T.C, Mauksch, L.B. (2016). This locates the patient in the centre of the triangle, and they are viewed through the lenses of the mental health professional, the physical health professional and the carer/family.	Thank you for your comment and for sharing these example of models of care. We will review the evidence for the most effective way of delivering collaborative care and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.

			Fogarty, T.C, Mauksch, L.B. (2016). The Tri-Optic II: Embracing the Family Voice. *Families, Systems, & Health.* pp 1-3. 34,1	
Association for Family Therapy and Systemic practice (UK)	6	151-162	Given the statements about relatively greater burden of severe and enduring mental illness upon some groups and contexts we suggest that guidance also targets discrimination within services and in society, and increases awareness of the links between poverty, the experience of publicly-funded care, and the experience of severe and enduring mental illness. In addition, stigma against those experiencing severe and enduring mental illness should be addressed as part of any strategy to increase community and employment involvement.	Thank you for your comment. We will make recommendations based on the evidence but will carry out an equality impact assessment at each stage of the guideline development to ensure these are applicable to all groups of service users and so reduce discrimination.
Beat	General	General	Despite the broad definition of 'Rehabilitation' on page 1, overall the draft scope appears to suggest that the guideline will focus predominately on the operation of dedicated NHS Rehabilitation services rather than taking a 'whole system approach'.	Thank you for your comment. The guideline will focus on NHS-led services but will also include social care and independent provision where applicable.
Beat	General	General	We are surprised to see that the draft scope for the forthcoming guideline on 'Rehabilitation in adults with severe and enduring mental illness' excludes people with severe and enduring eating disorders (SEED). People with SEED experience both severe symptoms and a long history of illness, although as with other mental health conditions there is not a single agreed definition. NHS Improvement say on their website that: "… there is currently no single agreed definition of which conditions/criteria would constitute SMI. The term is generally restricted to the psychoses,	Thank you for your comment. While we recognise the needs of people with severe and enduring eating disorders we believe that the type of rehabilitation services required by this population is entirely different to that required by people with complex psychosis and other severe mental health disorders and that it would therefore not be possible to combine these populations into a single guideline. This does not preclude people with eating disorders from accessing psychological therapies.

			including schizophrenia, bipolar disorder, delusional disorder, unipolar depressive psychosis and schizoaffective disorder. It is acknowledged that there is substantive criticism of this definition; personality disorders can be just as severe and disabling, as can severe forms of eating disorders, obsessive compulsive disorder, anxiety disorders and substance misuse problems." The term 'Severe and enduring mental illness' should be applied to some patients with eating disorders due to the severity of their conditions, their longevity and since, like Schizophrenia, they require coordinated and often prolonged engagement with specialist mental health services working effectively with other agencies (Robinson, 2014). People with SEED typically experience all the complex problems listed in the bullet points on page 2 of the draft scope (lines 38-48). Anorexia has the highest Standardised mortality rate (SMI) of any psychiatric disorders (Arcelus, et. al., 2011). Eating disorders, particularly in those who experience severe symptoms over many years have significant impacts on the quality of life of both the person with the eating disorder and their family/carers. Eating disorders and particularly SEED, are also associated with high health service costs and lost employment (PwC, 2015).	

			Whilst a NICE guideline on eating disorders (NG69) was published last year, this was focused on psychological therapies rather than the kind of broader interventions aimed at reducing social isolation and improving occupational health which would be suggested by the definition of rehabilitation on page 1 of this draft scope. Whilst full recovery from an eating disorder is certainly possible for people with SEED, and it is important that these patients can access the psychological therapies recommended in NICE NG69, interventions aimed at improving quality of life can be highly valued and beneficial. Le Grange et al (2012) and others have shown the potential to significantly improve quality of life for people with severe and enduring anorexia nervosa.	
Beat	General	General	If the final scope of this guideline maintains the exclusion of conditions other than Psychoses, then the title should be changed to reflect this. If the title was retained this would be likely to further consolidate the interpretation that an eating disorder cannot be classed as a 'Severe and enduring mental illness'. The interpretation of this term by commissioners and NHS managers can have real consequences for people with Severe and enduring eating disorders (Robinson, 2014). The National Quality Board (NQB) guidance requires that all inpatient, outpatient and community patient deaths of people with severe mental illness (SMI) should be subject to case record review.	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people and amended the title accordingly. However, while we recognise the needs of people with severe and enduring eating disorders we believe that they type of rehabilitation services required by this population is entirely different to that required by people with complex psychosis and related severe disorders and that it would therefore not be possible to combine these populations into a single guideline. We do not think this should affect the classification of eating disorders by the National Quality Board.

Beat	1-2	24-32	On average around 1 in 5 people with Anorexia Nervosa or Bulimia Nervosa experience a protracted (enduring) course of illness (Steinhausen, 2002; Steinhausen and Weber, 2009). The proportion of people with severe and enduring mental illness who are suffering from an eating disorder is unknown due to the absence of a comprehensive national data set and inconsistencies in the definition of what constitutes 'severe and enduring' or a 'Severe mental illness (SMI)'. Furthermore, people with complex psychoses may be more likely to receive a diagnosis than those with severe and enduring eating disorders. Anorexia is often experienced as ego-syntonic and many sufferers have low self-esteem. Many of those who have suffered from an eating disorder for several years experience social isolation, becoming cut off from friends and family. All of this contributes barriers to help-seeking and diagnosis.	Thank you for your comment. While we recognise the needs of people with severe and enduring eating disorders we believe that they type of rehabilitation services required by this population is entirely different to that required by people with complex psychosis and related severe disorders and that it would therefore not be possible to combine these populations into a single guideline.
Beat	6	155	The draft scope says that the Equality Impact Assessment would "*explain why any groups were excluded from the scope*", however the Equality Impact Assessment does not explain the exclusion of mental health conditions other than psychosis (including eating disorders).	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people. However, while we recognise the needs of people with severe and enduring eating disorders we believe that they type of rehabilitation services required by this population is entirely different to that required by people with complex psychosis and related severe disorders and that it would therefore not be possible to combine these populations into a single guideline. We have now added this to the equality impact assessment.
British Association for Psychopharmacology		206	Excluding an analysis of the effectiveness of specific interventions for complex psychosis will limit the usefulness of the guideline. There is a large evidence base	Thank you for your comment. We think that the population covered by this rehabilitation guideline will need optimization of therapy beyond that included in the existing

			for some interventions, eg clozapine, that is particularly relevant to people with complex psychosis and not covered in terms of this patient population in the other relevant NICE guidelines	NICE guideline and so this will be the focus on the evidence review.
British Association for Psychopharmacology		304	This needs to specify and include pharmacological additions including reference to clozapine (inc in schizophrenia guidelines) but over and above this- many patients will have clozapine resistant/ultra resistant symptoms	Thank you for your comment. We recognize that many people will have resistant symptoms and this question will review the evidence to determine the best way to optimize treatment in these people.
British Association for Psychopharmacology		314	Healthy living is a misnomer for a group of patients with very poor physical health – what interventions are needed to improve physical health and prevent the consequences of poor physical health including weight management, obesity management, CV risk, diabetes care etc etc	Thank you for your comment. We recognise that this group of people may have poor physical health and have included a question to examine the evidence for the most effective way to improve health, including accessing physical health services and health monitoring.
British Association for Psychopharmacology		339	Including medication	Thank you for your comment. We will consider the evidence for the interventions that are valued by service users to identify if this includes medication.
British Association for Psychopharmacology		348	One of the main outcomes needs to be guidance for optimising pharmacological management and monitoring needed therein	Thank you for your comment. There is already existing NICE guidance that covers optimising and monitoring treatment which the guideline committee may cross-refer to. In addition, we have added additional outcomes of medication adherence and reduction or cessation of medication.
British Association for Psychopharmacology	7	189	The scope refers to 'Delivering optimised treatments for people with complex psychosis to help recovery and prevent relapse', which presumably includes pharmacological interventions although this is not explicitly stated. In addition to the prevention of relapse and control	Thank you for your comment. We will be reviewing the evidence for the most effective interventions to optimize pharmacological treatment and agree that this may improve engagement in other interventions too.

			of symptoms, a key treatment aim with medication in people with a complex psychotic illness can be to improve their ability to engage in psychological interventions and rehabilitation endeavours as well as their social engagement.	
British Association for Psychopharmacology	8	206	It is noted that the 'Effectiveness of individual treatments for complex psychosis' is an area that is outside the scope. This seems at first sight to be at odds with the inclusion of the 'optimised treatments' (see comment above). If the 'individual treatments for complex psychosis' being referred to here are the experimental medication combinations and augmentation regimens for refractory illness, that should perhaps be clearly indicated.	Thank you for your comment. We have clarified this phrase to state that we will not cover 'Comparative effectiveness of standard doses of individual pharmacological treatments for complex psychosis' as this is already covered by other guidelines.
British Association for Psychopharmacology	8	210	Reference to NICE guideline for Psychosis in Children and Young People- as many of these with childhood or early onset psychosis will have poorer prognosis and will graduate to rehab services as young adults	Thank you for your comment. Although this guideline will look at rehabilitation for adults, we have added this guideline to the list of related NICE guidance.
British Association for Psychopharmacology	10	283	*Identifying people who would benefit most from mental health rehabilitation services.* Comment: key in this assessment is the stage at which people can be identified. There is emerging data to suggest that early failure to respond to even a single antipsychotic can predict those with subsequent resistant psychosis. This could serve as a warning flag for further assessments to indicate suitability for referral to rehabilitation services. Early has got to be better in this sense as in first presentation of psychosis and whilst this is an area ripe for further research (perhaps a NICE research priority area to be identified) there is existing data to guide such decisions.	Thank you for your comment. The review of evidence for identifying people who would most benefit from rehabilitation may well identify these kinds of factors.

			One assessment that is neglected is that of neurocognitive functioning which is one of the strongest predictors of longer term functional outcome (prospective evidence in early intervention in psychosis settings). In this sense it would seem formal cognitive assessment should be considered for all people who are thought suitable for rehab services although there is a limited research to inform these decisions.	
British Association for Psychopharmacology	11	299	*Organisation, function and structure of services, including inpatient and community-based rehabilitation units and teams.* Comment: as part of the economic assessment it would be informative for trusts and commissioners to have formal health economic analytic evidence on which to base decisions for rehab services in statutory or independent sector provision. The Schizophrenia Commission identified independent sector provision of rehab services as a drain on mental health NHS resources and it would be informative for this to be formally assessed.	Thank you for your comment, which will be taken into consideration when determining the economic priority topics in the guideline.
British Association for Psychopharmacology	12	336	*Collaborative care planning and service user experience.* Comment: the recognition of the importance of family views about interventions is important and welcome but there is very little focus on assessing the effect of family and carer involvement in the rehabilitation process (and in rehabilitation facilities). Given the robust evidence of the importance of family support and interaction for relapse in psychosis, as detailed in NICE guidance CG178 in recommending family intervention, the lack of consideration of family within the rehab context seems an oversight.	Thank you for your comment. We agree that the involvement with family is important and have amended the question on collaborative working to include families and carers as well.

British Association of Art Therapists (BAAT)	4	115-19	We endorse the need to build on the recommendations of the JCPMH to ensure the appropriate commissioning of local services.	Thank you for your comment and for endorsing our use of this existing guidance.
British Association of Art Therapists (BAAT)	6	166	Groups that will be covered are stated as adults "with complex psychosis". If this is the case, then the title of the guideline scope and the eventual guideline should make this clear, which the scope title does not at present – it appears to capture a broader subgroup: "severe and enduring mental illness".	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.
British Association of Art Therapists (BAAT)	7	186	"Identifying people who would benefit most from rehabilitation services": We recommend that in order not to exclude potentially informative research evidence, this be expanded to "who would benefit most from what types or components or packages of rehabilitation support or interventions and in what contexts" – i.e. embracing the "context-mechanisms-outcome" model (Pawson Pawson, R. and Tilley, N. (2004) Realistic Evaluation. London: The Cabinet Office http://www.communitymatters.com.au/RE_chapter.pdf	Thank you for your comment. This question will be finalised by the guideline committee and will form the basis for a detailed review protocol which will define the literature search in more detail and should capture some of the details you have suggested.
British Association of Art Therapists (BAAT)	7	187-8	"Organisation, function and structure of services": We recommend this include any services or interventions following which participants who were identified as having complex psychosis that had not responded to previous treatment are functioning significantly better. Potentially this may or may not be within designated rehabilitation services but the evidence could still be relevant.	Thank you for your comment. As this guideline focusses on rehabilitation services we will be looking for evidence of services or interventions that can be delivered within this setting, but agree that some of the evidence may be from other settings.
British Association of Art Therapists (BAAT)	7	189-90	"Delivering optimised treatments": This depends crucially on assessment, so perhaps evidence on how the assessment process contributes to the optimisation of treatments. If assessment is not sufficiently comprehensive and tailored to the individual, treatment	Thank you for your comment. We agree that assessment is important and the committee may choose to look at this.

			may not be optimised. For example childhood trauma or trauma due to previous experiences within or related to the mental health system (such as forcible restraint and injection, or forcible arrest by the police) may be missed, as may sleep difficulties.	
British Association of Art Therapists (BAAT)	7	191-6	"Therapeutic programmes … activities of daily living": It would be important to seek evidence that might illuminate why programmes on self-care, life skills etc do not always result in improvement. Reasons for this could include (1) insufficient attention to individuals' hopes and interests, (2) insufficient attention to unwanted effects of medication, (3) the degree to which staff have been able to win the person's trust, instil hope and support self-efficacy, which in turn can be linked to (3) staff training needs and morale, (4) the culture of a service and the influence of targets it is obliged to meet. (5) If the service user has experienced childhood trauma or racial or other forms of discrimination and exclusion and these have not been addressed, this can lower their levels of hope.	Thank you for your comment and suggestions of barriers to successful daily living. We will be evaluating the evidence on effective interventions and making recommendations based on this evidence and the expertise of the guideline committee.
British Association of Art Therapists (BAAT)	7	198-200	"Healthy living" – this should include sleep, for which there is growing evidence of its involvement in the occurrence or exacerbation of psychotic phenomena (Davies, G., Haddock, G., Yung, A.R., Mulligan, L.D. and Kyle, S.D. (2017), "A systematic review of the nature and correlates of sleep disturbance in early psychosis", *Sleep Medicine Reviews*, Vol. 31, pp. 25-38, doi: 10.1016/j.smrv.2016.01.001; Lunsford-Avery, J.R. and Mittal, V.A. (2013), "Sleep dysfunction prior to the onset of	Thank you for your comment and for providing this information on sleep. We have added sleep to the question on interventions for healthy living.

			schizophrenia: a review and neurodevelopmental diathesis-stress conceptualization", *Clinical Psychology: Science and Practice*, Vol. 20 No. 3, pp. 291-320; Reeve, S., Sheaves, B. and Freeman, D. (2015), "The role of sleep dysfunction in the occurrence of delusions and hallucinations: a systematic review", *Clinical Psychology Review*, Vol. 42, pp. 96-115, doi: 10.1016/j.cpr.2105.09.001). In addition to addictions mentioned, other forms of addiction, e.g. excessive time online including that which interferes with sleep, need also to be considered – and what maintains such addictions and what might re-instigate them if a person returns to lower support or home environment where these began or became entrenched.	
British Association of Art Therapists (BAAT)	7	202	"Collaborative care planning and service user experience": The previous consultation of service users was in 2011, and as this scoping document acknowledges, there have been changes since then, including closure of rehabilitation units since 2012, and only half of NHS trusts having community rehab teams. It is important to consider service user and carer experience but what is available may need to be supplemented by further consultation.	Thank you for your comment. We have amended the two planned questions about collaborative care planning to include a greater emphasis on the involvement of families and carers, to include 'care, support and approaches' and reprioritised this section above the section looking at specific interventions.
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British Association of Art Therapists (BAAT)	10	283-4	"Identifying people who would benefit most from mental health rehabilitation services": We recommend that in order not to exclude potentially informative research evidence, this be expanded to "who would benefit most from what types or components or packages of rehabilitation support or interventions and in what contexts" – i.e. embracing the "context-mechanisms-outcome" model (Pawson Pawson, R. and Tilley, N. (2004) *Realistic Evaluation*. London: The Cabinet Office http://www.communitymatters.com.au/RE_chapter.pdf. There may be a lack of evidence but if so, this should be flagged up.	Thank you for your comment. This question will be finalised by the guideline committee and will form the basis for a detailed review protocol which will define the literature search in more detail and should capture some of the details you have suggested.
British Association of Art Therapists (BAAT)	10	285-6	"Which people … are likely to benefit most from referral…?": Similarly to above, we suggest expand this to "what types or components or packages of rehabilitation support or interventions and in what contexts?"	Thank you for your comment. This question will be finalised by the guideline committee and will form the basis for a detailed review protocol which will define the literature search in more detail and should capture some of the details you have suggested.
British Association of Art Therapists (BAAT)	10	287-90	Barriers: This should include evidence on the effect of service closures and the effects of social disadvantage such as experience of exclusion or lack of transport where there is a community service to which service users would need to travel regularly. The difficulty that some people can have leaving their house or flat also needs	Thank you for your comment and for listing some of the potential barriers. We will be evaluating the evidence on issues that pose barriers and making recommendations based on this evidence and the expertise of the guideline committee.

			consideration, and unwanted effects of medication for some people. Some may also have been in the mental health system a long time and experienced coercive treatment and being given or acquired negative ideas about their recovery prospects. These may need to be addressed in order to win some people's trust and enable them to be hopeful.	
British Association of Art Therapists (BAAT)	10	291-4	"Organisation, function and structure of services" – "effectiveness of rehabilitation services compared with standard care": We suggest expand this to "What is the effectiveness of rehabilitation services of different types and for which patients with complex psychosis compared with standard care of what types and for whom?" Perhaps this is what would be done, but it seems important to capture the specific nature of any services and of the people they serve, and to try to ascertain as far as possible why a particular service had better outcomes, for whom and in what context, since people with the same diagnosis can have very different needs. "Standard care" can also vary by location.	Thank you for your comment. This question will be finalised by the guideline committee and will form the basis for a detailed review protocol which will define the literature search in more detail and should capture some of the details you have suggested.
British Association of Art Therapists (BAAT)	11	295-6	The question here could also be expanded to "What is the effectiveness of inpatient rehabilitation services compared with community-based rehabilitation services for whom and in what contexts?"	Thank you for your comment. This question will be finalised by the guideline committee and will form the basis for a detailed review protocol which will define the literature search in more detail and should capture some of the details you have suggested.
British Association of Art Therapists (BAAT)	11	299-301	Barriers to integrated care pathways – yes very important	Thank you for your comment. We agree that it will be important to identify barriers to integrated care pathways.
British Association of Art Therapists (BAAT)	11	304-6	"What principles should guide adjustments to standard treatments in the management of the underlying psychosis in people using rehabilitation services?" This seems an	Thank you for your comment and informing us about this literature on stress, trauma and sleep. We will be evaluating the evidence on principles that guide

			important question given that psychosis can have many different causes, and recent evidence about the effects of childhood adversity and adult exclusion and prolonged stress as causes of a large proportion of psychotic experience (e.g. Read, J., Fosse, R., Moskowitz, A. and Perry, B. (2014), "The traumagenic neurodevelopmental model of psychosis revisited", *Neuropsychiatry*, Vol. 4 No. 1, pp. 65-79). Depending on what environmental factors may be maintaining psychosis, or unaddressed childhood experiences or trauma may need to be addressed, there probably needs to be less reliance on "standard treatments" that are based on the assumption of one main cause. There may be a need to consider increasing the support for people to reduce or stop antipsychotic medication when it is causing excessive daytime drowsiness or difficulty getting up in the morning (Faulkner, S. and Bee, P. (2017), "Experiences, perspectives and priorities of people with schizophrenia spectrum disorders regarding sleep disturbance and its treatment: a qualitative study", *BMC Psychiatry*, Vol. 17 No. 1, p. 158, doi: 10.1186/s12888-017-1329-8), or causing weight gain and consequent reduced self-esteem.	adjustment to standard treatments and making recommendations based on this evidence and the expertise of the guideline committee.
British Association of Art Therapists (BAAT)	11	307-12	"Therapeutic programmes specific to rehabilitation … activities of daily living": It would be important to look at what works for whom, when, how and in what contexts.	Thank you for your comment. This question will be finalised by the guideline committee and will form the basis for a detailed review protocol which will define the literature search in more detail and should capture some of the details you have suggested.
British Association of Art Therapists (BAAT)	11	313	"Vocational rehabilitation" – yes, crucial.	Thank you for your comment. We agree that interventions that increase vocational participation will be an important part of the recommendations.

British Association of Art Therapists (BAAT)	11	314	"Healthy living": This needs to include poor sleep and the effects of antipsychotic medication on sleep architecture and timing. Excessive daytime sleepiness can make it difficult for people to imagine being able to work or attend college, or to get good grades in any education or training course.	Thank you for your comment. We have amended the question on healthy living to include sleep.
British Association of Art Therapists (BAAT)	11	317-18	"What interventions specific to rehabilitation are effective for people with complex psychosis to improve their activities of daily living?": Why only "specific to rehabilitation"? Should it not be any intervention that has been made available to people deemed to have complex psychosis, especially in light of closures of rehab services in recent years? Depending on what research is available it might amount to the same thing but arguably should not be restricted to what is offered as part of rehabilitation services, in order not to miss any potentially effective interventions. It should be specific to the people with this diagnosis who may need rehabilitation, rather than to services.	Thank you for your comment. As this guideline focusses on rehabilitation services we will be looking for evidence of services or interventions that can be delivered within this setting, but agree that some of the evidence may be from other settings.
British Association of Art Therapists (BAAT)	11	319-26	The same seems to apply to the questions here as for 317-18.	Thank you for your comment. As this guideline focusses on rehabilitation services we will be looking for evidence of services or interventions that can be delivered within this setting, but agree that some of the evidence may be from other settings.
British Association of Art Therapists (BAAT)	12	327-332	The same seems to apply to the questions here as for 317-18.	Thank you for your comment. As this guideline focusses on rehabilitation services we will be looking for evidence of services or interventions that can be delivered within this setting, but agree that some of the evidence may be from other settings.

British Association of Art Therapists (BAAT)	12	336-40	"Collaborative care planning": This should extend to anyone the service user feels is part of their social network and should be involved if they are willing to help support the person. This could include an employer or education or training provider.	Thank you for your comment. We have amended this question to include families and carers. It already includes 'providers' which would include employers or training providers.
British Association of Art Therapists (BAAT)	12	341-44	"Transition from rehabilitation services to other parts of the mental health system or … primary care": An additional question should be "How can arbitrary target-based discharge be avoided?" or "What systems or leadership need to be in place to ensure that discharge is about what the individual person needs and is ready for, and not what the service needs?"	Thank you for your comment. We have added an additional question to the scope 'What processes are needed to support successful transitions?' to cover this aspect of transitions.
British Association of Art Therapists (BAAT)	12	353	Outcomes – "Successful discharge": Although this may seem an obvious indicator of a good outcome, and the word "successful" seems to imply something more than simply discharge, there is a danger in focusing on discharge as an outcome, in that it is not in itself an indicator of an outcome that is most meaningful to individual service users in terms of maximising their life chances and social inclusion. If included, the definition of "successful" would be paramount.	Thank you for your comment. We will always consider a range of outcomes for each intervention and so discharge would only form part of the assessment of how beneficial to a person's life the intervention had been. 'Successful' discharge includes continuing to remain in the community without further readmissions to hospital, as well as participating in the community to the degree that the person desires.
British Association of Art Therapists (BAAT)	12	354	"Independent or successful community living" – very important, but must be defined as what the service user feels is successful community living. It would be easy for this to be defined as "not using services" or "maintained" in the community (i.e. their home) on medication, which could mean the person is not really living a meaningful life.	Thank you for your comment. We will always consider a range of outcomes for each intervention and so independent or successful community living would only form part of the assessment of how beneficial to a person's life the intervention had been. 'Successful' discharge includes continuing to remain in the community without further readmissions to hospital, as well as participating in the community to the degree that the person desires.

British Association of Art Therapists (BAAT)	13	364	Perhaps an additional outcome should be "successful reduction or cessation of antipsychotic medication" since this would potentially increase life chances and reduce likelihood of developing diabetes and cardiovascular problems.	Thank you for your comment. We have added an additional outcome relating to reduction or cessation of medication, as you have suggested.
British Liver Nurses' Association (BLNA)	3	86	What is the reference for the 50% figure etc	Thank you for your comment. This figure is taken from the Royal College of Psychiatrists website information on rehabilitation services (https://www.rcpsych.ac.uk/healthadvice/treatmentswellbeing/rehabilitationservices.aspx).
British Liver Nurses' Association (BLNA)	General	General	Although there is a strong recognition of alcohol and substance misuse. Has the term Dual Diagnosis been deliberately omitted?	Thank you for your comment and for your recognition of the fact that we have included alcohol and substance misuse. However, we think the term 'dual diagnosis' could be confusing to non-experts as it could mean a diagnosis of a number of concurrent conditions. We have therefore chosen to specify the co-existing conditions by name, where applicable.
Cheshire and Wirral Partnership NHS Foundation Trust			Consider the use of the Lester Scale in assessment, intervention and audit of physical comorbidities; The Lester Positive Cardiometabolic Health Resource (CMH-resource) - Further information http://www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/nationalschizophreniaaudit/cmhresourceinformation.aspx	Thank you for your comment. We will make the guideline committee aware of this resource.
Cheshire and Wirral Partnership NHS Foundation Trust			Policies to include Improving the mental health of people with serious mental illness; a practical toolkit, NHS England, May 2016.	Thank you for your comment and for making us aware of the publication. We will make the guideline committee aware of it and it will provide useful background information, but as this document is an evaluation of 4 pilot sites, and there are other national policy documents that it

				was important to include, it was not prioritised for inclusion in the scope.
Cheshire and Wirral Partnership NHS Foundation Trust			Opening question ~2 This guideline should address the general population suffering from severe and enduring mental illness as; - the nosography of mental health disorders is not exact, - the term “psychotic” is no longer a single core characteristic of severity of serious mental disorders. - So called “antipsychotic” medications are now widely used in the treatment of non psychotic disorders such as Bipolar and Depression, potentially exposing individuals to the same risk of cardiometabolic adverse effects. - Individuals suffering from such conditions, psychotic or not, could potentially benefit from similar interventions. - The evidence of benefits from interventions in Early Intervention is increasingly found to be applicable to other conditions, at their Early Intervention stage such as Bipolar, and to a lesser degree in other stages of recovery, although the impact might not be as important as in EI.	Thank you for your comment. We have amended the groups covered by this guideline to ‘complex psychosis and other severe mental health conditions’ so it will include a wider group of people.
Cheshire and Wirral Partnership NHS Foundation Trust			Whole document Consider changing “Rehabilitation” for “Recovery” or “long term Recovery”; it is more constructive. Rehabilitation implies some form of criminal behaviour!	Thank you for your comment. We believe that ‘recovery’ is a process that is relevant across all mental health services. This guideline focuses on tertiary rehabilitation services for people with particularly complex mental health problems.

Cheshire and Wirral Partnership NHS Foundation Trust	2	33-34	Not only people with newly diagnosed psychosis will developed the complex problems and comorbidities described thereafter between 38-48.	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.
Cheshire and Wirral Partnership NHS Foundation Trust	2	50	Not only necessary for "sustained community discharge" but most importantly and positively for "meaningful lives" or long term recovery.	Thank you for your comment. We have added the term 'meaningful lives' to this sentence.
Cheshire and Wirral Partnership NHS Foundation Trust	3	59-69	• Consider wider perspective on morbidity associated with severe mental disorders, rather than narrowing the focus on Schizophrenia. For instance using the WHO study; World Health Organisation (WHO). THE GLOBAL BURDEN OF DISEASE: 2004 UPDATE *www.who.int* 2004;NA: 1-160 .	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.
Cheshire and Wirral Partnership NHS Foundation Trust	4	92	In policies, consider including mention of Dr David Shiers Declaration on Meaningful Lives	Thank you for your comment. We will make sure the guideline committee is aware of this declaration.
Cheshire and Wirral Partnership NHS Foundation Trust	6	166	For adults with severe and enduring mental disorders instead of "complex psychosis"	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.
Cheshire and Wirral Partnership NHS Foundation Trust	10	285; 289;318 ;320;32 2;325;3 28;331	Replace complex psychosis by Serious and Enduring Mental Disorders	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.
Cheshire and Wirral Partnership NHS Foundation Trust	12	350	Consider assessing the impact of physical fitness on its own, on recovery	Thank you for your comment. The outcomes will be used to assess the effectiveness of interventions, including physical activity, on the success of rehabilitation-specific

				interventions. The guideline committee will agree which combination of outcomes to use for different interventions.
College of Mental Health Pharmacy (CMHP)	General	General	Whilst we note that this scope document refers to complex psychosis that has not responded to treatment, we would still recommend a mention of the value of medication, even if it's use may have resulted in a partial recovery. Furthermore, for those patients on regular medication there ought to be a recommendation for a reasonable time-interval for review of medication by a specialist mental health team.	Thank you for your comment. We agree that medication, and its regular review are important and are already covered in existing NICE guidance. For this guideline we will be evaluating the evidence for the optimization of medication, which will include review, in people who have not fully responded.
College of Mental Health Pharmacy (CMHP)	General	General	We note that the professional representative committee reviewing this guidance does not include a specialist mental pharmacist. We feel that specialist mental health pharmacists play an important role in rehabilitation processes (Finley,P.R. *et al,* 2003). We feel that it would be appropriate for NICE to acknowledge that whilst it would not be reasonable to include a pharmacist in the development committee for the **whole** of this guideline which has very little medication-related content, they intend to seek specialist pharmacist input to advise on the points in this guideline where the potential benefit of involving specialist mental health pharmacist(s) in medication-related areas can be highlighted. **Reference** Finley, P.R., Crismon, M.L. and Rush, A.J., 2003. Evaluating the impact of pharmacists in mental health: a systematic review. Pharmacotherapy: The Journal of Human Pharmacology and Drug Therapy, 23(12), pp.1634-1644.	Thank you for your comment. We have agreed that the committee composition will be expanded to include a mental health pharmacist as a co-opted member, who will attend guideline committee meetings when evidence relating to pharmacotherapy is being reviewed.

College of Mental Health Pharmacy (CMHP)	7	189-190	We recommend that where the draft scope document states “optimised treatments” it should state that the medication will have already been reviewed by a specialist mental health team, and where possible, by a specialist mental health pharmacist.	Thank you for your comment. We will review the evidence for the principles for optimizing treatments and make recommendations based on the evidence and the knowledge and expertise of the guideline committee. We would not usually include such specific details about who will have reviewed the medication in the scope but this may be included in the detailed review protocol for this question.
College of Mental Health Pharmacy (CMHP)	7	191-200	The draft scope does not include self-medication in the therapeutic programmes. The objective of self-medication programmes is to educate patients about their medicines and give them increasing responsibility for taking medication unsupervised. This is often initiated during in-patient stay or on rehabilitation units but needs monitoring in the community. Self-medication is an important part of the rehabilitation process- it significantly reduces the burden to social services of care packages for administration of medication and forms an important part of a rehabilitation programme which improves the chances of successful outcome through the increased chances of independent living.	Thank you for your comment. We have now included self-medication as a component of the review question on healthy living.
College of Mental Health Pharmacy (CMHP)	11	307-312	We feel that therapeutic programmes should include self-medication programmes (see comment 1 for details).	Thank you for your comment. We have amended the healthy living question to include self-medication.
College of Mental Health Pharmacy (CMHP)	11	314	Whilst we support that health monitoring has been included, we would like to point out that patients on antipsychotics need monitoring for metabolic side-effects. These include alterations in glucose metabolism, lipid abnormalities and weight gain. Furthermore, those on the antipsychotic called clozapine, used in treatment resistant	Thank you for your comment. Monitoring for metabolic side-effects of drugs and clozapine monitoring will be covered under the question on physical health monitoring.

			schizophrenia, need mandatory blood tests (full blood count) to check for agranulocytosis and occasional blood plasma levels to check for toxicity or compliance.	
College of Mental Health Pharmacy (CMHP)	11	315	Whilst we support smoking cessation services, we would like to point out that : a) stopping or reducing smoking can affect blood plasma levels of certain psychotropic medication. For example, clozapine, an antipsychotic prescribed in treatment resistant schizophrenia, can be increased even to toxic levels if the patient stops smoking. b) some stop-smoking medications, for example varenicline, can cause psychiatric side-effects such as depression, anxiety, hallucinations, suicidal ideation, and aggression.	Thank you for your comment and for pointing out these interactions which we will take into consideration when evaluating the evidence for smoking cessation.
College of Mental Health Pharmacy (CMHP)	11	326	We recommend that “health monitoring” should include metabolic monitoring for antipsychotics and blood tests that are mandatory to supply of the antipsychotic called clozapine. (Please see comment 5 for rationale)	Thank you for your comment. We agree that monitoring for metabolic side-effects of drugs and clozapine monitoring will be covered under the question on physical health monitoring.
College of Mental Health Pharmacy (CMHP)	12	327-329	We would recommend that the draft scope should state that the “intervention” will have taken advice from specialist mental health services such as specialist mental health pharmacist or the community mental health team (if there is one for an individual) before going ahead with advising patients to stop smoking or starting smoking cessation medication. (Please see comment 6 for rationale)	Thank you for your comment and for pointing out these issues with smoking cessation which we will take into consideration when evaluating the evidence for smoking cessation. We would not usually include this level of detail in the scope draft questions but it may be included in the detailed review protocol for this question.

College of Mental Health Pharmacy (CMHP)	12	354	We feel that self-medication (please see comment 1) could be a helpful intervention to support independent living.	Thank you for your comment. We have amended the healthy living question to include self-medication.
College of Mental Health Pharmacy (CMHP)	12	357	We would recommend that the service user experience should state a shared decision making approach, as advocated by NICE, where patient involvement in decisions about their care is encouraged.	Thank you for your comment. We agree that shared decision-making is important and have included the service users in the question on collaborative care planning and service user experience.
College of Mental Health Pharmacy (CMHP)	13	359-360	We are surprised that there is no mention of medication adherence here. We recommend that if an outcome of relapse or re-admission is going to be assessed, then surely medication adherence should also be considered because it is likely to have a significant impact on patients' mental stability and hence rate of relapse.	Thank you for your comment. We have added an additional outcome relating to medication adherence, as you have suggested.
Community Housing and Therapy (CHT)	General		A few caveats: A 'systematic review of the literature' should not be confused with evidence: it is only an academic meta-analysis constrained by the chosen criteria for including/excluding particular sets/types of literature, and limited by the availability of published material Overly focusing on the work of current NHS provision would be to deny innovative practice Quantity does not equate to quality – just because there are more studies of a particular type of intervention, it does not mean that it is more effective, just that it lends itself better to academic studies It would be helpful therefore to reaffirm that NICE guidance is something to think about, coming from a particular	Thank you for your comment. NICE guidelines make evidence‑based recommendations on a wide range of topics, from preventing and managing specific conditions, improving health, and managing medicines, to providing social care and support. To ensure fairness in the allocation of health and social care resources across these different areas we use a consistent process (as described in Developing NICE guidelines: the manual). Guidance is based on the best available evidence of what works. We use a wide range of different types of evidence and other information depending on what the guideline committee agrees is relevant for each topic– from published (or unpublished) studies, to testimony from practitioners and people using services.

			perspective within a particular epistemology and ontology, not a prescription for service design	
Community Housing and Therapy (CHT)		317 - 330	Limiting the questions to 'What interventions specific to rehabilitation…' means you will circumscribe the answers received (and thus the 'evidence') by how you define the phrase 'specific to rehabilitation'. If you only look at evidence from NHS-classified 'rehabilitation units', without looking at other services that are rehabilitative, you wlll miss out much of importance. Specifically, we recommend you look into therapeutic communities, both here and in other parts of the world (and consider evidence from books and non-English speaking publications); therapeutic communities have a long history of effective rehabilitation of people with diagnoses of complex psychosis, and of complex personality disorder.	Thank you for your comment. The literature search will be constructed to include a range of terms broad enough to capture evidence about any interventions that could be delivered by rehabilitation services, whether this is provided by the NHS or other providers. If evidence for therapeutic communities is identified this will be included, but it is unlikely that we will review non-English evidence.
Community Housing and Therapy (CHT)	2		We welcome the definition of complexity	Thank you for your comment. We agree that it is important to be clear about the definition of complex psychosis, and have amended this definition to reflect the inclusion of people with other severe mental health conditions.
Community Housing and Therapy (CHT)	3	80-85	Makes the assumption that 'lack of local rehabilitation services' means lack of NHS services, and the further assumption that 'treatment through the independent sector means 'out of area treatments' (OAT's). It further makes the assumption that OAT's are by definition bad, whereas for some people moving away from the area - and indeed family - within which their	Thank you for your comment. We have amended the text relating to out of area treatments to reflect the fact that they are not always provided by the independent sector, and that they are not always detrimental.

			mental health has become compromised, is a positive move forward in life and is of itself rehabilitative	
Community Housing and Therapy (CHT)	4		It seems a bit limited to take at face value the NHS rehabilitation commissioning guidance and the Five Year Forward View for Mental Health: these come from the people who have cut mental health services and closed down the rehabilitative units, as noted on p3 lines 86-88	Thank you for your comment. This section of the scope provides some background information on national policy and commissioning guidance in this area and therefore we think it is important to refer to these documents in the scope.
Community Housing and Therapy (CHT)	5	136	The guidance should also be for charities and private sector (lines 140-143), and should take into account evidence of their practice, however published and whatever the methodologies, because much of the rehabilitative work, and most of the innovation, is undertaken outside the NHS. The NHS does not provide rehabilitative services that meet the needs of the majority of people experiencing mental distress/illness, for example young people, and especially doesn't meet the needs of those from socially excluded groups such as e.g. some ethnic minorities or homeless people, as your scoping document recognises. It is therefore important to look as at wide a range of evidence and of types of organisation as possible.	Thank you for your comment. Charities and the private sector are included in the list of those who the guideline is for, but as there is no obligation for these organisations to implement the guidance they are in the second part of the list. We appreciate the role of charities and independent providers and they will be represented on the guideline committee. Furthermore, the evidence review will not focus only on interventions and good practice within the NHS and public sector, but those delivered by charities and the private sector too.
Community Housing and Therapy (CHT)	7	189-190	This (and p11 lines 302-306) surely contradicts p8 line 206 – how can you evaluate 'delivering optimised treatments for people with complex psychosis' (line 189) without looking at 'effectiveness of individual treatments for complex psychosis' (line 206)? Probably best to drop both – treatment and rehabilitation are linked (for example, longterm consumption of psychopharmacology reduces recovery rates and limits degree of recovery) and there is a very good argument that rehabilitative services are the only true treatments (the others being just ways of	Thank you for your comment. We have clarified this phrase to state that we will not cover 'Comparative effectiveness of standard doses of individual pharmacological treatments for complex psychosis' as this is already covered by other guidelines, but will include how treatments can be optimised for this specific population with complex psychosis.

			managing mental distress/illness), but these arguments go well beyond the scope of this document, so probably best avoid the whole question.	
Diabetes UK	General		SMI is twice as common among people with Type 2 diabetes as the general population (NDA, 2018). The draft scope acknowledges that physical health problems such as diabetes present a particular challenge for people who have developed psychosis and that rehabilitation is essential to address this. We think that the guidance would be strengthened by including 'health management' (not just 'health monitoring') under the 'healthy living' section of Key area 4 'Therapeutic programmes'. This would underline the importance of supporting people with SMI to manage their diabetes and explore how this can most effectively be achieved in rehabilitation services.	Thank you for your comment. Diabetes, as well as other concurrent medical conditions, will be included in the health monitoring section, and we agree that the role of the rehabilitation services is to identify and monitor physical health and to ensure that people are able to manage their medical conditions in conjunction with the appropriate services and practitioners.
Diabetes UK	2	44	The draft scope recognises that a significant number of people newly diagnosed with psychosis go on to develop complex problems such as diabetes with a negative impact on their daily functioning and chances of rehabilitation. Diabetes UK recommends that the scope includes reference to the NICE guideline (NG28) Type 2 diabetes in adults: management so that its recommendations of care and management are included. This will enable inpatient and community rehabilitation units and teams to provide the required care and support for people with SMI to manage their diabetes.	Thank you for your comment. We have added a cross-reference to NG28 as you suggested.
Diabetes UK	7	2	(Question 1) We recommend that the guideline considers best practise of management of diabetes in adults and	Thank you for your comment and for making us aware of this document.

			children with psychiatric disorders in inpatient settings as set out in the Joint British Diabetes Society for Inpatient Care (JBDS) guidelines (section 11.3.6, page 23) and its recommendations (section 11.4).	
Diabetes UK	11	297	We welcome that this guideline recognises that people who are newly diagnosed with psychosis are at risk of developing diabetes. We think that one required component of an effective rehabilitation pathway is to include a risk assessment in order to prevent (or delay the onset of) type 2 diabetes. Inpatient and community-based rehabilitation teams should therefore actively seek out and offer risk assessments to those newly diagnosed with psychosis as their condition increases the risk of developing type 2 diabetes.	Thank you for your comment. Diabetes, as well as other concurrent medical conditions, will be included in the health monitoring section, and we agree that the role of the rehabilitation services is to identify and monitor physical health and to ensure that people are able to manage their medical conditions in conjunction with the appropriate services and practitioners.
Diabetes UK	11	307	We also recommend that this scope considers to include the use of proven behaviour change techniques when designing therapeutic programmes for the categories specified under healthy living in community-based rehabilitation units. This can be essential in preventing (or delay the onset of) type 2 diabetes among people with severe mental illness.	Thank you for your comment. We will be looking for evidence for interventions that improve the physical health (including detection and management of conditions such as diabetes) of the people covered by this guideline.
Diabetes UK	11	324	Due to the increased risk of type 2 diabetes among people newly diagnosed with psychosis, interventions for their engagements in healthy living particularly exercise should consider the second recommendations given in the NICE guideline Physical activity: exercise referral schemes .	Thank you for your comment. When making recommendations on exercise, the committee will consider if it is appropriate to include a cross reference to this NICE guidance.
Independent Mental Health Network		357	Service user experience – To review increasing feelings of self-worth, self- esteem pre and post treatment.	Thank you for your comment on this particular outcome and we agree with your more detailed definition but would

				not include this level of detail in the scope. The list of outcomes in the scope is a suggested list and the guideline committee will agree the final wording of the outcomes and which combinations of outcomes are appropriate for each review question.
Faculty of Dental Surgery.	7	193	Self-care should be personalised/individualised.	Thank you for your comment. We agree that self-care will be different for different people.
Faculty of Dental Surgery.	7 &11	198 & 326	Very pleased to see that Oral Health is still retained within the Guideline scope.	Thank you for your comment. We agree that oral health is important to consider as part of the physical health of people covered by this guideline.
Faculty of Dental Surgery.	10	287	Noted a new addition relating to family, cultural, ethnicity and communication – excellent!	Thank you for your comment and your appreciation of these additions.
Faculty of Dental Surgery.	11	299	Good to see the 'inclusion of barriers and facilitators'.	Thank you for your comment, and for appreciating the inclusion of barriers and facilitators.
Faculty of Dental Surgery.	N.B. original 12	331	On the first draft circulated on page 12, it had included a reference to 'Values' . This seems to be a lost and important opportunity to see what the people with severe and enduring mental illness value?	Thank you for your comment. The values are still included in the questions in section 3.5.
Independent Mental Health Network	5	139	Delete this line as we felt it was not necessary.	Thank you for your comment. The remit for NICE guidelines is to provide guidance to the NHS, social care and public sector bodies, as well as service users. We recognise the important role charities and other non-statutory bodies play but as they our outside NICE's mandate that are included in a separate list.
Independent Mental Health Network	5	140	We felt this also needed to include supported employment providers	Thank you for your comment. We have added 'supported employment providers' to the list.
Independent Mental Health Network	5	144	Further* *and higher* education providers *need to be clear that people aged 16 and 17 in FE are not covered under this guideline.	Thank you for your comment. We agree that education providers will need to be aware of the age limit for this scope.
Independent Mental Health Network	5	147	It was also felt that substance misuse providers should be added as another stakeholder	Thank you for your comment. We have added 'substance misuse providers' to the list.

Independent Mental Health Network	6	169	What does 'not responded to treatment' mean? Need to be more explicit about definitions- defined more precisely- could it include not fully responded to treatment? Still has morbidity? We felt this should also include the negative symptoms of psychosis.	Thank you for your comment. We have amended the wording of this definition to make it clearer that it is people who have not benefitted from standard mental health care and treatment and whose condition is still impacting severely on their life and functioning.
Independent Mental Health Network	7	186	People who would benefit most- we felt this should also include those who have made an element of recovery but with extra input could make more of a recovery and be less likely to relapse. How will these people be identified e.g. OT, psychology. Would be helpful to have some assessment tool guidance.	Thank you for your comment. We will review the evidence for who will benefit most and make recommendations based on the evidence and the expertise and advice of the guideline committee. We did not prioritise including a question on who should do this assessment as it may be any member of the multidisciplinary team.
Independent Mental Health Network	7	191 - 200	191-200: general comment is to align these to Care Act eligibility outcomes i.e. (a)managing and maintaining nutrition; (b)maintaining personal hygiene; (c)managing toilet needs; (d)being appropriately clothed; (e)being able to make use of the adult's home safely; (f)maintaining a habitable home environment;	Thank you for your comment. We believe the two lists are comparable, but the Care Act list details eligibility criteria and does not include some of the skills we have identified as important (such as budgeting). We have amended the question on collaborative care to include families and carers however, as you suggest.

			(g)developing and maintaining family or other personal relationships; (h)accessing and engaging in work, training, education or volunteering; (i)making use of necessary facilities or services in the local community including public transport, and recreational facilities or services; and (j) Carrying out any caring responsibilities the adult has for a child. Also to include a reference to identifying and supporting carers as part of the holistic support around a person who would benefit from rehabilitation services? Another view was - Whilst agreeing that attention should be drawn to the Care Act eligibility outcomes, do not think those outcome measures should replace the current wording as it is wider in its scope.	
Independent Mental Health Network	7	198	Healthy Living - pull out and/or replicate 'exercise' as it is more important than just healthy living- it is also part of	Thank you for your comment. We agree that exercise could be part of healthy living or self-care but we will look at the evidence for exercise interventions but will only

			self-care. Think this was agreed as replicate rather than pull out.	make one set of recommendations on exercise so we do not wish to duplicate this in the scope.
Independent Mental Health Network	7	202	Collaborative Care Planning - We felt this should include the carer experience, also that this needs to be done in a triangulated way to include both relatives and carers as appropriate. Historical carer experience could also be helpful. Historical carer experience should carry equal weight provided carer involvement is agreed with the individual or the individual does not have capacity. Support needs of the carer to be included	Thank you for your comment. We have amended this question to include families and carers.
Independent Mental Health Network	8	203-204	We felt this needs more clarification about what this means- is it pathways from and to all parts of the system for people needing rehab for severe and enduring mental health needs ?	Thank you for your comment. This includes transition between the rehabilitation services and other services, and this is better defined in the question in section 3.5.
Independent Mental Health Network	10	287-290	This needs to be really explicit about equalities issues/protected characteristics: there can be systemic/structural barriers to access for people with protected characteristics. Also ensuring the services themselves are not seen as barriers. Also ensuring the service providers themselves do not have system driven or attitude driven (perceived or real) barriers to engagement or receiving the right treatment for the individual	Thank you for your comment and suggestions of the likely barriers. We will be evaluating the evidence on issues that pose barriers and making recommendations based on this evidence and the expertise of the guideline committee.
Independent Mental Health Network	10-12	280-347	• General comments about questions to be asked, things that are important to individuals: • pace of treatment and support available should be individualised;	Thank you for your comment and suggestions of what is important to individuals. We have covered most of these topics in the questions already and we will be evaluating the evidence on these issues and making

			• recovery/rehab needs to take into account the person's baseline; • different types of education/courses/support available e.g. OU course, taking the individual's needs into account; looking at other ways to spend money e.g. training PTs in mental health; • awareness of relapse prevention/crisis prevention; proper support after hospital discharge; • somewhere safe to live; help with benefits system; psychological help to adjust to 'new reality'; flexible reintroduction to work; focus on carers/families alongside individuals • We also felt that peer support should be embedded in to the pathway.	recommendations based on this evidence and the expertise of the guideline committee.
Independent Mental Health Network	11	316	Please consider changing the word 'drug' for 'substances'	Thank you for your comment. This has been changed to 'substance misuse'.
Independent Mental Health Network	12-14	348-364	We feel this needs to include the following outcomes: • clarity of accountability and how this is monitored; • personalised/individualised rehabilitation- e.g. to achieve participation in education, need to know the educational experience beforehand/the baseline.	Thank you for your comment. We did not included these in the list of outcomes as we think there are unlikely to be reported as outcomes in the evidence. However, the list of outcomes in the scope is a suggested list and the guideline committee will agree the final wording of the outcomes and which combinations of outcomes are appropriate for each review question.
Institute of Mental Health, Employment and Mental Health Network	6	166	The may be a need to reduce the age range to 16 to include early intervention in psychosis service	Thank you for your comment. The focus of this guideline will be on adult mental health services but the recommendations it makes may be applicable to those in adolescent mental health service from 16 to 18.

Institute of Mental Health, Employment and Mental Health Network	6	168	There is an argument for widening the focus of the scope to be all types of severe and enduring mental illness, not just complex psychoses. This is because most employment-related rehabilitation programmes do not distinguish between different types of mental health diagnoses in this way.	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.
Institute of Mental Health, Employment and Mental Health Network	7	176	There is a need to broaden the scope beyond NHS and local authority funded organisations to include third sector organisations, as many relevant rehabilitation services are delivered through third sector organisations.	Thank you for your comment. NICE guidance is developed for implementation by publicly-funded bodies (the NHS, social care and other statutory bodies), and for organisations providing services commissioned by the NHS or social care. It is hoped that third sector organisations providing services independently will use the guidance too, but it is outside of NICE's mandate.
Institute of Mental Health, Employment and Mental Health Network	7	187	We would like to stress the importance of referrals to rehabilitation services related to employment, and how dependent this is on the organisational culture and beliefs of individual clinicians.	Thank you for your comment. We hope the guideline will reduce some of the variation in practice that you describe.
Institute of Mental Health, Employment and Mental Health Network	8	203	There is an issue of services for the transient population, such as University students, who spend time away from their local services where they are registered, and therefore have difficulties accessing appropriate rehabilitation services.	Thank you for your comment. We believe that most university students with complex psychosis and other severe mental health conditions would receive rehabilitation services from providers local to their family home or permanent address. However, the committee will be considering barriers to accessing services and may consider transient populations such as students within this review.
ISPS UK	General	General	Throughout the document there is very little emphasis on involving family, friends, others with lived experience as partners, despite the strong evidence that including them improves the outcome and therefore saves money.	Thank you for your comment. We have amended the question on collaborative care to include families and carers.

Rehabilitation in adults with complex psychosis and other severe mental health conditions

Consultation on draft scope
Stakeholder comments table

17/04/2018 to 15/05/2018

ISPS UK	General	General	Throughout the document emphasis on 'interventions', treatments offered by services, and no mention of the skills and abilities of an individual. The emphasis throughout is on services 'intervening' in someone's life. In my experience the individual should be taking the lead whenever possible, making choices even if we don't like them. This is much more likely to develop an individual who can live independently, doing what is important for them.	Thank you for your comment. The introduction to the scope defines that the main purpose of rehabilitation services is to enable people to regain their skills and functioning and this will be considered when looking at the detailed review questions. We will also be taking into consideration the NICE guideline on 'Service user experience in adult mental health'.
ISPS UK	General	General	I think that services should be available to all with severe and enduring problems. It should be about quality of life, not diagnosis. Problems and diagnosis change over time particularly if approaches are successful and then services may be withdrawn just when the individual needs them most. Also those with very poor quality of life can take up considerable time and energy from services.	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.
ISPS UK	6	169	Should say standard approaches currently offered by Mental health services and not 'Treatment' There are other approaches that have been shown to be effective that are not currently offered.	Thank you for your comment. We have amended the wording here to 'standard mental health care and treatment'.
ISPS UK	10	291	Some additional questions re organisation, function and structure. How is effectiveness influenced by (1) ward/unit atmosphere and (2) service user and staff satisfaction?	Thank you for your comment. We will looking at the evidence base for effectiveness of rehabilitation services and this may include an evaluation of factors that impact on this effectiveness.
ISPS UK	11	307	Effect on quality of life seems a striking omission from list 4.1. - 4.6, and crucial to add. Also need to consider effectiveness in relation to: quality of relationships with family and friends; social networks	Thank you for your comment. Quality of life is an outcome that will be used to assess the effectiveness of interventions, and is included in the list of outcomes in section 3.6. Interventions to improve inter-personal functioning are included in question 4.2.
ISPS UK	11	307	All of these programmes should involve social networks as partners.	Thank you for your comment. We have included a specific question on collaborative care and included family and

				carers in this, but recognise that they may also form part of the interventions we will review for all therapeutic programmes.
ISPS UK	14	379	Identifying and building on each individual's skills and abilities should be included early on.	Thank you for your comment. We have incorporated a box on 'assessing people's needs and strengths' into the pathway as you suggested, and this will be included in the question on identifying who would benefit most from rehabilitation services.
Janssen	General	General	We thank NICE for the opportunity to comment on the draft scope for the NICE clinical guideline on *Rehabilitation in adults with severe and enduring mental illness.* We strongly support and welcome the development of a clinical guideline in this area. There is a significant need to ensure people with severe mental illness are able to live autonomous, high functioning and rewarding lives. Currently many people are unable to find the support they require and there is limited guidance regarding the rehabilitation of people with serious mental illness.	Thank you for your comment. We are pleased that you are supportive of the development of this guideline.
Janssen	6	165-171	We understand that the focus of the guideline will be 'adults (aged 18 years and older) with complex psychosis.' Furthermore that 75% of people with severe mental illness have a diagnosis of complex psychosis. However, we believe that there is an urgent need to support the remaining 25% of people with other mental health conditions. Their needs will be different to those with psychosis and they will need separate recommendations regarding programmes and treatments to support recovery, relapse and rehabilitation. By focusing of complex psychosis alone it raises an equity issue given that people with other severe mental illnesses will not receive the same appropriate level of support and	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.

			rehabilitation, as those with complex psychosis. We therefore urge NICE to expand the scope of the guideline to look more broadly at severe mental illnesses rather than focus on psychosis alone.	
Janssen	7-8		We believe that there is currently a missed opportunity from not reviewing the effectiveness on individual treatments for complex psychosis within the guideline. We note that one of the key areas that the guideline will focus on is: 'delivering optimised treatments for people with complex psychosis to help recovery and prevent relapse.' However, we also note that guideline will not look at the 'effectiveness of individual treatments for complex psychosis.' We are unclear how NICE will be able to optimise treatments if they are not specifically looking at the effectiveness of treatments to support recovery and relapse from complex psychosis. We note that *NICE CG178: psychosis and schizophrenia in adults: prevention and management* has not been updated to reflect the effectiveness of some treatments since 2009 [Full guideline, Section 10.6.3 pg 348-349]. There has been a significant amount of new evidence published since then regarding the treatment of psychosis, which is not incorporated in the guideline. For example, no new evidence has been incorporated looking at availability of new long acting antipsychotics like Xeplion (paliperidone palmitate 1-monthly LAI, Abilify Maintena (aripiprazole LAI) and Trevicta (paliperidone palmitate 3-monthly LAI). We therefore believe that it is important that NICE review the effectiveness of treatments to establish which treatments should be optimised within the pathway for complex	Thank you for your comment. This guideline will not compare the effectiveness of standard treatments for complex psychosis and other severe mental health conditions as this is already covered in existing NICE guidance (CG178) and the scope has been clarified to explain this. However, it will include additional augmentation or additional treatments that may be used in this population with severe and complex psychosis and related conditions.

			psychosis and to help recovery and prevent relapse. Basing it on NICE CG 178 may not lead to the optimised use of treatments for the pathway, especially due to the complex nature of the disease in the population of interest.	
Leeds and York Partnership NHS Foundation Trust	10	292	The needs of those with complex psychosis, substance use and significant risks who engage poorly with services should not be forgotten. There is a clear need for Assertive Outreach Teams (as well as community rehabilitation teams) and given that it is often this group who are placed in OOA units it must be seriously considered as to whether the withdrawal of such services nationally has contributed to the exponential rise in the numbers of patients in such placements.	Thank you for your comment. We are aware that there has been conflicting evidence of the benefit of assertive outreach teams that has led to some disinvestment. However, these may be considered when looking at the evidence for the most effective structure of care teams.
Mental Health Matters	General	General	In response to the question 1 (Which interventions or forms of practice might result in cost saving recommendations if included in the guideline?): **24 hour supported accommodation:** an increase in the level of support which sits between hospital and independent living could significantly reduce the strain on emergency services and readmissions to hospital, and therefore result in significant cost savings. For some individuals, specifically those without robust support networks in place, the transition from hospital to living independently within the community is too great a step. The reduction in support needs to be more gradual and 24 hour supported housing would provide a crucial stepping stone within this transition. The out of hours support available through 24 hour supported housing services	Thank you for your comments and suggestions, which will be taken into consideration when deciding upon the economic priority topics in the guideline.

			would reduce reliance on ambulance and Accident and Emergency services. **24 hour walk in clinics**: mental health is a 24 hour issue however the provision of 24 hour mental health services is minimal. This has a significant impact upon the use of emergency services out of hours as the individuals have nowhere else to go. The provision of 24 hour walk in clinics, with CPN's, support workers and social workers on site, would enable individuals, and their families/carers, to access immediate help without accessing emergency services or hospital, ultimately reducing crisis admissions. **Alternative 24 hour services:** services such as 24 hour crisis houses, service user run sanctuaries and 24 hour home treatments can provide an effective alternative to ambulance, police and accident and emergency services. Not only could these services be accessed directly by the individuals themselves but the emergency services could also refer into them. Sometimes an individual may just need some time away from their home environment and services like this provide that facility. They could then support the individual to resolve any issues and return to the community, removing the need for emergency services and/or hospital readmission. In order to be successful these services need to be supported by local communities, this will build trust and make it more likely that an individual will access the	

			service if they need it. Therefore, there should be an emphasis on ensuring services of this nature are located within different communities, staffed by people who reflect the local community and designed with cultural considerations in mind (e.g. separate facilities for women). **Assertive outreach:** at present the assertive outreach work provided by non-statutory services is time limited (usually 12-16 weeks). Although this timeframe usually enables the formalities of independent living to be completed e.g. arranging benefits and rent payment, it does not always allow for time to be spent with the individual in building their confidence and helping them to integrate within the local community. Each individual is different and therefore the amount of support required is different. Assertive outreach should be delivered until the individual reaches a certain level of independence. This level could be directly linked to that which correlates with successful rehabilitation. This would significantly reduce the likelihood of relapse and readmission to hospital. Additionally, the outreach worker would work directly with all others involved in the individuals care, specifically housing providers, to prevent issues such as rent arrears and anti-social behaviour occurring. This would help to sustain tenancies, reducing costs to housing providers and decreasing the risk of homelessness. Additionally, this would significantly help individuals with additional considerations and associated behaviours, such as	

			autism, which make it more difficult for an individual to integrate within a community. **24 hour helpline:** a 24 hour helpline should be available to anyone with severe and enduring mental health illness regardless of the area within which they live. Helplines can effectively de-escalate crisis, removing the need for emergency services to be involved and preventing relapse. **24 hour mental health drop in centres for the homeless:** some individuals with severe and enduring mental illness either choose not to live within a home, or have been unable to successfully live within a home. We need to ensure that these people have access to specialised support and rehabilitation services in order to prevent relapse and readmission. The mainstream services available, and those mentioned above, are not always appropriate or accessible to someone who is homeless.	
Mental Health Matters	General	General	There is a need for stronger links between drug and alcohol services, community mental health services, probation and charity/voluntary sector services. As a high percentage of mental health service users self-medicate with drugs and alcohol, and many have been involved in the criminal justice system, they have very complex needs. At present many drug and alcohol services will not work	Thank you for your comment. We have included a specific question in the scope about effective interventions for substance misuse and a question about collaborative working which we hope will lead to recommendations that address this issue.

			with an individual until their mental health needs are addressed, and mental health services will not work with individuals until their drug/alcohol needs are addressed. This does not help the individual, stalls rehabilitation and increases the likelihood of relapse. All agencies need to work together rather than as separate entities and deliver a more structured wrap around service to the individual. This collaborative working should be emphasised within the guideline.	
Mental Health Matters	5	140	Due to the significant and effective role they can play within community rehabilitation, it is felt that charities and other non-statutory organisations should be included within the primary list of bodies for whom this guideline is for (line 126), rather than the secondary list (line 139). This will help to emphasise the important and effective role third sector organisations can play within community mental health services.	Thank you for your comment. The remit for NICE guidelines is to provide guidance to the NHS, social care and public sector bodies, as well as service users. We recognise the important role charities and other non-statutory bodies play but as they our outside NICE's mandate that are included in a separate list.
Mental Health Matters	6	166	The guideline should include people who do not have psychosis but who have other forms of severe and enduring mental illness for the following reasons: • There does not appear to be an explanation as to why individuals with severe and enduring mental illness but without psychosis should not be included within the scope of this guideline. As there is no other specific guideline relating to rehabilitation in place for these individuals, there is a risk that the services they receive will be less effective, less efficient and less joined up. Additionally, the rehabilitation interventions and emphasis on collaborative working outlined within	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.

			the draft scope can also be effective for those who may not have psychosis but have other complex mental health needs. • If effective service pathways are built around only those with complex psychosis, in order to enable individuals with other complex mental health needs to access the service pathways, diagnosis of complex psychosis may increase.	
Mental Health Matters	6	173	The guideline should include people with moderate or severe learning disabilities because at present this is not covered by any other guideline. Therefore, there is a risk that individuals with both learning disabilities and complex mental health needs will receive less effective and less efficient services than those individuals who do not have learning disabilities. However, with reasonable adjustments, the rehabilitation interventions and emphasis on collaborative working outlined within the draft scope could also be effective for those with learning disabilities. We are currently learning that IAPT services can be accessible and effective for people with learning disabilities and we are working to ensure they are. We should be doing the same with regard to rehabilitation services.	Thank you for your comment. We are aware that people with moderate and severe learning disabilities are primarily looked after by learning disability services and so are not a key focus for this guideline, but hope that as with IAPT the rehabilitation services will also be accessible to people with learning disabilities where appropriate.
Mental Health Matters	7	182	Day services are considered as a method to deliver some of the key activities outlined in section 3.3 e.g. life skills, social skills, healthy living. These services would be delivered alongside the recovery model and provide an opportunity for individuals to socialise and learn within a non-goal orientated and supportive environment. It is important that these day services are accessible to all	Thank you for your comment. We will be looking at the evidence to determine what constitutes an effective rehabilitation service and this may include day services. The guideline will undergo an equality impact assessment to ensure that none of the recommendations disadvantage people in the groups you have listed.

			groups including B.M.E, women, refugees and people with learning disabilities.	
Mental Health Matters	12	348	We recommend that the following outcomes are added to the list at section 3.6: • Isolation (unsure as to whether this is covered by social functioning but feel that it is significant outcome and should be referred to specifically). • Tenancy sustainment (although independent community living is listed, it is felt that it is important to specifically mention tenancy sustainment due to the benefits this can have on both the individuals wellbeing and the savings made through an individual not moving from tenancy to tenancy).	Thank you for your comment. We agree that isolation is covered under social functioning and tenancy sustainment under independent community living. However, we have specified 'social skills' and 'maintaining a tenancy' under the specific questions looking at the activities of daily living.
National Collaborating Centre for Mental Health	General	General	Population: The draft scope currently covers only adults with complex psychosis who require rehabilitation. To focus the guideline on only this population means that other individuals who do not have psychosis but do live with complex and severe enduring mental illnesses, are at risk of being excluded from rehabilitation pathways and rehabilitation services. These people may also suffer from complex problems that significantly affect their functioning, and so may require rehabilitation so they can be discharged from acute mental health inpatient care back to the community. Focusing the guideline on complex psychosis runs the risk of creating gaps in services and will lead to disparities in access. Commissioners and providers may use the guideline's narrow population focus to narrow the acceptance criteria into rehabilitation services, which will leave many people either stuck in	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.

			acute units, or unable to function independently in the community. Rehabilitation services are aimed at more than just people with complex psychosis, and the guideline should reflect this.	
National Collaborating Centre for Mental Health	General	General	A practice that may result in cost savings will be for rehabilitation services to link with voluntary or community sector (VCS) services that can offer an alternative to rehabilitation and provide supported accommodation. Strong relationships across services will enable people to be linked in with their community, which will strengthen people's connections to their local area, and encourage them to be involved in other activities which may assist in their recovery and enable them to be discharged back to independent living in the community quickly. This may need to be evidenced by evaluation reports completed by VCS services, any cost effectiveness studies that have looked at alternatives to rehabilitation, and any economic reports that have assessed the benefits or links between engaging in community activities and discharge from services.	Thank you for your comment. This will be taken into consideration when deciding upon economic priority topics in the guideline. A systematic review of the economic literature will be conducted as part of the guideline development process and any relevant cost-effectiveness studies will be included if they are of sufficient quality.
NHS England	**General**		**Scope of guideline:** • There is clear rationale to extend the focus beyond complex psychosis only, which is a small subgroup of the overall cohort of people with severe and enduring mental illness who would benefit from rehabilitation. Further, a notable proportion of people requiring rehabilitation will have significant comorbidities and a complex range of needs, reducing the applicability of a guideline that only considers one discrete diagnosis.	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people. The title of the scope issued for consultation reflects the original guideline commission, but as the included population has now been refined the title of the scope has been amended accordingly.

			• The current title of the guideline is misleading if other types of SMI are to be excluded from the scope. Whilst 3.1 clarifies the focus of the guideline, the overall title risks that the guidance will be seen to cover all that is needed for SMI in terms of rehabilitation rather than for the specific sub-group of those with complex psychosis. This could lead commissioners to thinking rehabilitation was just needed for this sub-group – one unintended consequence could be fewer people having timely access to mental health rehabilitation. • Is the reason for the narrow focus on complex psychosis to make the development process more manageable? This consideration needs to be balanced with the usefulness of the guideline for commissioners and providers of mental health rehabilitation pathways, which will very likely be designed to support more people with SMI other than those with complex psychosis as well as those with significant comorbidities.	
NHS England	**General**		**interventions or forms of practice** • For info - NHS Improvement is leading a strand of work to identify optimum mental health rehabilitation pathways through the *Getting It Right First Time* programme.	Thank you for your comment. We are aware of this work and hope to be able to refer to it while developing this guideline.

NHS England	3	70	Current practice – can the 2012 national survey be referenced? Does the information around reduction in units come from the recent CQC report?	Thank you for your comment. The 2012 national survey was used to write this section of the scope (but it is not usual practice to provide a fully referenced 'current practice' section).
NHS England	3	80-85	What definition of out of area has been used to make this calculation? A definition has not been formally agreed by NHS E / I / CQC meaning that this may well be an under or over estimation of cost.	Thank you for your comment. The definition of out of area was as reported in the paper 'A fair deal for mental health services' published in the Psychiatric Bulletin and the data is from the recent CQC report on inpatient mental health rehabilitation services in England.
NHS England	3	87	Query: Do these Trusts have rehab functions within broader community based MH teams?	Thank you for your comment. We believe that in general, trusts do not have rehabilitation functions within their community mental health teams.
NHS England	4	104	Could the reference to this NHS England guidance be included? We're not sure which document is being referred to and therefore how recent it is.	Thank you for your comment. The title and year of publication of this guidance have now been included in the document
NHS England	4	115-119	The JCPMH guidance talks about rehab for services for people with complex mental health needs – could the scope of this guideline not match this existing guidance in terms of clinical cohort?	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people, which is akin to the scope of the JCPMH guide.
NHS England	6	164-173	Scope – as per general comments above.	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.
NHS England	7	182-204	**Key areas that will be covered** – these seem very reasonable and leave the scope open for being iterative as it develops. Many of the areas for exploration would benefit all people with SMI beyond those with just complex psychosis, which strengthens the argument for expanding the scope (particularly point 2 and points 4-7).	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.

NHS England	10	271-279	**Economic aspects -** This is key – identifying improved use of total public funding and the return on investment in terms of improved outcomes for the people, their supporters and local communities.	Thank you for your comment. We will consider the economic implications of all recommendations that are made, but will use cost-effectiveness assessments where appropriate rather than 'return on investment'.
NHS England	10	291	Could we ensure that query 2.1 covers both: - the evidence base for effectiveness of interventions delivered by rehabilitation services - the evidence base for why these specific interventions need to be delivered by a specific rehab service and not by generic Community Mental Health Services?	Thank you for your comment. We will look at the evidence base for the effectiveness of interventions, and the effectiveness of rehabilitation services compared to standard care, which will address both your suggestions.
Northumberland Tyne and Wear NHS Foundation Trust		285-286	- multiple admissions, length of stay, comorbidities	Thank you for your comment. We will review the evidence for which people are most likely to benefit from rehabilitation services and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust		291-292	The scope should look at including various levels of Inpatient and Community Rehabilitation. Our Trust has Complex care, High Dependency Units and Move on inpatient rehabilitation services within the Trust and community rehabilitation team (within each locality). Inpatient rehabilitation services in NTW have been developed in line with the template described by Paul Wolfson, Frank Holloway and Helen Killaspy from the Faculty of Rehabilitation and Social Psychiatry of the Royal College of Psychiatrist (Enabling recovery for people with complex mental health needs: A template for rehabilitation services, 2009). Having the Step up Hub/ community rehabilitation service has had an impact on the engagement, continuity of care, readmission rates and reduction in the bed days.	Thank you for your comment and explaining how your services are configured. We will review the evidence for the required components of an effective rehabilitation service and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.

			A few consultants work across the inpatient rehabilitation and community rehabilitation teams which provides continuity of care. A Trust wide service aims to provide a pathway from acute wards, PICU, out of area treatments in private hospitals (OATs), and forensic services to a community residence of some kind.	
Northumberland Tyne and Wear NHS Foundation Trust		297-298	The scope should consider an appropriate referral system with timely referral, an environment appropriate to service user needs, MDT discharge pathway with good support from social services, availability of supported accommodation with inreach from the Community rehabilitation teams	Thank you for your comment and this suggestion. We will review the evidence for the required components of an effective rehabilitation service and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust		299	The scope should consider recommending Community Rehabilitation Teams to be a part of the rehabilitation pathway to be most effective	Thank you for your comment. We will review the evidence for the required components of an effective rehabilitation service and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust		302	: Are medication treatments included in this guideline? Has clozapine had an adequate trial? Wait 6 months, if improvement is inadequate despite 6 month trial and at a therapeutic dose (plasma levels in range) look at augmentation strategies eg. Amisulpride, aripiprazole, lamotrigine etc..	Thank you for your comment and for suggestions on how therapy can be optimized. We will evaluate the evidence for the optimization of therapy and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust		303:	Referral to tertiary services for second opinion?	Thank you for your comment. Inpatient rehabilitation services are usually regarded as tertiary services themselves.

Northumberland Tyne and Wear NHS Foundation Trust		304	Clozapine, augmentation, treating comorbidities, minimising side effect, physical health care	Thank you for your comment and these suggestions of the principle of optimizing therapy. We will review the evidence for the optimization of therapy and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust		304-306	Duration of illness Response to treatment Family history Comorbidities Age of onset of illness Duration of untreated illness Insight	Thank you for your comment and these suggestions for the principles that should guide adjustment to therapy. We will review the evidence for the optimization of standard treatments and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust		314:	Service User should be encouraged to attend their dentist where possible for check-ups, advice on dental hygiene/caries	Thank you for your comment. Oral health is included in the scope, and included in the interventions to improve engagement in a healthy life.
Northumberland Tyne and Wear NHS Foundation Trust		319-320	Psychology input, family therapy, promoting social inclusion, OT input	Thank you for your comment and these suggestions for interventions that could improve inter-personal functioning. We will review the evidence for interventions to improve inter-personal functioning and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust		321	: Engagement with local recovery colleges/college courses should be encouraged	Thank you for your comment. Interventions to improve engagement with education are included in the scope.

Northumberland Tyne and Wear NHS Foundation Trust		321-323	Recovery College, voluntary work, paid employment, meaningful activities	Thank you for your comment and these suggestions to improve engagement in community activities. We will review the evidence for interventions to improve community engagement and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust		324:	Weight management options including metformin, other strategies, exercise therapy, referrals for bariatric surgery	Thank you for your comment. We have added weight management to the question relating to health living interventions.
Northumberland Tyne and Wear NHS Foundation Trust		324-326	Exercise therapy Healthy diet Promoting and embedding Lifestyle changes Education regarding benefits of a healthy lifestyle	Thank you for your comment and these suggestions for interventions to improve healthy living. We will review the evidence for interventions to improve engagement in healthy living and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust		327	smoking cessation strategies, mindful of interactions with certain medications on stopping smoking e.g. clozapine would require dose adjustments if SU stops smoking. Use of varenciline (underused at present in this population, however effective treatment strategy) – see attached documents	Thank you for your comment and for highlighting the interaction between smoking and anti-psychotic medication. We will ensure the guideline committee is aware of this when they consider smoking cessation interventions for this population.
Northumberland Tyne and Wear NHS Foundation Trust		327-329	Psychoeducation regarding smoking and its effects, interactions with medication especially clozapine, availability of NRT	Thank you for your comment and these suggestions to improve engagement in smoking cessation. We have now included smoking cessation under the section on healthy living and will review the evidence the effectiveness of smoking cessation services and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.

Northumberland Tyne and Wear NHS Foundation Trust		330:	Help with alcohol cravings nalmefene, naltrexone, link in with substance misuse services for advice on managing this. Encourage service user to attend any external meetings to support with this. Psychosocial counselling on substance misuse can be offered by staff on the ward- motivational interviewing	Thank you for your comment. We will review the evidence for interventions for addressing substance misuse and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust		330-332	Dedicated dual diagnosis worker Psychology embedded in the team Dedicated OT	Thank you for your comment and these suggestions to improve engagement in substance misuse services. We will review the evidence for interventions to improve engagement in substance misuse services and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust		334	Different levels of supported accommodation available, Transition opportunities available once goals are reached- , goal orientated, positive enforcement Collaborative approach with patients and carers	Thank you for your comment and these suggestions for the features of supported accommodation. We will review the evidence for the features of supported accommodation and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust		339-340	Long engagement Continuity of care Increased support during transition period Shared language	Thank you for your comment and these suggestions of what is valued by service users. We will review the evidence for what is valued and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust	7	187	And staffing of services	Thank you for your comment. We will be considering the evidence for the most appropriate type of staff, the skills they require and the composition of teams.
Northumberland Tyne and Wear NHS Foundation Trust	7	189	The scope should include consideration of emerging evidence regarding the widespread use of structured MDT approaches to assessment and formulation of bio-psycho-social needs.	Thank you for your comment. We will be considering the evidence for the most appropriate type of staff, the skills they require and the composition of teams, including multidisciplinary teams.

Northumberland Tyne and Wear NHS Foundation Trust	7	189	It is essential that the scope considers ways of optimising delivery of psychological treatment In inpatient Rehab services. The Care Quality Commission (CQC) showed only 29% of inpatients had been offered talking therapies and nearly a quarter of all respondents had asked for therapy but did not receive it (CQC, 2009). Lack of access to therapy either prolongs admissions or means that if patients are discharged due to pressure on beds their needs are not met resulting in high rates of readmission or suicide (Mental Health Task Force, 2016).	Thank you for your comment. We will be considering the evidence for interventions that are most effective at achieving beneficial outcomes for service users, including psychological therapies, and making recommendations based on this evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust	7	189	Implementation of NICE evidenced therapies is complex, training in one approach , for example family interventions does not itself lead to its implementation in routine services (Burbach, 2012). Support has to come from all levels of the organisation , in terms of strategy, provision of protected time for implementation, supervision and training.	Thank you for your comment. We agree that implementation of NICE guidelines can be complex but the committee will give consideration to implementation throughout the development process.
Northumberland Tyne and Wear NHS Foundation Trust	7	189	Evidence also suggests access to NICE therapies is necessary but not sufficient for inpatients services for the following reasons. Within outpatient trials, therapy is typically delivered as 16-20 weekly sessions of around an hour each. This model will not work in the majority of inpatient settings. Therapy needs to be adapted because of problems with cognitive functioning, long standing problems with self -regulation and higher levels of distress than is usual in community services.	Thank you for your comment. We will be reviewing the evidence for how therapies can be optimized in inpatient services and making recommendations based on the evidence and the knowledge and expertise of the guideline committee.

Northumberland Tyne and Wear NHS Foundation Trust	7	189	The scope should also consider the role of skilled assessment of psychological needs including the use of psychometric and neuropsychological assessments where appropriate. Therapeutic interventions based on a range of NICE guidelines and other evidence based models of formal psychological therapy are required.	Thank you for your comment and for suggesting the use of assessment tools and formal psychological therapy. We will review the evidence for the components of an effective rehabilitation pathway and develop recommendations based on the evidence and the knowledge and expertise of the guideline committee.
Northumberland Tyne and Wear NHS Foundation Trust	7	191	When considering therapeutic programmes for patients the scope should consider psychologically informed groups e.g. informed by mindfulness and emotional regulation or psycho-education.	Thank you for your comment. Psychologically informed groups will not to be excluded from our evaluation of the evidence for therapeutic programmes.
Northumberland Tyne and Wear NHS Foundation Trust	7	196	Social skills groups is overly generic and these skills tend to be a by-effect of attendance to other groups.	Thank you for your comment. The more detailed question for this area in section 3.5 will evaluate the evidence for interventions which improve inter-personal relationships.
Public Health England	General	General	Public Health England (PHE) supports the inclusion of co-occurring mental health, and alcohol and drug use conditions. PHE published guidance on this issue last year: https://www.gov.uk/government/publications/people-with-co-occurring-conditions-commission-and-provide-services We would suggest some extensions/improvements to the scope as below.	Thank you for your comment and for making us aware of this Public Health England document. We have addressed your specific comments below.
Public Health England	General	General	We suggest that the guideline includes the impact of mental ill health on musculoskeletal (MSK) conditions as there is a correlation between people who have a mental health condition who develop a MSK condition such as chronic back pain and neck pain.	Thank you for your comment. Musculoskeletal conditions, as well as other concurrent medical conditions, will be included in the health monitoring section, and we agree that the role of the rehabilitation services is to identify and monitor physical health and to ensure that people are able

			Reference: Arthritis UK - Musculoskeletal health – a public health approach https://www.arthritisresearchuk.org/policy-and-public-affairs/policy-reports/musculoskeletal-health-a-public-health-approach.aspx	to manage their medical conditions in conjunction with the appropriate services and practitioners.
Public Health England	General	General	We recommend the scope is expanded to include all those with severe and enduring mental illness and not just those with complex psychosis to ensure the best possible care and services for all individuals.	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.
Public Health England	General	General	The scope of the document needs to ensure physical activity interventions that can support rehab. Although there is limited research on the direct benefits for severe and ensuring mental illness, there is evidence for lower levels of activity in this group and also benefits for symptoms such as sleep and mood, and for social inclusion.	Thank you for your comment. We have included exercise and activity in the areas we will be considering relating to healthy living.
Public Health England	2	48	It would help readers understand the context if the scope included some indication of the size and nature of the problem of co-occurring mental health, and alcohol and drug use conditions across the rehab population, including the impact of these conditions on delaying discharge from in-patient rehab. Reference: https://www.gov.uk/government/publications/people-with-co-occurring-conditions-commission-and-provide-services	Thank you for your comment and for providing us with the link to this document which will provide useful background information for the committee. We have discussed the co-morbidities that exist in people with complex psychosis and other severe mental health conditions in the scope, including other mental health conditions and substance misuse but in order to keep the scope to a manageable size have not included details of the prevalence of all these conditions.

Public Health England	7	198	PHE suggest replacing exercise with physical activity. Also we would suggest “healthy living” be changed to “lifestyle interventions” to emphasise that there are specific benefits and challenges for this group.	Thank you for your comment. We will be considering interventions that improve engagement in healthy living and the list of examples we have given is not exhaustive and have included activity and exercise. We will also be including monitoring for physical health issues so we think this is encompassed better in the term ‘healthy living’ as ‘lifestyle interventions’ may imply it is limited to self-directed interventions such as diet, exercise and smoking cessation only.
Public Health England	7	199	Smoking cessation is associated with lower levels of anxiety, depression and stress, improved view of quality of life and positive mood and dosage of some medicines used to treat mental health problems can be reduced. PHE recommend that smoking cessation’s contribution to improvements in mental health, which include lower psychiatric readmission should be reviewed in the context of this scope to maximise the public heath gains in these settings. http://tobaccocontrol.bmj.com/content/early/2016/05/17/tobaccocontrol-2015-052728	Thank you for your comment. We agree that smoking cessation is important in this population and will be looking for evidence of the most effective interventions.
Public Health England	7 and 11	199-200 and 315-316	Although cessation or abstinence from drugs and alcohol may be desirable goals, many patients will not be able to achieve it, at least not in the short term, so there needs to be some inclusion of harm reduction education and interventions here or separately. Question 4.6 on page 12 better represents this issue as separate from smoking cessation and about improving engagement in “addressing substance misuse”	Thank you for your comment. As you have identified we have a separate question looking at interventions to improve engagement for substance misuse, and this does not assume that complete cessation will be achieved.

Public Health England	9	253	We recommend inclusion of links to relevant NICE guidance on smoking which relate to mental health. For example: https://www.nice.org.uk/guidance/ph48 https://www.nice.org.uk/guidance/ph45	Thank you for your comment. The committee may choose to cross-refer to this existing NICE guidance if appropriate, when making recommendations on smoking cessation.
Public Health England	10	271	We recommend consideration is given to the economic impact of reduced prescribing of antipsychotic medication associated with smoking cessation.	Thank you for your comment. This aspect will be considered when determining the economic priority topics in the guideline.
Public Health England	11	321	We recommend the scope also includes interventions to improve community living in addition to interventions to improve engagement in community activities. This would include interventions that increase social networks, access to green space to support recovery. References: PHE A guide to community-centred approaches for health and wellbeing Power to Change Treating mental health in the community: A policy review	Thank you for your comment. We have included questions on interventions to improve inter-personal functioning (which will include social networks) and engagement in community living (which will include leisure activities such as visits to outside spaces).
RCSLT	General	General	We are concerned that speech, language and communication needs of people with severe mental illness are not adequately considered within this guideline. Many mental health conditions such as psychosis have communication difficulties commonly associated with them or they can be a side effect of medication. People with communication problems experience ineffective support as they struggle to explain their concerns around mental health which leads to inaccurate assessment and interventions and inappropriate referrals.	Thank you for your comment and for supplying these references. We appreciate that some people with severe mental illness may have communication problems and will take this into consideration throughout the development of the guideline. However, although we agree there may be benefit from speech and language therapy we did not prioritise any interventions which are specific to rehabilitation for inclusion in this scope.

			We strongly recommend that communication needs are added to the scope of the guideline. **Evidence** Schizophrenia • Whittaker et al. (1994) suggested people with schizophrenia performed significantly poorer than healthy controls on measures of social communication. • A Cochrane review by Almerie et al. (2015) indicates that social skills training may improve the social skills of people with schizophrenia and reduce relapse rates. • Stephane et al. (2007) conclude that people with schizophrenia may have a language-specific differential impairment. Psychopathy • 84% of people in contact with psychiatric services had language impairment and 74% had broader communication difficulties • Research suggests that individuals with psychopathy may have more subtle problems with emotional and interpersonal aspects of language. They understand and apply the meanings of emotional words but do not experience the affective value attached to them (Hare *et al.* 1998).	

			• Louth *et al.* (1998) showed that adults with psychopathy were insensitive to the emotional connotations of language. • Blair *et al.* (2006) suggested that the semantic representation of emotional words is dysfunctional in individuals with psychopathy.	
RCSLT	General	General	We are also concerned that eating, drinking and swallowing needs (dysphagia) of people with severe mental illness are not considered, despite the fact that specific mental health conditions such as psychosis have these difficulties commonly associated with them. People with severe mental illness need to be observed and monitored for any signs of dysphagia and referred to a speech and language therapist to support and manage swallowing problems. Unidentified and unsupported eating, drinking and swallowing needs can lead to malnutrition, dehydration, choking, or aspiration pneumonia requiring hospital admission and in some cases causing death. We recommend that consideration of dysphagia is added to the scope of the guideline. Evidence • There is a greater prevalence of dysphagia in acute and community mental health settings compared to the general population. There is also evidence for an elevated rate of death due to choking in mental health settings partly due to the effects of medication.	Thank you for your comment. We appreciate that some people with severe mental illness may have dysphagia and also eating and drinking problems. Although we did not prioritise any interventions which are specific to rehabilitation for inclusion in this scope, we will discuss with the committee the inclusion of dysphagia as an outcome at the review protocol stage.

RCSLT	NICE Question	NICE Question	**Which interventions or forms of practice might result in cost saving recommendations if included in the guideline?** Speech, language, communication and swallowing difficulties must be identified and supported to ensure that treatment resources are not wasted. People with severe mental illness who have communication difficulties struggle to access verbally mediated interventions such as psychotherapy, anger management or individual or group based talking therapy. This is because they are largely verbally and language based. As communication skills underpin ability to access language based interventions, difficulty in this area will prevent access to rehabilitation. The Royal College of Speech and Language Therapists recommend that speech and language therapy and interventions for swallowing difficulties are examined. An economic evaluation of the value of speech and language therapy, conducted by Matrix Evidence (a consultancy company which specialises in social return on investment studies) found cost savings across a range of clinical areas which can be applied to the mental health setting.	Thank you for your comment, which will be taken into consideration when determining the economic priority topics. The report by Matrix Evidence would not be directly relevant to the guideline as it considers a societal perspective rather than the NHS and PSS perspective which is typically considered in NICE guidelines.
RCSLT	6	160	The Royal College of Speech and Language Therapists is concerned that speech and language therapy is not considered despite specific consideration being given to people with mild learning disabilities or autism. People with learning disabilities or autism will have difficulty communicating and will have difficulty accessing the information they need to use services. As a result they	Thank you for your comment. We have included a review question on interventions specific to rehabilitation to improve inter-personal functioning and social skills, which will include communication issues, and will consider the needs of the population for whom the guideline relates (those who may have difficulty in communicating).

			are more likely to experience negative communication in health services. We recommend that communication must be central to this guideline and the role of speech and language therapists in supporting communication is considered.	
RCSLT	6	166	The scope of the guideline only includes psychosis and not any other severe mental health conditions. This guideline should only restrict the scope to rehabilitation in psychosis if the current depression and bipolar guidelines cover rehabilitation. At present the depression and bipolar guidelines do not have a strong focus on rehabilitation. The Royal College of Speech and Language Therapists seeks assurance from NICE that other severe mental health conditions such as depression and bipolar will be updated to cover rehabilitation in these separate guidelines.	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and related severe mental health conditions' so it will include a wider group of people.
RCSLT	6	166	If the guideline is only going to only cover psychosis then we recommend that the title is changed as it is misleading at present.	Thank you for your comment. As we have amended the groups covered by this guideline to 'complex psychosis and related severe mental health conditions' to include a wider group of people, we have also modified the title to reflect this.
RCSLT	7	183	The Royal College of Speech and Language Therapists recommends that access to treatment programmes is also examined more widely. Many people with mental health problems will also have communication problems which will make it difficult for them to access rehabilitation and treatment programmes due to the verbal nature of these interventions which require significant understanding and expressive language	Thank you for your comment. We appreciate that some people with severe mental illness may have communication problems making it difficult for them to access rehabilitation and treatment programmes. We will take this into consideration throughout the development of the guideline.

			skills. If people cannot access such interventions then they cannot benefit from them.	
RCSLT	7	192	The Royal College of Speech and Language Therapists recommends that communication is considered in "activities of daily living". This is relevant to all the categories of "self-care", "life skills" and "social skills". The ability to communicate, be understood and understand is crucial to all areas of daily living and we use communication to convey our wishes and feelings. Difficulties speaking and understanding can be isolating and prevents you from simple everyday tasks we take for granted, such as saying when you are in pain and getting your needs met. Support with communication is crucial to allow people to achieve functional outcomes and to integrate socially and participate in daily life.	Thank you for your comment. and suggestion. We have included a review question on interventions specific to rehabilitation to improve inter-personal functioning and social skills, which will include communication issues.
RCSLT	7	197	The Royal College of Speech and Language Therapists recommends that communication must be considered as part of vocational rehabilitation. Communication difficulties are a significant barrier to work and affect a wide range of people. Communication skills are a crucial skill to allow people to express themselves, understand others and for thinking, learning and social interaction in the workplace. The ability to communicate, be understood and understand is crucial to the key area of vocational rehabilitation.	Thank you for your comment and suggestion. We will consider communication issues when we review the evidence for interventions specific to rehabilitation that improve engagement in community activities, including work.

RCSLT	7	198	The Royal College of Speech and Language Therapists recommends that eating, swallowing and drinking needs (dysphagia) is added to the category of “healthy living”. If left unmet, eating, drinking and swallowing needs can lead to malnutrition, dehydration, choking, aspiration pneumonia and even death. Identifying and supporting these needs is a matter of priority for patient safety and to improve quality of life for the individual. Evidence • There is a greater prevalence of dysphagia in acute and community mental health settings compared to the general population • There is also evidence for an elevated rate of death due to choking in acute mental health settings partly due to the effects of medication The risk of death due to choking in people with schizophrenia has been reported as at least 30 times more likely than in the general population (Kulkarni et al., 2017)	Thank you for your comment. We appreciate that some people with severe mental illness may have dysphagia and also eating and drinking problems. Although we did not prioritise any interventions which are specific to rehabilitation for inclusion in this scope, we will discuss with the committee the inclusion of dysphagia as an outcome at the review protocol stage
RCSLT	10	288	The Royal College of Speech and Language Therapists agrees that the barriers people with co-existing conditions such as neurodevelopmental, mental health and cognitive problems face when accessing rehabilitation services must be considered. As communication is the common thread across these conditions, people will experience numerous barriers which result in poor service interaction and negative outcomes. These barriers can include people being unable to explain their concerns around mental health	Thank you for your comment. We have included a question that addresses exactly this point: ‘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?’

			which can lead to inaccurate assessment and interventions and inappropriate referrals.	
RCSLT	10	290	The Royal College of Speech and Language Therapists would like clarification from NICE if they will look at the wider barriers that people may face. Many interventions are verbally delivered, such as talking therapies, and due to the nature of this intervention people cannot access them due to their poor language skills. The Royal College of Speech and Language Therapists hopes that NICE will examine the delivery method and content of the interventions too.	Thank you for your comment. We have included a question that addresses exactly this point: '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?' We also have questions that aim to identify the most effective interventions for this group of people.
RCSLT	11	308	The Royal College of Speech and Language Therapists recommends that communication is considered in "activities of daily living". This is relevant to all the categories of "self-care", "life skills" and "social skills". The ability to communicate, be understood and understand is crucial to all areas of daily living. It allows us to express ourselves and understand others. Many aspects of social cognition can impact upon forming and maintaining relationships and manage in the community. Support is essential to allow people to socially participate in community life and to achieve functional outcomes.	Thank you for your comment and suggestion. We have included a review question on interventions specific to rehabilitation to improve inter-personal functioning and social skills, which will include communication issues.
RCSLT	11	313	The Royal College of Speech and Language Therapists recommends that communication is considered in vocational rehabilitation.	Thank you for your comment and suggestion. We will consider communication issues when we review the evidence for interventions specific to rehabilitation that improve engagement in community activities, including work.

			Communication difficulties are a significant barrier to work and affect a wide range of people. Communication skills are crucial for social interaction and engagement in the workplace, yet the importance of communication skills is often underestimated.	
RCSLT	11	314	The Royal College of Speech and Language Therapists recommends that eating, swallowing and drinking needs (dysphagia) are added to the category of “healthy living”. There is a greater prevalence of dysphagia in mental health settings compared with the general population. Managing these needs is a patient safety issue and improves quality of life. If left unidentified and unmet dysphagia leads to malnutrition, dehydration, choking, aspiration pneumonia and even death.	Thank you for your comment. We appreciate that some people with severe mental illness may have dysphagia and also eating and drinking problems. Although we did not prioritise any interventions which are specific to rehabilitation for inclusion in this scope, we will discuss with the committee the inclusion of dysphagia as an outcome at the review protocol stage
RCSLT	11	315 And 326	The Royal College of Speech and Language Therapists recommends that access to treatment programmes is also examined more widely. Many people with mental health problems struggle to access rehabilitation and treatment programmes, such as psychotherapy or anger management, due to the verbal nature of these interventions. Many people lack the requisite understanding and expressive language skills needed to access such interventions. These programmes can be modified to require a lower level of language to support equal access to them.	Thank you for your comment. We have included a question that addresses exactly this point: ‘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?’

Rehabilitation in adults with complex psychosis and other severe mental health conditions

Consultation on draft scope
Stakeholder comments table

17/04/2018 to 15/05/2018

RCSLT	12	351	The Royal College of Speech and Language Therapists recommends that social participation is added as a short, medium and long term outcomes.	Thank you for your comment. The outcomes list will be refined by the committee when developing the review protocols and depending on what outcomes are reported in the literature, but some of the outcomes already included (social, functioning, activities of daily living, independent or successful community living, participation in education, gaining or maintaining employment) will address social participation.
RCSLT	40	2	The Royal College of Speech and Language Therapists welcomes the recognition of cognitive impairments in people with severe mental illness. People with cognitive difficulties struggle with sending, receiving and interpreting communication. We recommend that the communication problems in people with cognitive impairments are examined and considered within this guideline.	Thank you for your comment. and suggestions. We have included a review question on interventions specific to rehabilitation to improve inter-personal functioning and social skills, which will include communication issues.
Royal College of General Practitioners			**Which interventions or forms of practice might result in cost saving recommendations if included in the guideline?** It is unlikely that significant costs in monetary terms will be saved but the human cost for patients and their friends and family could be massive in creating good rehabilitation services. It may become cost ineffective as a number of these patients currently die prematurely. I would target a less severe patient group as well, see your second question below, that may well be cost effective.	Thank you for your comment. Economic consideration in the guideline extends beyond cost savings. Interventions are considered in cost-effectiveness terms meaning that the effectiveness of interventions is crucial.
Royal College of General Practitioners			**Do you agree that the population of interest in this scope should be people with complex psychosis? Or should it also include people who do not have**	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis

			psychosis but who have other forms of severe and enduring mental illness? Please justify your response. This is a great question. Two parts Concentrate on psychosis and research the outcomes first before introducing a more heterogenous group which will have a number of severe personality disorder types included, they may require different rehabilitation programmes I do not agree with the group targeted as being the most in need. I would like this to be offered to all patients with psychosis. The definitions of rehabilitation were both good. So line 168 describes “complex psychosis is defined as enduring psychosis that has not responded to treatment” but apart from line 38 the other aspects used to define complex illness are those that are commonly found in patients who have psychosis at a less severe level. As a GP the large majority, (personal view) of people who have experienced psychosis do not become “normal” but have many of the features of complex illness and with more structured support could become “normally functioning” with enough health/social care resource. It is this group, who may socially, personal health-wise and work wise engage if carefully directed and monitored and would achieve the greatest outcome in all areas; including for friends and family members. That is not to say I don’t want the “resistant to treatment” cases to have rehabilitation but the figure of 25% having complex needs and 75% therefore being okay, doesn’t feel correct. The stress and change in life of psychotic illness I believe is under-estimated and most of my patients are not “cured” or “normal” but can get	and other severe mental health conditions’ so it will include a wider group of people. We think that a large proportion of people who experience psychosis are supported successfully by standard services. This guideline is focused on the small proportion (25%) who develop complex mental health problems and who have not responded optimally to standard care and treatment.

			to 70-80% improvement. My view is that getting this group to 100% would be the great via increased rehabilitation services.	
Royal College of Nursing	General	General	The Royal College of Nursing (RCN) welcomes the proposals by NICE to develop guidelines for the rehabilitation in people with severe and enduring mental illness. The RCN invited members who care for people with mental illness to review and comment on its behalf. The comments below reflect the views of our reviewers.	Thank you for your comment and for inviting your members to comment.
Royal College of Nursing	Questions	2	In relation to the question posed by NICE: *Do you agree that the population of interest in this scope should be people with complex psychosis? Or should it also include people who do not have psychosis but who have other forms of severe and enduring mental illness? Please justify your response.* This seems quite a narrow focus as many people with debilitating illnesses require rehabilitation. For example, people with severe Obsessional Compulsive Disorder or those with a retractable depression may equally be severely impacted in their day to day functioning. One might, therefore, ask if it is the symptoms that we look at but rather the debilitating impact the illness has on the individual.	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.
South Yorkshire Office of the Police & Crime Commissioner	13	364	Suggest to add to the proposed outcomes that may be considered when considering evidence: the demand placed on Police and other emergency services	Thank you for your comment. We have decided not to include this in our outcomes as we do not think this outcome will be reported in the evidence, but would

				welcome consultation comments from the police as stakeholders.
Tees Esk and Wear Valleys NHS Foundation Trust	General	General	**Q1 on p1 of comments form:** Which interventions or forms of practice might result in cost saving recommendations if included in the guideline? • Coordinated handover of service users from inpatients to the community • Family members and carers to be included in service users' care plans to help support them when they become unwell.	Thank you for your comment. This aspect will be considered when determining the economic priority topics in the guideline.
Tees Esk and Wear Valleys NHS Foundation Trust	General	General	**Q2 on p1 of comments form:** Do you agree that the population of interest in this scope should be people with complex psychosis? Or should it also include people who do not have psychosis but who have other forms of severe and enduring mental illness? Please justify your response. • It should include people who have other forms of severe and enduring mental illness. This would help ensure appropriate support and a clear pathway for service users with personality disorder and their families.	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people.
Tees Esk and Wear Valleys NHS Foundation Trust	8	203/204	Coordinated handover of service users from inpatients to the community should be included in the guidelines.	Thank you for your comment. We have added a new question to the scope 'What processes are needed to support successful transitions?' to address this issue.
Tees Esk and Wear Valleys NHS Foundation Trust	10	271	Economic aspects appear to be about cutting funding and reducing services due to a lack of funding. Instead of working smarter by organisations working in collaboration with each other and themselves. People need to be considered as a person and not a funding cost to the service. If people are supported to rebuild their lives in the	Thank you for your comment. Economic considerations in the guideline extend beyond finding areas where there may be cost savings. Consideration will be given to the cost-effectiveness of recommendations that are made. This includes consideration of effectiveness as well as cost.

			community, they will learn the skills to cope with when they feel unwell. They will also know when to ask for help before relapsing. A prevention service would be helpful and might cut the cost of hospital admissions dramatically by supporting family members and carers to help the service user.	Prevention services are not covered in the scope of the guideline but differences in relapse rates may be picked up in the questions considering the effectiveness of rehabilitation services.
Tees Esk and Wear Valleys NHS Foundation Trust	10	287	Current problems existing which pose barriers for people with complex psychosis in accessing rehabilitation services include that there are no rehabilitation services available. Also, some people come from a background where they feel they need to cope alone by themselves otherwise they will be seen as a failure. Another is fear that their children will be taken away from them.	Thank you for your comment and suggestions of the likely barriers. We will be evaluating the evidence on issues that pose barriers and making recommendations based on this evidence and the expertise of the guideline committee.
Tees Esk and Wear Valleys NHS Foundation Trust	10	293	The current structure of services provided in the community is disjointed. They operate in silos without passing on critical information to ensure the service user is safe-guarded.	Thank you for your comment. Collaborative care planning is one of the topics which is included with the aim of improving collaborative working and reducing 'silos'.
Tees Esk and Wear Valleys NHS Foundation Trust	11	299	One barrier to reintegrated rehabilitation care pathways involving multiple providers (including health, social care, non-statutory, independent and voluntary services) is a lack of communication or collaborative working between them.	Thank you for your comment and for suggesting potential barriers. We will be evaluating the evidence on issues that pose barriers and making recommendations based on this evidence and the expertise of the guideline committee.
Tees Esk and Wear Valleys NHS Foundation Trust	11	304	The following principles should guide adjustments to standard treatments in the management of the underlying psychosis in people using rehabilitation services: • Use of medications following specific guidelines • Training in illness self-management • Case management based on principles of assertive community treatment	Thank you for your comment and for suggesting these principles. We will be evaluating the evidence on principles that will guide adjustment to standard treatments and making recommendations based on this evidence and the expertise of the guideline committee.

			• Family psychoeducation • Supported employment • Supported accommodation • Integrated substance abuse treatment. However, few patients actually receive these evidence-based interventions because they are not provided in routine mental health settings. (taken from https://www.google.co.uk/search?hl=en&q=principles+to+guide+adjustments+to+standard+treatments+in+managing+psychosis&meta=&safe=vss&gws_rd=ssl)	
Tees Esk and Wear Valleys NHS Foundation Trust	11	317	All aspects mentioned in your proposal should be included for a person's activities of daily living. An important aspect missing currently from services is helping people with budgeting, maintaining a tenancy and social skills. These aspects should be paramount and essential parts of providing services to the patient. In addition, there is no support for people to rebuild their relationships or how to be a parent again.	Thank you for your comment. We also think that budgeting, maintaining a tenancy and social skills are important and will be looking for evidence for these interventions. We will also be looking for evidence for interventions to improve inter-personal functioning and this may include personal relationships and parenting.
Tees Esk and Wear Valleys NHS Foundation Trust	14	379	People who ask for help should be considered as appropriate for rehabilitation services. Promoting recovery and prevention should also be paramount. Promotion of social skills will also help people to reengage with society and have relationships again.	Thank you for your comment. We will be evaluating the evidence about which people will benefit most from rehabilitation services, the effectiveness of interventions to promote rehabilitation and inter-personal functioning, and making recommendations based on this evidence and the expertise of the guideline committee.
The Royal College of Psychiatrists	General	General	The scope of the review should also specifically cover older adults of pensionable age who are also often in rehabilitation units and have specific needs based on their age and comorbidties. In particular, the outcomes in terms	Thank you for your comment. There is no upper age limit so older adults are included in the scope. However we have identified that older adults may need special consideration and included them in the equality impact assessment.

			of activities of daily living and vocational rehabilitation can be very different.	
The Royal College of Psychiatrists	General	General	Why the guideline is needed – whilst this talks about the epidemiological data it does not give a flavour of what rehabilitation services can offer to patients with complex mental health problems which require novel therapeutic approaches to manage their condition. For example it does really provide a brief overview that there is no guidance in this area at present that these patients fall outside of what the NICE guidance would use from clinical trials. It does not talk about the multiple different disciplines involved in the rehabilitation such as occupational therapy and psychology.	Thank you for your comment. The beginning section of the guideline provides an overview of what rehabilitation services provide. We appreciate that rehabilitation services require a multidisciplinary team and have reflected this in the composition of the guideline committee which includes a wide range of professionals including occupational therapists and psychologists.
The Royal College of Psychiatrists	General	General	Why is the Mental Health Act not mentioned in the legislation that is important nor the Human Rights Act? These are important legislation within a psychiatric rehabilitation setting.	Thank you for your comment. We have included the Mental Health Act in the scope but did not think the Human Rights Act was specific to this guideline so have not included it.
The Royal College of Psychiatrists	General	General	There needs to be comment about which nations we are covering because commissioning is different within the devolved nations compared to England.	Thank you for your comment. 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.
The Royal College of Psychiatrists	General	General	When we say practitioners does that need to be elaborated on further?	Thank you for your comment. We have used the word ‘practitioners’ deliberately to cover any health or social care professional who may be involved in delivering services, as this may vary between services and different parts of the country.
The Royal College of Psychiatrists	General	General	The National Rehabilitation Psychology Interest Group commented that due to the tight timescale it was not possible to come to a joint position to feedback, and they therefore agreed that each of our Psychology colleagues	Thank you for your comments. 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

			should use a direct feedback process to our Psychiatry colleagues. The economic aspects differ between NHS England and NHS Scotland with NHS England having a higher percentage of privatised health service provision. There also seems to be a current political UK government agenda to underfund health services to the point of failure and thereafter to open up healthcare provision to the private sector. They suggested that Scotland specific standards, guidelines and accreditation systems should possibly be developed. They had already been concerned in the context of adoption of AIMS/AIMS-R accreditation standards that these were allowing private healthcare companies to gain accreditation as well. While this might be part of healthcare provision in England, to my knowledge provision of Rehab services in Scotland does not extend to private providers. By adopting UK wide standards and accreditation systems we might be in danger of opening a back door for private companies to "sue their way into a public healthcare system". There is a possibility that, after BREXIT completion, there might be a temptation for the UK government to try and negotiate access for international private healthcare companies to the whole of the UK. Perhaps we might want to consider trying to keep NHS Scotland as distinct as possible in all areas from NHS England? Successful Rehabilitation with SEMI is dependent on successful co-operation with Social Care services. The systems and economies of Health and Social Care integration differ between England and Scotland.	Executive. We are therefore unable to develop Scotland-specific guidelines, and the guideline will not consider the difference between the use of private providers between England and Scotland. Likewise, the guideline will not take into account the specific differences between health and social care integration between England and Scotland.

Rehabilitation in adults with complex psychosis and other severe mental health conditions

Consultation on draft scope
Stakeholder comments table

17/04/2018 to 15/05/2018

The Royal College of Psychiatrists	General	General	The NCCMH are currently working on a Mental Health Pathway doc and should be considered in tandem with the NICE guidance	Thank you for your comment. We are aware that this guidance is being developed and believe that when it is available it will be relevant to this guideline committee.
The Royal College of Psychiatrists	General	General	The consultation should include service users and carers. Even police might be able to make a valuable contribution in the consultation as a "community stakeholder" as they have a significant intermediary role during severe dangerous episodes.	Thank you for your comment. Consultation is open to all organisations who represent service users and carers, as well as the police.
The Royal College of Psychiatrists	General	General	Social anxiety is a critical factor in isolation and relapse. Without interaction and stimulation, service users are left to only their thoughts which can increase paranoia and escalate relapse. Peer support/mentor/recovery support workers/youth workers etc. can provide weekly interaction and encourage and support engagement in activities. Recovery hubs, stimulating environments should be available in all areas within a reasonable travelling distance and not be limited by geographical boundaries.	Thank you for your comment. We will be evaluating the evidence for interventions that improve inter-personal functioning and making recommendations based on the evidence and the knowledge and expertise of the guideline committee.
The Royal College of Psychiatrists	General	General	Having purpose and opportunity can help focus. Maximise on Social Value Act and get supply chain and developers to provide opportunities e.g. therapeutic earnings, short term/p/t work placements, apprenticeships etc. There should be plenty of opportunities for environmental therapy (which is proven to be extremely beneficial) within grounds maintenance contracts with Trusts, local authorities etc.	Thank you for your comment. We will be evaluating the evidence for interventions that improve engagement in community activities including work and making recommendations based on the evidence and the knowledge and expertise of the guideline committee.
The Royal College of Psychiatrists	General	General	We note the guidelines refer to people with anxiety and depression as co-morbidities, whereas we would argue rehab services can benefit patients where this is their primary diagnosis, particularly from a functional perspective as using a graded approach is one of the core approaches we would use with this client group for rehab back to the	Thank you for your comment. We have amended the groups covered by this guideline to 'complex psychosis and other severe mental health conditions' so it will include a wider group of people, who have psychosis as their primary diagnosis but anxiety and depression would fall into the 'other conditions'.

			wider community, and the guidelines acknowledge this to some extent in stating 'may involve comorbidities and the effects of trauma, and impacts on a person's social, interpersonal and occupational functioning'. I'd also argue we could evidence this with case examples where rehab has been effective with clients for whom this is their primary diagnosis. In terms of interventions or forms of practice to support cost savings, that's a wider issue for the NHS in terms of partnership working/funding; a lot of clinicians' time is spent in meetings/writing reports etc. in order to decide who pays for what when it all comes out of a public fund, all of which takes away from clinical time to improve clinical outcomes. Along a similar line, and more of a locally specific issue; access to specialist services, e.g. in-reach, employment services such as Aspiro would enable more recovery focussed interventions and reduce the need for nurses and OTs trying to in some way be all things to all people in contacting benefits agencies etc.	The cost saving suggestions are unlikely to be addressed by the guideline as they fall outside the perspective which is normally adopted (NHS and PSS perspective).
The Royal College of Psychiatrists	General	General	The settings need to be perhaps more defined as time goes on rehabilitation occur at all stages and settings within a patient's journey from an acute ward to a nursing home or supported accommodation. The guidance needs to have boundaries such that it does not become too broad to be useful.	Thank you for your comment, but we think that a successful rehabilitation service must cross boundaries between settings so we have left this open deliberately.
The Royal College of Psychiatrists	3	88	We suggest to include severe and enduring eating disorders in the scope of the guideline. Severe and enduring anorexia nervosa presents the same characteristics as complex psychosis, 'which for the	Thank you for your comment. While we recognise the needs of people with severe and enduring eating disorders we believe that they type of rehabilitation services required by this population is entirely different to that required by

			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.' Furthermore, recent GWAS evidence suggests that there is a genetic overlap between anorexia nervosa, schizophrenia, bipolar disorder and depression, so the divide between these diagnostic categories may not be biologically robust. https://www.sciencedirect.com/science/article/pii/S0924977X16305776 The needs of the patients for rehabilitation do not necessarily differ based on diagnosis.	people with complex psychosis and other severe mental health conditions and that it would therefore not be possible to combine these populations into a single guideline.
The Royal College of Psychiatrists	6	151	Equality Considerations: In our opinion, women are unfairly excluded from this guideline by excluding severe and enduring eating disorders (particularly anorexia nervosa). Eating disorders affect 1.2 million people in the UK, and the majority of them are females. https://www.beateatingdisorders.org.uk/media-centre/eating-disorder-statistics Anorexia nervosa has the highest rate of mortality and multimorbidity of all mental disorders, and a significant proportion of patients (20-30%) suffer a life long course, which necessitates multiple and often lengthy hospital admissions. At present, there is no alternative to repeated hospitalisation in the management of these patients, as historical practices exclude them from psychiatric rehabilitation services. The proposed new guidelines offer an opportunity to change this in the future.	Thank you for your comment. While we recognise the needs of people with severe and enduring eating disorders we believe that they type of rehabilitation services required by this population is entirely different to that required by people with complex psychosis and other severe mental health conditions and that it would therefore not be possible to combine these populations into a single guideline.

The Royal College of Psychiatrists	6	151	Equality issues should also cover older adults of pensionable age whose needs are either neglected or excluded because of age and comorbidity.	Thank you for your comment. There is no upper age limit so older adults are included in the scope. However we have identified that older adults may need special consideration and included them in the equality impact assessment.
The Royal College of Psychiatrists	6	161	Please include severe and enduring eating disorders.	Thank you for your comment. While we recognise the needs of people with severe and enduring eating disorders we believe that they type of rehabilitation services required by this population is entirely different to that required by people with complex psychosis and related severe disorders and that it would therefore not be possible to combine these populations into a single guideline.
The Royal College of Psychiatrists	6	163-172	In 3.1 the issue of trauma is brought up but there might also be brain injuries, developmental disorders such as ADHD and ASD within this or even mild learning disabilities.	Thank you for your comment. A separate NICE guideline is under development covering rehabilitation following traumatic injury. People with the other conditions you have listed (ASD, ADHD) are not specifically excluded from the scope if these are co-existing conditions, but the focus is on people with a primary diagnosis of complex psychosis or other severe mental health conditions.
The Royal College of Psychiatrists	7	182	Psychosocial education is critical if service users are to understand and be better equipped to manage their mental health	Thank you for your comment. We will be evaluating the evidence for interventions that improve outcomes in rehabilitation services and making recommendations based on the evidence and the knowledge and expertise of the guideline committee.
The Royal College of Psychiatrists	7	186	*Identifying people who would benefit most from mental health rehabilitation services.* *Which people with complex psychosis are likely to benefit most from referral to rehabilitation services?* Those who	Thank you for your comment and suggestions of which people are most likely to benefit from rehabilitation services. We will be evaluating the evidence to identify this group and making recommendations based on the

			have complex psychosis, are treatment resistant whether to pharmacological or non-pharmacological methods, have functional difficulties with activities of daily living but have a minimal level of engagement are most likely to benefit from rehabilitation services.	evidence and the knowledge and expertise of the guideline committee.
The Royal College of Psychiatrists	10	280	Could 3.5 (4) also include a question on reducing psychological distress as this is related to quality of life and also the ability to engage in the community, work etc. Maybe a question like: What interventions specific to rehabilitation are effective for people with complex psychosis to reduce their level of psychological distress?	Thank you for your comment. We think that psychological distress is secondary to complex psychosis and we discussed the possibility of using psychological distress as an outcome measure but have focussed on using non-symptom-related outcome measures instead.
The Royal College of Psychiatrists	10	285-286	multiple admissions, length of stay, comorbidities	Thank you for your comment. We will review the evidence for which people are most likely to benefit from rehabilitation services and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
The Royal College of Psychiatrists	10	287	*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?* There a number of medical and social barriers accessing rehabilitation services. Across the country rehabilitation services are closed down in an effort to save money. This leads to complex patients falling through the net and recurrent reattendance at A&E departments and pressure onto other aspects of the social care and wider system with through social services, police, ambulance etc.	Thank you for your comment and for suggesting some of the barriers. We will review the evidence for the barriers and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.

			Patients with complex mental health problems often have poorer links to their community and their family. Ethnicity just adds one more barrier because cultural differences mean it is even more difficult to access and identify appropriate settings where their needs will be met. Patients with communication difficulties and ASD often are not referred to rehabilitation services because often there is not sufficient knowledge of the benefits of psychological intervention and longer care planning with trials of medication to	
The Royal College of Psychiatrists	10	291	*2.1 What is the effectiveness of rehabilitation services compared with standard care?* It is well known that rehabilitation services reduce readmission to hospital and help to provide maintenance of patients with complex psychosis by providing intensive support. There is a greater amount of time to understand the disorder and how it affects the patient but also to plan future care and provide handover to third sector providers following assessment so that they can continue to support patients into the community.	Thank you for your comment and for suggesting some of the benefits of rehabilitation services. We will review the evidence for the effectiveness of rehabilitation services and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
The Royal College of Psychiatrists	10	291-292	Some Trusts 3 types of inpatient rehabilitation services within the Trust and community rehabilitation team (within each locality). Having the Step up Hub/ community rehabilitation service has had a massive impact on the engagement, continuity of care, readmission rates and reduction in the bed days. A few consultants work across the inpatient rehabilitation and community rehabilitation teams which provides continuity of care. A Trust wide service provide a pathway from acute wards, PICU, out of area treatments in private hospitals (OATs), and forensic services to a community residence of some kind	Thank you for your comment and for describing some of the existing models of care. We will review the evidence relating to the structure, function and organisation of services and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.

The Royal College of Psychiatrists	11	295	*2.2 What is the effectiveness of inpatient rehabilitation services compared with community-based rehabilitation services?* Community based rehabilitation services is a broad term and it is difficult to compare their functions as they are more complementary.	Thank you for your comment. We will review the evidence to try and determine the respective roles of inpatient and community based care and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
The Royal College of Psychiatrists	11	297	*2.3 What are the required components of an effective rehabilitation pathway?* Involvement of families and carers, psychiatry, psychology, OT, nursing staff. Rapid access and response. Availability of therapeutic activities. Seamless transition between services whether from acute psychiatric units, LSU etc. back if necessary. Positive risk formulation.	Thank you for your comment and for suggesting some of the required components. We will review the evidence for the components and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
The Royal College of Psychiatrists	11	299	*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)?* Lack of integration of health and social care. Funding difficulties. Providers vary with smaller providers often ignored. Statutory framework delays such as Court of Protection. Delays with social worker assessment for accommodation or the identification or wrong accommodations. Poor communication between different aspects of the pathway.	Thank you for your comment and for suggesting some of the barriers and facilitators. We will review the evidence for the barriers and facilitators and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
The Royal College of Psychiatrists	11	304	*3.1 What principles should guide adjustments to standard treatments in the management of the underlying psychosis in people using rehabilitation services?* Not quite clear what this question is asking. Use of more complex psychopharmacology, in some cases this might end up being off licence usage. Doses maybe lower or higher than usual. Psychological work may have to be slowed down or engagement may take longer.	Thank you for your comment and for suggesting some of the principles. We will review the evidence for the principles to guide adjustment and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.

			Occupational therapy approaches may need to be moderated to allow people to gain independence.	
The Royal College of Psychiatrists	11-12	317-332	4.1 – 4.6 should be based on a literature review and critical appraisal of the current evidence available and is more complicated that can be described here.	Thank you for your comment. The NICE methodology includes a systematic literature review and evaluation of the evidence available.
The Royal College of Psychiatrists	12	334	*5.1 What features of supported accommodation and housing promote successful community living in people with complex psychosis?* Quality wraparound support, it very much depends on the patient's needs. Support needs to be tailored and dynamic. It needs to be person centred and individualised as much as possible.	Thank you for your comment and for suggesting some of the features of supported accommodation. We will review the evidence for supported accommodation and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
The Royal College of Psychiatrists	12	339	*6.2 What interventions are valued by people with complex psychosis who are cared for by rehabilitation services, and valued by their families?* Psychological and occupational therapy interventions, information around the diagnosis, medication and how to support their relatives. Sometimes it is medication and nursing support.	Thank you for your comment and for suggesting some of the interventions that are valued by people. We will review the evidence for what people value and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.
The Royal College of Psychiatrists	12	343	*7.1 What are the criteria for transition from rehabilitation services to other parts of the mental health, social care and primary care systems?* There aren't really any hard and fast rules. Usually it is when people reach stability or have achieved their rehabilitation goals. Often it is that they no longer need the intensity of input or they recognise the need for less intervention and can take ownership of this.	Thank you for your comment and for suggesting some of the transition criteria. We will review the evidence for the transition criteria and make recommendations based on the evidence and the knowledge and expertise of the guideline committee.

The Royal College of Psychiatrists	12	348	Section 3.6 does not mention psychological distress (distress also includes management of experiences, for example hearing voices. It is really hard to concentrate on cooking for example if you're experiencing command hallucinations etc.). This has a big impact on functioning and so it would be useful to identify interventions which reduce distress in this population.	Thank you for your comment. We have discussed the possibility of using psychological distress as an outcome measure but have focussed on using non-symptom-related outcome measures instead.