

**National Institute for Health and Clinical Excellence**

**Schizophrenia in children and young people**

**Scope Consultation Table**

20 December 2010 – 17 January 2011

No	Type	Stakeholder	Order No	Section No	Comments Please insert each new comment in a new row.	Developer's Response Please respond to each comment	Change to Scope
1	SH	Alder Hey Children's NHS Foundation Trust	14.01	general	- excluding young people with a learning difficulty - where else will these young people with dual diagnoses be considered?	Thank you for your comment. In light of your concern, we have revised the scope and the guidance will now be relevant to children and young people with a mild LD.	4.1.1 c
2	SH	Alder Hey Children's NHS Foundation Trust	14.02	general	- not including primary prevention...this is a chance to look at whether there are ways of predicting, pre-empting and preventing psychosis occurring.	Thank you for your comment. The guideline will now address the management of at-risk mental states (for psychosis) and psychosis in children and young people prior to a diagnosis of schizophrenia.	Title, 4.1.1 b + 4.3.2 b
3	SH	Association for Family Therapy and Systemic Practice	13.01	General & 4.1.2	It would be helpful for this guideline to include 'psychoses' in the title and the area covered, because of the nature of the pre-diagnosis problems – and early interventions are beneficial.	Thank you for your comment; we agree and the guideline title will now include 'psychosis' as well as 'schizophrenia'.	Title
48	SH	Association for Family Therapy and Systemic Practice	13.02	3.2	The value of early interventions with families will address complex issues for the child / young person as well as helping families to make a difference to how they support him/her and address issues that need change or better management. There are different ways in which this is being done within the UK, and the articles and models do not necessarily address work with under 18s, but will be used by the teams with this approach. The effectiveness of training models needs to be considered because of the value of teams working with families.	Thank you for your helpful comments. We will bear these points in mind when developing the guideline and our research team will review the references you have provided.	n/a

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					<p>Somerset: Burbach, F &amp; Stanbridge, R. (2006): Somerset's family interventions in psychosis service: an update. <i>Journal of Family Therapy</i>.28.39-57..</p> <p>Burbach, F., Fadden, G. &amp; Smith, J. (2009). Family interventions for First Episode Psychosis In P. French, M. Read, J. Smith, M. Rayne, &amp; D. Shiers: <i>Promoting Recovery in Early Psychosis</i>. Oxford: Blackwell Publishing Ltd.</p> <p>Meriden: Articles may be found on the website, covering the model, training and other family issues, eg. Smith, J. Fadden, G. and Taylor, L. (2009) The Needs of siblings in First Episode Psychosis. In P. French, M. Read, J. Smith, M. Rayne, &amp; D. Shiers: <i>Promoting Recovery in Early Psychosis</i>. Oxford: Blackwell Publishing Ltd.  <a href="http://www.nice.org.uk/media/sharedlearning/299_299_suppinfo.pdf">www.nice.org.uk/media/sharedlearning/299_299_suppinfo.pdf</a></p>		
74	SH	Association for Family Therapy and Systemic Practice	13.03	4.3.1	<p>Finland has developed <b>very</b> effective early interventions that are also used in some areas of the UK. Although these do not specifically address under 18s, an article on working with young people will be published shortly:  Seikkula, J. Aaltonen, J.,Aalakara, B.,Haarakangas, B., et al (2006): Five-year experience of first-episode nonaffective psychosis in open-dialogue approach: Treatment principles, follow-up outcomes, and two case studies. <i>Psychotherapy Research</i>. 16.2.214-228  Rakkolainen &amp; Aaltonen in <i>Psychotherapeutic Approaches to Schizophrenic psychoses: past Present, Future</i>, Eds. Alanen et al. Routledge, 2009) see p166 and 295</p>	Thank you for your comment. Our research team will review the references you have provided.	n/a
43	SH	Association of Child	7.01	3.1f	Greater recognition and understanding of optimal therapeutic approaches to children and young	Thank you for your comments.	n/a

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		Psychotherapists			people with schizophrenia should be more comprehensively addressed in psychology and psychotherapy trainings to give psychological therapists better clinical and theoretical knowledge of psychosis and more confidence in helping such patients.		
53	SH	Association of Child Psychotherapists	7.02	3.2c	The list of psychological treatments should include interventions offered by psychodynamically-trained clinicians, including some child and adolescent psychotherapists and some adult-trained psychotherapists who work with adolescents in tier 3 and 4 settings. Such clinicians successfully utilise their in-depth training in modified interventions for children and adolescents. A particular focus would be establishing consistent emotional containment in the patient, as severe anxiety is a central clinical challenge.	Thank you for your comments. The scope already includes psychodynamic psychotherapy and psychoanalysis, and searches for trials within this area will pick up trials that contain the interventions that you describe, if they have been undertaken and published. There were very few such trials in the adult literature.	n/a
56	SH	Association of Child Psychotherapists	7.03	3.2d & e	Early Intervention Services would normally be expected to provide a more comprehensive resource than a CAMHS could provide. This is especially true for young people and families who would need more intensive and flexible input outside the clinical setting and normal service hours. Investigation is needed into why EIS are so variable.	Thank you for your comments. The service provided by CAMHS and EIS will be looked at in detail by the GDG when developing the guideline. However, the guideline can only make recommendations based on the research evidence available.	n/a
58	SH	Association of Child Psychotherapists	7.04	3.2g	We are in agreement that "services for children and young people with schizophrenia need to be comprehensive and well integrated". It is vitally important that services for children and young people with schizophrenia have the resource and design to allow a consistent and more lengthy intervention, particularly for those patients with more complex and chronic conditions. The usual basic needs for trust, consistency of staffing and engagement and specialist treatment knowledge are particularly vital in the effective treatment of	Thank you for your comments.	n/a

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					this group.		
64	SH	Association of Child Psychotherapists	7.05	4.1.2b	Should the guideline also consider patients who present with acute psychotic episodes linked for example with drug-induced psychosis, borderline personality disorder or emerging bipolar disorder but without a diagnosis of schizophrenia?	Thank you for your query. We will consider the early 'pre-syndromal' presentation of psychosis before a diagnosis of schizophrenia or bipolar disorder. However, the existing guidelines on borderline PD, bipolar disorder and coexisting psychosis and drug misuse all include children and young people.	4.1.1 b + 4.3.2 b
83	SH	Association of Child Psychotherapists	7.06	4.3.1c	We welcome the list of interventions detailed here. We would add: 1) that individual and family interventions should generally both be provided in a single package by one team if possible; and 2) that further research is needed to help develop more effective specialist psychological interventions tailored to psychotic illness presentations which can be utilised across the major therapeutic modalities.	Thank you for your comments. We will bear these points in mind during guideline development.	n/a
89	SH	Association of Child Psychotherapists	7.07	4.3.1i	The organisation of care pathways and services should always adopt a CPA approach that identifies a named care coordinator to ensure effective communication and care planning between services, particularly CAMHS to CMHT and tier 3 and 4 services.	Thank you for your comment – we will bear this in mind when developing the guideline.	n/a
4	SH	Association of Child Psychotherapists	7.08	General	We welcome the scope's consideration of the impact on the family in terms of social, educational and financial issues and of the therapeutic help for the families in which the young person with schizophrenia lives. Such therapeutic help is essential in helping the development of the young person in terms of moving away from the family support system, becoming independent and moving into adulthood. Systemic family therapy could help to support the family, including siblings, to better understand the tensions that arise and what the future holds.	Thank you for your comments.	n/a
5	SH	Association of Child	7.09	General	The scope contains limited consideration of in-patient units for young people with schizophrenia.	Thank you, we agree that inpatient units are very important and the guideline will review tiers 1-4 and the	n/a

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		Psychotherapists			Medium-term residential treatment of up to six months, with regular contact and weekends with families, enables the delivery of intensive therapeutic programmes which can significantly help the young person with schizophrenia. Time spent away from the family is beneficial to help the young person to build a separate sense of identity – a complex task for a young person with this condition - at the same time as helping the family adapt, understand and make some changes. Monitoring of medication can also be offered within an in-patient environment.	relevant treatments you have raised. In-patient treatment is included within tier 4 CAMHS.	
6	SH	Association of Child Psychotherapists	7.10	General	Reference to the latest neuro-science research indicates the pliability of the brain in adolescents. This offers a window of opportunity for potential development and change. Intensive therapeutic work either as an in-patient or within an intensive outreach programme is important to capitalise on the mental state of flux that is characteristic of young people, maximise changes and consolidate those changes into adulthood.	Thank you very much for your informative comments.	n/a
7	SH	Association of Child Psychotherapists	7.11	General	Young people under 18 need full access to care, treatment and education. This combination is essential for those already with a diagnosis of schizophrenia in helping them to fulfil relationships and opportunities in their adult lives.	Thank you for your comment – we agree and this will be addressed in the guideline.	n/a
8	SH	British Psychological Society	8.01	General	The Society welcomes the fact that the scope for this review includes the consideration of psychosocial interventions in addition (although secondary) to pharmacology. We would recommend, however, that consideration be given to regarding psychosocial interventions as primary - with pharmacological intervention in children being considered as appropriate in more extreme cases (assuming, of course, the evidence supports this).	Thank you for your comments. We do not consider psychological interventions, or indeed any others, to be inferior or secondary to drug treatments. We determine anteriority in a care pathway on the basis of weighing up the evidence for benefits and side effects against the severity of illness, not by professional preference. All of our childrens' guidelines place self help and psychological interventions earlier on the care pathway as they are associated with less harm, IF there is evidence to support their efficacy. We will be presenting the chapters with pharmacology later in the guideline to	4.3.1 b + c

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						avoid misunderstandings.	
9	SH	British Psychological Society	8.02	General	<p>We profoundly regret the proposal to limit this scope to "children ... who have a clinical diagnosis of schizophrenia" and excluding "children ... with psychotic disorders other than schizophrenia..."</p> <p>While we accept that such guidelines are not the right places to consider "the validity of diagnosis", we consider excluding "primary prevention" to be wrong.</p> <p>We think this because it seems very likely that any guidelines for the treatment of schizophrenia will be used for other psychotic disorders. It seems wrong not to address issues of early intervention (as this is a key issue), including by discussion of pre-diagnostic or sub-syndromal patterns (as these will be matters for clinical intervention) and thereby also of primary prevention.</p> <p>We therefore recommend that the scope be significantly broadened - to childhood psychosis, including, but NOT limited to, diagnosed schizophrenia. In addition, while we accept that the validity of diagnosis is not a necessary issue, we recommend that the scope must include (at the minimum) secondary prevention - which we would define here as preventing sub-syndromal psychosis developing into schizophrenia.</p>	Thank you for your comments. We have amended the scope in light of your concerns. The guideline will now address the management of at-risk mental states (for psychosis) and psychosis in children and young people prior to a diagnosis of schizophrenia.	Title, 4.1.1 b + 4.3.2 b
10	SH	British Psychological Society	8.03	General	To take this point further, it is necessary to make a distinction between a single, resolved episode of psychosis, an emergent pattern of intermittent psychosis and an apparently established pattern of persistent psychosis in children. These considerations apply to adults too, of course, but, given our welcome emphasis on development and spectral classification (and formulation), it is only	Thank you for your comment. We have amended the scope in light of your concerns. The guideline will now cover psychosis as well as schizophrenia and the issues you have raised will be considered by the GDG. We will also refer the reader to the appropriate guideline (e.g. bipolar disorder) where other psychotic syndromes have been identified.	Title, 4.1.1 b + 4.3.2 b

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					logical to see all presentations of psychosis in children included.		
65	SH	College of Mental Health Pharmacists	19.01	4.1.2b	Clinicians are often reluctant to give an actual diagnosis of schizophrenia at this age, even though the pathology and symptomatology is indicative of schizophrenia. By being too prescriptive with the term and NOT considering 'psychosis', the literature that will be available, (from where the guideline will be developed), is therefore likely to be rather limited.	Thank you for your comment. We have amended the scope in light of your concerns. The guideline will now address the management of at-risk mental states (for psychosis) and psychosis in children and young people prior to a diagnosis of schizophrenia.	Title, 4.1.1 b + 4.3.2 b
79	SH	College of Mental Health Pharmacists	19.02	4.3.1b	Only a handful of current antipsychotic treatments are licensed in this age group, so treatment is mainly unlicensed. The published evidence base for these unlicensed treatments often falls short of the quality required to make a guideline recommendation. However, in practice, case reports and other lower quality studies are often all that is available. The guideline development group should be mindful of this.	Thank you for your comment – we will bear this in mind when developing the guideline.	n/a
86	SH	College of Mental Health Pharmacists	19.03	4.3.1d e & f	Not all acute psychotic episodes are treated exclusively with antipsychotic medication. Perhaps the term antipsychotic medication could be replaced by medication.	Thank you for your comment. The use of other medication is unlikely to have been adequately researched for us to review their use here. The use of other drugs to calm behaviour, such as lorazepam, is covered in the guideline on violence.	n/a
88	SH	College of Mental Health Pharmacists	19.04	4.3.1g	Much of the knowledge of the side effects is from adult patients so it is important that any recommendations concerning physical health monitoring reflects this. For example, realistic frequency of blood sampling since many children are reluctant to give blood; raised prolactin levels in children/adoles are not so problematic as in adults (need to consider the clinical relevance).	Thank you for your comments – we will bear these in mind when developing the guideline.	n/a
96	SH	College of Mental Health Pharmacists	19.05	4.3.2c	Will this exclude the management of aggression and other 'acting out' behaviours?	Thank you for your query. These areas will not be covered in this guideline. There is a previous guideline on the management of imminent violence.	n/a
68	SH	Department for Education	16.01	4.1.2c	We need an explication as to why it doesn't cover children and young people with coexisting	Thank you for your comment. In light of your concerns, we have revised the scope and the guidance will now be	4.1.1 c

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					learning disabilities, significant sensory or physical difficulties etc.	relevant to children and young people with a mild LD.	
11	SH	Department of Health	11.01	General	<b>Learning disability:</b> we feel that to exclude this could be seen as discriminatory.	Thank you for your comment. In light of your concern, we have revised the scope and the guidance will now be relevant to children and young people with a mild LD.	4.1.1 c
12	SH	Department of Health	11.02	General	<b>Management of violence:</b> could you please clarify why this sensitive issue has been specifically excluded.	We will refer to the existing guideline on management of violence. If a gap in evidence is identified in children and young people with schizophrenia we will make a specific reference under research recommendations.	n/a
13	SH	Eli Lilly & Co.	15.01	General	Eli Lilly and Company support the development of Guidelines for the treatment of schizophrenia in young people as we agree that there is a definite clinical need as presented in the draft scope. Lilly must point out that Zyprexa (olanzapine) is not licensed for the treatment of schizophrenia in children and adolescents aged <18 years (Zyprexa SPC). However we are aware that olanzapine is used in adolescents outside the licensed indication in clinical practice. There are clinical trial data for use in this population.	Thank you for your comments. We would be extremely interested in having access to your relevant clinical trial data.	
42	SH	Eli Lilly & Co.	15.02	3.1d	<p><i>Long term follow up studies in adults suggest that, after 5 years of illness one quarter of people recover completely. For most people the condition gradually improves over their lifetime and deteriorates in only 10% throughout life.</i></p> <p>Lilly does not agree with the statement that for most people schizophrenia improves over their lifetime and deteriorates in only 10% of patients. The Royal College of Psychiatrists states (RCP 2010):</p> <p><b>Outlook</b> <i>Many people with schizophrenia now never have to go into hospital and are able to settle down, work and have lasting relationships. For every 5 people with schizophrenia:</i></p>	Thank you for your comments. These figures are taken from long term empirical follow up studies separately undertaken by Bleuler and Ciompi. They followed up large cohorts of people diagnosed with schizophrenia for at least 5 years and followed for a minimum of 22 years (Bleuler). The pessimism felt by many psychiatrists, they concluded, was because many of those who do recover, never see their psychiatrists again. The Royal College of Psychiatrist's report is a little more pessimistic and is, quite clearly, a repost from a professional body, not an empirical study. It is also worth pointing out that some of the stigma associated with schizophrenia is related to a too pessimistic view, and service users find it problematic that professionals are overly pessimistic.	n/a

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					<ul style="list-style-type: none"> <li>▪ 1 will get better within five years of their first obvious symptoms.</li> <li>▪ 3 will get better, but will have times when they get worse again.</li> <li>▪ 1 will have troublesome symptoms for long periods of time.</li> </ul> <p>This suggests 20% will get better, 60% will get better but will have recurring episodes of symptoms and 20% will get worse. Lilly suggest amending the above statement to say</p> <p><b>Long term follow up studies in adults suggest that, after 5 years of illness one quarter of people recover completely. However schizophrenia in many patients, progresses over time with a long term and varied course.</b></p>		
50	SH	Eli Lilly & Co.	15.03	3.2b	Lilly suggest that the list of antipsychotic drugs used since the 1950s for the treatment of schizophrenia is amended to include <b>haloperidol</b> .	Thank you for your suggestion. The list is illustrative, not exhaustive. Haloperidol will be included in the analysis, along with all other antipsychotics.	3.2 b
51	SH	Eli Lilly & Co.	15.04	3.2b	<p><i>Initial speculation that the newer and more expensive "atypical" were superior to so called "typicals" evaporated. Nevertheless, the most commonly used drugs now are the newer ones (olanzapine and risperidone).</i></p> <p>Atypical antipsychotics have superior efficacy and safety over typical antipsychotics (Boter 2009, Davis 2003, Leucht 2009). However there are differences in efficacy and safety between atypicals (Leucht 2009). Lilly suggest amending the scope to say:</p> <p><b>Atypical antipsychotics have superior efficacy and safety over typical antipsychotics however there are differences in efficacy and safety between atypicals. The most commonly</b></p>	Thank you for your suggestion. However, the analysis undertaken for the adult guideline, and in fact many other analyses, including Leucht (2009), show that there are differences in potency and side effect profile between antipsychotics, but there is no class that has superior efficacy. It is also simply untrue that the newer drugs are safer than the older drugs. Olanzapine is associated with a much greater risk of diabetes than, say, haloperidol. Please look at the evidence in the adult guideline. Thank you for your suggested wording but it is not entirely accurate so is not appropriate to use in this context.	n/a

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					<b><i>used drugs now are the newer ones (olanzapine and risperidone).</i></b>		
81	SH	Eli Lilly & Co.	15.05	4.3.1b & 4.3.1c	The scope should ensure that the guideline makes recommendations and strategies which will ensure that clinicians involve patients and consent givers in the choice of medication/treatment and suggest ways that this can be measured.	Thank you for your comments. These areas will be looked at during guideline development.	n/a
87	SH	Eli Lilly & Co.	15.06	4.3.1f	In addition to promoting recovery after an acute psychotic episode, the scope should include guidance on <b><i>continuation/maintenance therapy</i></b> since schizophrenia progresses over time, with a long term and varied course.  This should include ongoing patient support, promoting patient education on the consequences of non-adherence and the prevention of relapse.	Thank you for your comments. Use of medication and a psychological or psychosocial intervention is suggested after an acute psychotic episode in 4.3.1 f. This area will be looked at in detail during guideline development.	n/a
80	SH	Eli Lilly & Co.	15.07	4.3.1b	The scope should ensure the guidelines specifically address dosing requirements of antipsychotic medications in adolescents and children.  It must be noted that compared to adults, lower doses of antipsychotic medications are often used in adolescents. The reason is that side effects such as weight gain and prolactin elevation may be greater in a younger population (Zyprexa SPC) and it is important to reduce these side effects where feasible.	Thank you for your comments. We have revised the scope in light of your comments so the guideline will now address modifications of dosing of antipsychotics when used in children and young people.	4.3.1 c
97	SH	Eli Lilly & Co.	15.08	4.4	An additional main outcome would be to have increased long term adherence to treatments as a result of increased patient support, education and follow up.	Thank you for your suggestion. The outcomes we want may not be available from the studies. The GDG will prioritise outcomes at the start, before we examine the evidence.	n/a
101	SH	Eli Lilly & Co.	15.09	4.4i	Lilly is unsure what is meant by this point and would like to ask for further clarification.	Thank you for your query. We agree and 'including involvement with forensic services' has been omitted from this section.	4.4 k
14	SH	Eli Lilly & Co.	15.10	General	<b>Suggested Clinical Questions:</b> What are the criteria for diagnosis for	Thank you for your suggested clinical question. We will outline in the guideline what criteria should be used for	n/a

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					schizophrenia in children and adolescents under 18 years?	defining schizophrenia.	
15	SH	Eli Lilly & Co.	15.11	General	<p><b>References:</b></p> <p>Boter H, Peuskens J, Libiger J, <i>et al.</i> Effectiveness of antipsychotics in first-episode schizophrenia and schizophreniform disorder on response and remission: an open randomized clinical trial (EUFEST). <i>Schizophr Res</i> 2009;115(2-3):97-103.</p> <p>Davis JM, Chen N, Glick ID. A Meta-analysis of the Efficacy of Second-Generation Antipsychotics. <i>Arch Gen Psychiatry</i> 2003;60:553-564.</p> <p>Eli Lilly and Company. Zyprexa (olanzapine) Summary of Product Characteristics (SPC).</p> <p>Leucht S, Corves C, Arbter D, et al. Second-generation versus first-generation antipsychotic drugs for schizophrenia: a meta-analysis. <i>Lancet</i> 2009; 373: 31–41.</p> <p>Leucht S, Komossa K, Rummel-Kluge C, <i>et al.</i> A Meta-Analysis of Head-to-Head Comparisons of Second-Generation Antipsychotics in the Treatment of Schizophrenia. <i>Am J Psychiatry</i> 2009;166:152–163</p> <p>Royal College of Psychiatrists (RCP). Schizophrenia Factsheet November 2010. Website accessed January 2011. <a href="http://www.rcpsych.ac.uk/mentalhealthinfoforall/problems/schizophrenia/schizophrenia.aspx">http://www.rcpsych.ac.uk/mentalhealthinfoforall/problems/schizophrenia/schizophrenia.aspx</a></p>	Thank you for these helpful references. Our research team will be reviewing them.	n/a
94	SH	Greater Manchester West Mental	9.01	4.3.2	<p>Clinical issues that will not be covered</p> <p>a) Validity of diagnosis.</p> <p>b) Primary prevention.</p>	Thank you for your comment. The guideline will address the recognition and early management of children and young people with psychosis and schizophrenia.	4.1.1 b + 4.3.2 b

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		Health Services NHS Foundation Trust			c) Management of violence in children and young people with schizophrenia." not sure that violence/risk can be so easily excluded	Management of violence is covered by a separate guideline. This guideline will consider gaps in evidence specific to children and young people.	
38	SH	International Society for the Psychological Treatments of the Schizophrenias & other psychoses	17.01	1 & general	Guideline title. It would be very helpful to clinicians to have a guideline which was labelled 'psychosis' or 'schizophrenia and other psychosis', rather than just 'schizophrenia' In the early stages of schizophrenia, a specific diagnosis may be difficult, yet similar considerations may apply, and it would be useful to be able to give patients and their families the NICE information for patients and public. The personal impact of receiving a diagnosis of schizophrenia is often negative and potentially traumatising given the largely negative public ignorance and prejudice about it. In support of a move	Thank you for your comments; we agree and the guideline title will now include 'psychosis' as well as 'schizophrenia'.	Title
16	SH	International Society for the Psychological Treatments of the Schizophrenias & other psychoses	17.02	general	Even if consideration of the validity and utility of the diagnosis 'schizophrenia' is outside the scope of the guideline, it seems inappropriate and unhelpful to use the term 'schizophrenia' in this document as if it were an uncontested concept. To use it in this way in a document that will be widely read and referenced will serve unhelpfully to support the unhelpful reification of the concept, and associated misunderstandings. It would be helpful to at least acknowledge that the diagnosis 'schizophrenia' is just one way of conceptualizing certain experiences and behaviour, and that other ways are possible and increasingly found more useful in clinical practice (see for example the BJPsych paper by van Os, 2009 re salience dysregulation syndrome).	Thank you for your comments. We understand the debates around this concept, however, our guidelines are not meant to address issues in a polemical way.  The purpose of the guideline is to provide evidence-based management recommendations to clinicians and service planners using the current DSM and ICD diagnostic systems. Alternative diagnostic systems and formulations of the same problems lie beyond the scope of this guideline.	n/a
17	SH	International Society for the	17.03	general	Children and Young people diagnosed with schizophrenia require specific and	Thank you for your comments – the GDG will bear these in mind when developing the guideline. We agree that	n/a

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		Psychological Treatments of the Schizophrenias & other psychoses			developmentally-appropriate early Intervention services. It is the clinical approach which is key to good outcomes, not the service configuration. Rigid adherence to service models is therefore unhelpful, and can have a negative impact on successful transitions.	the focus should be on effective care pathways rather than rigid service descriptions.	
63	SH	International Society for the Psychological Treatments of the Schizophrenias & other psychoses	17.04	4.1.2	<p>Exclusions of young people with psychosis but without a diagnosis of schizophrenia feels very unhelpful from a clinical point of view.</p> <p>Young people who receive a diagnosis of schizophrenia below the age of 18, will sometimes have associated neurodevelopment cognitive impairment and overlap with learning disability, pervasive developmental disorder will be common, with associated diagnostic challenges and delays in starting appropriate treatment. Similarly they will often have problems with substance misuse. Exclusion of these important groups seems most unhelpful.</p> <p>If earlier treatment is one of the desired outcomes of the guideline, then addressing these important barriers to early treatment seems important.</p> <p>Data emerging from the National Eden study suggests that unhelpful prolongation of DUP is more common in young people who have been through some CAMH services (Marshall, paper presented at IEPA meeting, November 2010, Amsterdam). This is not universally true and depends on the expertise available on a local basis.</p>	Thank you for your comments. We have amended the scope in light of your concerns. The guideline will now address the management of at-risk mental states (for psychosis) and psychosis in children and young people prior to a diagnosis of schizophrenia.	Title, 4.1.1 b + 4.3.2 b
77	SH	International Society for the Psychological Treatments of	17.05	4.3.1	<p>We welcome the wide range in the therapies to be considered.</p> <p>It would be helpful if consideration could be given</p>	Thank you for your comments. Many new approaches, including those you refer too, have no trial evidence to support their use. We are covering a wide range of interventions. If we do more, we would have to reduce	n/a

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		the Schizophrenias & other psychoses			<p>to more recent specific approaches being considered for use with psychosis eg. mindfulness, compassion focused therapy, working with voices</p> <p>We would strongly suggest that consideration is given to the overall psychological impact of arrangements for treatment. There are many aspects that may have a bearing on psychological wellbeing including. One example is the reliability and continuity of relationships with key staff. Another example is the way in which the young person's problems are conceptualized and discussed– the diagnosis of schizophrenia is often associated with unhelpful myths regarding biological determination, which is in turn associated with more stigmatising (and internally stigmatising) attitudes .</p> <p>We would strongly suggest that consideration is given to approaches such as the Finnish need-adapted model where the whole of treatment is based around psychosocial formulation and involvement of the family (see for example Rakkolainen &amp; Aaltonen in Psychotherapeutic Approaches to Schizophrenic psychoses, Eds. Alanen et al. Routledge, 2009)</p>	other, perhaps more pressing issues in the scope.	
98	SH	International Society for the Psychological Treatments of the Schizophrenias & other psychoses	17.06	4.4	<p>Important outcomes not listed</p> <ul style="list-style-type: none"> <li>- improvements in the experience of young people and their families</li> <li>- improvements in quality of life</li> <li>- indicators of social inclusion</li> </ul>	Thank you for your suggestions. We have added 'improvements in the experience of care for children, young people and their families' as a main outcome and have revised some of the other outcomes outlined in 4.4. However, please bear in mind that the outcomes we would like may not be available in the research upon which the guideline will be based.	4.4 e
69	SH	National CAMHS Support	4.01	4.1.2c	Are we certain that the needs of children and young people with LD and sensory/physical impairment's and with a diagnosis of	Thank you for your comment. In light of your concerns, we have revised the scope and the guidance will now be relevant to children and young people with a mild LD.	4.1.1 c

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		Service			schizophrenia are adequately covered in other NICE guidance?		
71	SH	National CAMHS Support Service	4.02	4.2c	I would also add those health workers in homeless charities	Thank you for your suggestion. We have amended the scope to include this setting.	4.2 c
90	SH	National CAMHS Support Service	4.03	4.3.1i	? should education services be included here?	Thank you for your query. Our focus is on healthcare settings although the guideline may well be relevant to other settings, including educational settings (see 4.2 c).	4.2 c
99	SH	National CAMHS Support Service	4.04	4.4	Should not reduction of self harm and suicide be an outcome?	Thank you for your query. We have amended the scope in light of your query and an additional main outcome has been included – 4.4 d 'better mental health and related outcomes'.	4.4 d
52	SH	National Mental Health Development Unit	1.01	3.2b	<p>Studies may have <b>underestimated</b> the amount of weight gain caused by antipsychotic medicines – see Alvarez article attached. The effects of such profound early weight gain may not only set up long term physical ill-health but may also fuel social exclusion and medicines non-compliance.</p> <p>Alvarez-Jimenez M, Gonzalez-Blanch C, Crespo-Facorro B, Hetrick S, Rodriguez-Sanchez JM, Perez-Iglesias R, et al. Antipsychotic-induced weight gain in chronic and first-episode psychotic disorders: a systematic critical reappraisal. CNS Drugs 2008;22(7):547-62. 2.</p>  <p>nario alvarez CNS22073.pdf</p>	Thank you for your comment. Our research team will review the article you have provided.	n/a
49	SH	National Mental Health Development Unit	1.02	3.2	<p>Emerging research on fish oils as a new way to target primary prevention in those at high risk of developing psychosis</p> <p>Aminger and colleagues 2010 publications</p>	Thank you for your comment. Our research team will review the trial you have referenced.	n/a

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					<p><b>Long-Chain <math>\omega</math>-3 Fatty Acids for Indicated Prevention of Psychotic Disorders</b></p> <p><b>A Randomized, Placebo-Controlled Trial</b></p> <p>G. Paul Amminger, MD; Miriam R. Schäfer, MD; Konstantinos Papageorgiou, MD; Claudia M. Klier, MD; Sue M. Cotton, PhD; Susan M. Harrigan, MSc; Andrew Mackinnon, PhD; Patrick D. McGorry, MD, PhD; Gregor E. Berger, MD</p> <p><i>Arch Gen Psychiatry.</i> 2010;67(2):146-154.</p>		
18	SH	Royal College of Nursing	12.01	General	The Royal College of Nursing welcomes proposals to develop this guideline.	Thank you.	n/a
40	SH	Royal College of Nursing	12.02	3.1c	There needs to be recognition of importance of family interventions and parent / carer support.	Thank you for your comment. These areas will be covered in the guideline as outlined in the scope e.g. 4.3.1 b and 4.4 e + h.	4.4 e
44	SH	Royal College of Nursing	12.03	3.1f	There needs to be something about developmental course of schizophrenia – many young people have a first episode which may develop into a mood disorder.	Thank you for your comment. The GDG will look at the instability and course of diagnosis.	n/a
45	SH	Royal College of Nursing	12.04	3.1i	There needs to be recognition that service context when working with CYP is different to that when working with adults – lack of intensive community / home based / crisis services means greater reliance on inpatient services.	Thank you for your comment. The guideline will address the differences between services provided for young people in early intervention services, in adult services and that provided by CAMHS, both in terms of research, and the pathway of care.	n/a
55	SH	Royal College of Nursing	12.05	3.2d	Tier 4 also refers to a range of community / home based intensive and outpatient services (see above)	Thank you for your comment. We will bear this in mind when interpreting the evidence and making recommendations. However, evidence reviews are unlikely to find outcomes associated with these local differences.	n/a
72	SH	Royal College of Nursing	12.06	4.2c	This needs to include schools and colleges	Thank you for your suggestion. We have amended the scope to include this setting.	4.2 c
73	SH	Royal College of Nursing	12.07	4.3	We would suggest that recovery should also focus on a return to education, employment and training	Thank you for your suggestions. The GDG will cover recovery in detail in the guideline.	n/a
19	SH	Royal College	5.01	General	The College thinks this scope is comprehensive	Thank you.	n/a

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		of Paediatrics and Child Health			and worthwhile. No obvious groups are excluded and key areas of practice are addressed.		
20	SH	Royal College of Paediatrics and Child Health	5.02	General	This is a welcomed initiative focusing on children and adolescents with schizophrenia. The guideline covers all the major areas of concern at the moment.	Thank you.	n/a
21	SH	Royal College of Paediatrics and Child Health	5.03	General	We think there needs to be a particular emphasis upon early intervention services (EIS), particularly where the services are organised and run by adult trained mental health workers.	Thank you for your comment. We agree and EIS will be covered in the guideline (please see 4.2 a and 4.3.1 i in the scope).	n/a
60	SH	Royal College of Paediatrics and Child Health	5.04	4.1.1 a	<p>We note that schizophrenia is a very difficult diagnosis to make when it first presents. Even if delusional disorder and schizoaffective disorder are included, the group of young people for whom the clinician can confidently make one of these three diagnoses is much smaller than the group of young people who will eventually grow up to be adults with a diagnosis of schizophrenia (or one of the other two). For instance, it is difficult in the early stages to distinguish between schizophrenia and bipolar disorder; or between psychotic illness that is <i>due</i> to substance misuse versus psychotic illness that is <i>comorbid with</i> substance misuse: indeed, some clinicians maintain that such a distinction should not even be attempted.</p> <p>Therefore this way of defining the scope seems excessively restrictive.</p>	Thank you for your comments. We have amended the scope in light of your concerns. The guideline will now address the management of at-risk mental states (for psychosis) and psychosis in children and young people prior to a diagnosis of schizophrenia.	Title, 4.1.1 b + 4.3.2 b
66	SH	Royal College of Paediatrics and Child Health	5.05	4.1.2b & c	We would like the rationale for exclusion of children and young people with learning disabilities or sensory disabilities explained. Unless these subgroups are considered systematically, the relevance of the clinical guidelines will be uncertain.	Thank you for your comments. In light of your concerns, we have revised the scope and the guidance will now be relevant to children and young people with a mild learning disability.	4.1.1 c
67	SH	Royal College of Paediatrics	5.06	4.1.2b & c	Excluding children and young people with learning	Thank you for your comments. In light of your concerns, we have revised the scope and the guidance will now be	4.1.1 b, 4.1.1 c +

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		and Child Health			<p>difficulties from such a guideline may be contrary to the Disability Discrimination Act; and excluding young people with Autism Spectrum Disorders may be contrary to the Autism Bill. Psychotic symptoms are commoner in both these groups than in the general population, and some of these young people may subsequently develop schizophrenia.</p> <p>Similarly, young people who use substances such as cannabis or amphetamines are more likely to develop psychotic symptoms, which in many cases may continue (with or without the substance misuse); and many such young people may subsequently satisfy the diagnostic criteria for schizophrenia.</p> <p>It would be much more egalitarian and clinically relevant to expand the scope to include all young people presenting with psychotic symptoms. If this is considered too broad, it could be restricted to those presenting with an acute psychotic episode or an insidious and prolonged onset.</p>	relevant to children and young people with a mild learning disability (please note that 4.1.2 c has now been omitted). However, the scope will be too large if ASD is included as well but there is currently an Autism Spectrum Conditions in Children and Young People guideline in development.	4.1.2 b
82	SH	Royal College of Paediatrics and Child Health	5.07	4.3.1b, d, e, f, g & h	This section in particular seems entirely reasonable and appropriate. The questions being asked are good.	Thank you for your comments.	n/a
91	SH	Royal College of Paediatrics and Child Health	5.08	4.3.1i	<p>It may be clinically and ethically inappropriate to specify how services should be organised and integrated for a narrow and difficult diagnosis such as schizophrenia than for a broad group of young people such as those presenting with a psychotic episode or insidious psychotic symptoms.</p> <p>Clinical experience suggests that it is sometimes difficult to provide a service for young people who have psychotic symptoms comorbid with other conditions such as learning difficulties, autistic</p>	Thank you for your comments. In addition to the organisation of services for young people with a formal diagnosis of schizophrenia, the guideline will consider the organisation of services for children and young people who present with suspected psychosis or 'at risk mental states' for psychosis and psychotic disorder prior to a diagnosis of schizophrenia.	4.1.1 b + 4.3.2 b

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					spectrum disorders or substance misuse because of boundary disputes between different helping agencies. For instance, an Early Intervention Service may refuse to accept such young people, who in their view do not have a 'pure' diagnosis of early onset psychosis. These young people may thereby be deprived of a service which they need just as much as those who have the 'pure' condition.		
95	SH	Royal College of Paediatrics and Child Health	5.09	4.3.2a	<p>While the remit of the guidelines is not to consider diagnostic issues, we think that validity of diagnosis should be included in the scope of the guideline. Poor outcomes could be as a result of an incorrect diagnosis.</p> <p>Given that the document states that health care professionals may have difficulty recognising schizophrenia in this age group (3.1 f) and that treatment (both pharmacological and non-pharmacological) is required it is surely important that the diagnosis is right before embarking on these therapies.</p>	<p>Thank you for your comments. Although the validity of diagnosis is outside of the scope, the guideline will now address the management of at-risk mental states (for psychosis) and psychosis in children and young people prior to a diagnosis of schizophrenia.</p> <p>The guideline will also consider what clinical features in the early presentation of psychosis may help guide subsequent diagnosis and clinical course.</p>	4.1.1 b + 4.3.2 b
22	SH	Royal College of Pathologists	2.01	General	This stakeholder responded with no comments to make.	Thank you.	n/a
23	SH	Royal College of Psychiatrists	21.01	General	I think the guideline will be useful and contains the right elements in the specification of the guideline – Section 4 seems the crucial one, the previous sections just set this up.	Thank you.	n/a
92	SH	Royal College of Psychiatrists	21.02	4.3.1i & 4.3.1j	I would suggest promoting 4.3.1.i and 4.3.1.j far higher. Recognition and antipsychotic drugs (4.3.1.a&b) are obviously important, but if young people don't access care, engage with it and get into logical care pathways then they're not going to be properly assessed and treated. The current order looks as though it's been written by a psychiatrist rather than a young person with schizophrenia.	Thank you for your comments. Items in the scope are not listed in order of importance.	n/a

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					This change of emphasis also sits more easily with 4.4.a – better recognition and earlier treatment.		
93	SH	Royal College of Psychiatrists	21.03	4.3.1j	4.3.1.j should be expanded “Ways to improve access to, and engagement with mental health services for ALL children and young people, including particular requirements of those from BME groups”. Access and engagement are highly problematic for all groups, not just BME.	Thank you for your comments. The problem of doing what you have suggested is that the specific needs of black and minority ethnic groups (access to services and engagement with professionals) are sufficiently pressing for this to be identified as a special need. The adult guideline also used this approach.	n/a
24	SH	Royal College of Psychiatrists	21.04	General	<p>Along those lines the guideline should also declare some kind of “vision” for management of young people – expert assessment and management by engaging, developmentally-sensitive, (age-appropriate) services offering person- and family-centred care in the least restrictive settings, ideally home-based and focussed on recovery and normal development in all domains of personal, social, educational and vocational, not merely symptom reduction though acknowledging this is usually a crucial aspect of care.</p> <p>I don't know whether one would expect the authors of the guideline or the guidance on the guideline to come up with this.</p>	Thank you for your comments – the GDG will bear them in mind when developing the guideline. We agree that key social, educational and vocational outcomes extend beyond symptom reduction and have included these in the scope under Section 4.4 Main outcomes.	n/a
39	SH	Royal College of Psychiatrists	21.05	3.1	In 3.1 Epidemiology, the main points for this age group with schizophrenia are not clear. Schizophrenia is vanishingly rare before puberty (or age 10 as stated), and then its incidence increases exponentially year by year into the twenties. Schizophrenia will be rarely encountered by generic CAMH teams but, on average, there will be far more 15-17 year olds than the younger groups. Reference to overall population statistics misses that. This is the group in the gap between child-focussed CAMH services and adult-focused	Thank you for your comments. It is worth mentioning that there is a rapid rise in incidence from mid-teens onwards coinciding with the transition between CAMHS and adult services. We will make sure this appears in the scope.	3.1 c

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					AMH service, education and occupation, child social care and adult social care, etc, etc, etc. This is why the care is so often poor.		
46	SH	Royal College of Psychiatrists	21.06	3.1i & 3.2f	3.1.i and 3.2.f make the same points but in a confusingly different order and emphasis – do BME have poor access and difficult engagement or are there more similarities than differences in pathways to care?? As I said above, access and engagement is generally problematic not only for BME groups.	Thank you for your comments. We agree and have omitted section 3.1.i.	3.1 i
47	SH	Royal College of Psychiatrists	21.07	3.1i	In 3.1.i It would be much clearer and less contentious to put the third sentence first, stating that rates of schizophrenia are higher in people from some BME groups, then it becomes less unexpected that service use differs.	Thank you for your comment. We have omitted section 3.1.i.	3.1 i
25	SH	Royal College of Psychiatrists	21.08	General	I think the review should address the question that arises from current practice about Early Intervention Services (and EIS in 3.2.e needs explaining at its first use, here). It has already been noted 3.1.f that schizophrenia is rare in the CAMH population and that staff there will understandably find it difficult to recognise an unfamiliar condition. EIS commonly go from age 17 upwards and are supposed to go down to 14 years of age and typically see most if not all the young people with schizophrenia that have contact with services and are expert at engagement, recognition and management. The active ingredients may not be clear but the disparity of expertise and geographical disparity of availability ought to be addressed, particularly given the recommendations of the NICE guidelines (referred to). I am not predicting the conclusions but it seems a proper topic for the review.	Thank you for your comments. The strengths and weaknesses of applying an adult-led EIS model to young people up to age 18 and the relationship of EIS to CAMHS will be considered by the guideline.	n/a
26	SH	Royal College of	21.09	General	Lack of comments on other sections indicates I think they are OK. Clearly, the evidence-free zone	Thank you for your comments.	n/a

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		Psychiatrists			in which most antipsychotic drugs are prescribed you those under 18 is of great concern although, personally, I think the same principles of good practice adhered to which ever side of 18 a young person finds themselves will serve most of them reasonably well. The situation for early teens and even younger is much, much less clear, and the questions about for how long should antipsychotic treatment be maintained is a crucial one for young people.		
41	SH	Sheffield Children's NHS Foundation Trust	10.01	3.1d & general	Important to speak with service users (parents/carers and children/young people) about what they consider to be signs of "recovery". The guidance and literature review protocol would benefit from a clear section about how "signs of recovery" were chosen and include a range such as social life, engagement in education/activity, quality of life, as well as symptoms.	Thank you for your comments. The guideline can only address service users' views through secondary review or analysis of individual stories, however, this is problematic in guidelines on children. In terms of trying to identify how "signs of recovery" were chosen, we will only be able to use what the primary research used.	n/a
57	SH	Sheffield Children's NHS Foundation Trust	10.02	3.2f	We are not comfortable with the language used "much of the difference in service provision seems to be determined by poor access and more difficult engagement with services". We feel this statement should reflect that the majority of mental health services for children and young people are not configured in a way which encourages/promotes engagement from some groups of young people.	Thank you for your comment. We have amended this section to reflect your concerns.	3.2 f
27	SH	Sheffield Children's NHS Foundation Trust	10.03	general	We would be very interested for the guidance to have information on what settings/professionals are picking up the sign of schizophrenia in young people.	Thank you for your comment. Healthcare settings and professionals will be discussed in detail in the guideline.	n/a
59	SH	Sheffield Children's NHS Foundation Trust	10.04	4.1.1	We would like to see the guidance include a specific consideration of socially excluded young people including those who are looked after/adopted and those who are engaging in offending/forensic behaviour.	Thank you for your comments. We have not included this setting or group specifically as this group and these settings would expand the size of the guidance beyond manageability. However, we have included reference to these settings in 4.2 c.	4.2 c

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					Also reference to the interplay and presentation of temporal lobe epilepsy and schizophrenia and guidance on management.		
62	SH	Sheffield Children's NHS Foundation Trust	10.05	4.1.2	We feel that it is important for this guidance to include young people with a learning disability. We should promote comprehensive CAMHS which will deal with children and young people with learning disability who presents with schizophrenia and or schizoaffective disorder and the prevalence rates are higher in this group. Also important to highlight either in "included or excluded" are young people with Autistic Spectrum Disorders.	Thank you for your comment. In light of your concern, we have revised the scope and the guidance will now be relevant to children and young people with a mild LD. However, the scope will be too large if we include ASD as well.	4.1.1 c
28	SH	Sheffield Children's NHS Foundation Trust	10.06	general	In terms of "equality of the scope" I think that the guidance itself is too specific in terms of using the term schizophrenia and should be broadened to target children and young people who are presenting with some symptoms yet do not qualify for diagnosis. I think this makes the guidance more clinically relevant and I completely agree with the comment of Group A in response to point 4a) in the stakeholder workshop notes (page 3).	Thank you for your comment. We have amended the scope in light of your concerns. The guideline will now address the management of at-risk mental states (for psychosis) and psychosis in children and young people prior to a diagnosis of schizophrenia.	Title, 4.1.1 b + 4.3.2 b
78	SH	Sheffield Children's NHS Foundation Trust	10.07	4.3.1a	Scope needs to be broadened/made more explicit by including - risk factors for developing schizophrenia (in order to increase recognition) - what are early signs of developing schizophrenia and who in society is likely to identify these signs. - where do young people usually present early in the development of their illness? - Is there evidence that training/education for particular groups of professionals increases early recognition? - Is there evidence that community based psychoeducation increases early recognition? - screening tools and clinical interviews that are recommended should be included.	Thank you for your suggestions. We have amended the scope in light of your concerns. The guideline will now address the management of at-risk mental states (for psychosis) and psychosis in children and young people prior to a diagnosis of schizophrenia.	Title, 4.1.1 b + 4.3.2 b

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					Guidelines on medication need and its monitoring need to link to the POMH –UK recommendations for this age group.		
84	SH	Sheffield Children's NHS Foundation Trust	10.08	4.3.1c	Could the interventions be broadened to include "support" e.g. from support and social groups etc. that EIS often provides? Also could educational and group interventions be included? When recommending particular psychological interventions, it is helpful to be realistic as to what is possible in the majority of CAMHS services. May need to refer to National benchmarking document and mapping exercise.	Thank you for your suggestions. We have listed the interventions that have the best chance of underpinning evidence. We cannot look at educational interventions as the scope is already very broad.	n/a
29	SH	Sheffield Children's NHS Foundation Trust	10.09	General	Should there be a section that reviews the evidence of the effectiveness of service structures in comparison to each other? CAMHS vs. EIS etc. This seems important to include even if there is no evidence.	Thank you for your comment. This comparison will be covered in the guideline as outlined in the scope (4.2 a+b and 4.3.1 i).	n/a
30	SH	Sheffield Children's NHS Foundation Trust	10.10	general	Agree with comments made in the stakeholder workshop about resistance to treatment although would prefer it to be called engagement in treatment.	Thank you for your comment but 'engagement in treatment' is not the same as 'resistance to treatment'. However, treatment as a whole will be looked at extensively in the guideline.	n/a
31	SH	Sheffield Children's NHS Foundation Trust	10.11	General	Agree with comments made in the stakeholder workshop that the guidelines should have a section on risk assessment and using the MHA with this group of young people.	Thank you for your comments. Although guidelines in mental health frequently refer to the mental health act, and risk assessment, this is rarely on the basis of any evidence. The use of the MHA is clearly not a matter of evidence, and assessing risk is something everyone does but based upon very little evidence for the value of this. As such, these matters are likely to be looked at by the GDG but can not form part of the scope.	n/a
32	SH	Sheffield Children's NHS Foundation Trust	10.12	General	Could the guidance have a section on the cultural differences in the way that symptoms of schizophrenia are interpreted to increase the cultural scope?	Thank you for your comment. 4.3.1 j and 4.4 f in the scope outline that the guideline will look at ways to improve access to, and engagement with, mental health services for children and young people from BME groups.	n/a
85	SH	Social Care	3.01	4.3.1c	Suggest changing to <i>family interventions</i> ,	Thank you for your suggestion. This has been amended.	4.3.1 b

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		Institute for Excellence			<i>including family therapy</i>		
100	SH	Social Care Institute for Excellence	3.02	4.4b	Suggest changing to <i>Treatment and care based on etc</i>	Thank you for your suggestion. This has been amended.	4.4 b
54	SH	South West Yorkshire Partnership NHS Foundation Trust	18.01	3.2c & e	The term 'family therapy' as used here is often interpreted as systemic or narrative family therapy. The term more commonly used in the evidence base for schizophrenia and in the NICE Guideline for Schizophrenia CG82 is 'family interventions' (as is used also in this document in section 4.3.1 (c)).	Thank you for your comment. We have replaced the term 'family therapy' with 'family interventions' throughout the scope.	3.2 a + c
61	SH	South West Yorkshire Partnership NHS Foundation Trust	18.02	4.1.1 & 4.1.2	<p>With regards to groups that will and will not be covered, defining the population as only those with a diagnosis of schizophrenia, schizoaffective disorder and delusional disorder, risks making this guideline less helpful to young people experiencing psychosis but where the formal diagnosis is unclear (potentially a much larger population than those with a formal diagnosis).</p> <p>The NICE Guideline for Schizophrenia CG82 advises that it also relates to people without a formal diagnosis; "1.2.2.2 Early intervention services should aim to provide a full range of relevant pharmacological, psychological, social, occupational and educational interventions for people with psychosis, consistent with this guideline." Could this guideline mirror this, and state that it too would also apply to people with 'psychosis'?</p>	Thank you for your comments. We have amended the scope in light of your concerns. The guideline will now address the management of at-risk mental states (for psychosis) and psychosis in children and young people prior to a diagnosis of schizophrenia.	Title, 4.1.1 b + 4.3.2 b
33	SH	University of Edinburgh	6.01	general	Throughout the guidelines and scope there needs to be a clear CAMHS perspective on assessment, management and intervention of this disorder group, including developmental and systemic reformulation of concepts based on adult services.	Thank you for your comments – we will bear them in mind when developing the guideline.	n/a
70	SH	University of	6.02	4.2	There needs to be a broadening of the Tier 3/4	Thank you for your comment – we will bear this in mind	n/a

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		Edinburgh			CAMHS service models, including day service provision and intensive home treatment options that are being developed in many CAMHS settings for this group of service users.	when developing the guideline. The guideline will address the differences between services provided for young people in early intervention services, in adult services and that provided by CAMHS, both in terms of research, and the pathway of care.	
75	SH	University of Edinburgh	6.03	4.3.1	We feel it is important to within a CAMHS context there needs to be clear primacy of psychosocial treatment, separate from medication treatments and evidence based psychological therapies as adjuncts. Thus separating psychological therapy and psychosocial interventions.	Thank you for your comment. However, this is not possible from the literature; what counts as psychosocial and what counts as psychological and social varies from commentator to commentator. The important issue is ensuring we cover all the relevant interventions.	n/a
76	SH	University of Edinburgh	6.04	4.3.1	Again, within a CAMHS context it would be preferable to define recovery less in terms of symptomatic recovery, but with a clear focus on emotional disorders and emotional recovery within this group, including developmental recovery in particular in terms of individuals' social and educational development.	Thank you for your comment. The GDG will bear these points in mind when looking at data on recovery.	n/a
34	SH	Welsh Assembly Government	20.01	General	We welcome the proposed study into this area of Children & Young People's mental health.	Thank you.	n/a
35	SH	Welsh Assembly Government	20.02	General	It is clear from the document that much of the evidence currently looks at psychosis in general and not just Schizophrenia. We would be concerned if this evidence was not included given the difficulties of formally diagnosing the condition in young people, the move of many services to focus on psychosis and the ongoing debate regarding classification in mental health. A narrow view, whilst possibly providing simpler outcomes, would run the risk of being less useful for the work of those who deal with young people on a daily basis.	Thank you for your comment. We have amended the scope in light of your concerns. The guideline will now address the management of at-risk mental states (for psychosis) and psychosis in children and young people prior to a diagnosis of schizophrenia.	Title, 4.1.1 b + 4.3.2 b
36	SH	Welsh Assembly Government	20.03	General	Whilst over 18 are not considered, recommendations regarding the matching of this document to the equivalent adult document would be helpful, particularly if there is a variation of	Thank you for your comment – we will bear this in mind when developing the guideline.	n/a

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					evidence, to facilitate transition.		
37	SH	Welsh Assembly Government	20.04	General	Future versions should possibly be all age or 15 year old plus to match the epidemiology of this illness and the early intervention or young adult services that have been developed as a result if evidence proves them useful	Thank you for your comment. This will be considered by NICE, the NCCMH and the topic selection panel.	n/a