NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

HEALTH AND SOCIAL CARE DIRECTORATE QUALITY STANDARD CONSULTATION SUMMARY REPORT

1 Quality standard title

Bipolar disorder, psychosis and schizophrenia in children and young people

Date of Quality Standards Advisory Committee post-consultation meeting: 15 July 2015

2 Introduction

The draft quality standard for bipolar disorder, psychosis and schizophrenia in children and young people was made available on the NICE website for a 4-week public consultation period between 26 May and 23 June 2015. Registered stakeholders were notified by email and invited to submit consultation comments on the draft quality standard. General feedback on the quality standard and comments on individual quality statements were accepted.

Comments were received from 11 organisations, which included service providers, national organisations, professional bodies and others.

This report provides the Quality Standards Advisory Committee with a high-level summary of the consultation comments, prepared by the NICE quality standards team. It provides a basis for discussion by the Committee as part of the final meeting where the Committee will consider consultation comments. Where appropriate the quality standard will be refined with input from the Committee.

Consultation comments that may result in changes to the quality standard have been highlighted within this report. Comments suggesting changes that are outside of the process have not been included in this summary. The types of comments typically not included are those relating to source guidance recommendations and suggestions for non-accredited source guidance, requests to broaden statements out of scope, requests to include thresholds, targets, large volumes of supporting information, general comments on the role and purpose of quality standards and requests to change NICE templates. However, the Committee should read this summary alongside the full set of consultation comments, which are provided in appendices 1 and 2.

3 Questions for consultation

Stakeholders were invited to respond to the following general questions:

- 1. Does this draft quality standard accurately reflect the key areas for quality improvement?
- 2. If the systems and structures were available, do you think it would be possible to collect the data for the proposed quality measures?
- 3. For each quality statement what do you think could be done to support improvement and help overcome barriers?

Stakeholders were also invited to respond to the following statement specific questions:

- 4. For draft quality statement 1: How would you define the symptoms of possible bipolar disorder in children and young people?
- 5. For draft quality statement 1: Would it be possible to measure whether children and young people presenting in primary care with symptoms of possible bipolar disorder or psychosis are referred to a specialist mental health service? Please explain your answer.

- 6. For draft quality statement 6: Are children and young people with bipolar disorder prescribed antipsychotics for longer than 12 weeks? If so, is this a rare or frequent occurrence?
- 8. For draft quality statement 8: What is the key area for quality improvement for education and training provision for children and young people with bipolar disorder, psychosis or schizophrenia?

4 General comments

The following is a summary of general (non-statement-specific) comments on the quality standard.

- Stakeholders welcomed the quality standard and hoped it will drive improvement in service provision.
- The equality and diversity considerations were felt to be comprehensive.
- There was a suggestion that stronger links should be made to national standards and initiatives such as the Early Intervention in Psychosis waiting standard, local transformation guidance and the new prevalence survey.
- More emphasis is needed on the importance of being optimistic about the recovery that a young person can make.
- The need for training of teachers and non-specialist staff, particularly those working in specialist education settings, should be included.
- It was questioned why the three topics of bipolar disorder, psychosis and schizophrenia have been considered together.

Consultation comments on Introduction

- The figures on prevalence of psychotic disorders and psychiatric admissions for schizophrenia were questioned.
- The statement about limited evidence of efficacy of antipsychotics was challenged.
- The introduction should include an explanation of 'at risk mental state'.
- It should also emphasise the impact on carers health and wellbeing and the importance of giving carers information and support in their own right.

Consultation comments on data collection

- There was some agreement that it would be possible to collect the data for the quality standard measures if appropriate systems and structures were available.
- Some stakeholders suggested, however, that collecting the data for the quality standard will be challenging given existing resources within many child and adolescent mental health services (CAMHS) and Early Intervention in Psychosis (EIP) teams and a current lack of appropriate systems and structures for data collection.
- It was felt that the quality standard may require significant development of IT systems including appropriate data linkage between GP IT systems and CAMHS secondary care health systems, as well as using a standard CAHMS system nationally.

5 Summary of consultation feedback by draft statement

5.1 Draft statement 1

Children and young people presenting in primary care with symptoms of possible bipolar disorder or psychosis are referred to a specialist mental health service for assessment.

Consultation comments

Stakeholders made the following comments in relation to draft statement 1:

- It would be helpful if the statement could include a time frame.
- The inclusion of schizotypal personality disorder within the definition of possible psychosis was challenged because it is not in ICD-10 and is rarely diagnosed in CAMHS.
- There was support for encouraging early referral but recognition that the statement will require specialist mental health services to be more flexible in accepting referrals for patients with symptoms that may not meet certain diagnostic criteria.

 Stakeholders suggested the statement should include referrals from the wider community beyond primary care, including schools and colleges, as this will ensure earlier referrals are made and is the approach used by many EIP teams.

Consultation question 4

Stakeholders made the following comments in relation to consultation question 4: 'How would you define the symptoms of possible bipolar disorder in children and young people?'

- Some stakeholders were concerned that the symptoms of possible bipolar disorder in children and young people vary significantly from patient to patient and it may not be possible to define this clearly.
- Other stakeholders described the following symptoms of possible bipolar disorder in children and young people.
 - Elation, grandiosity and episodicity are most important.
 - Sexual disinhibition needs to be assessed depending on the age of the young person as in children and younger adolescents it may indicate sexual abuse.
 - Irritability on its own will not be enough to warrant diagnosis.
 - Increased activity needs to be considered in light of pre-existing ADHD, which may also be comorbid and complicate diagnostic assessments.
 - Severe depression that affects cognitive function and speech, which may be coupled with mania or hypomania triggered by anti-depressants.
 - It is important to recognise and record that bipolar disorder can occur alongside other difficulties such as anxiety and depression, ADHD, and substance misuse.
 - A family history of bipolar is likely in children and young people with bipolar disorder.
- A stakeholder suggested that parents/carers should be encouraged to notice changes in their child's behaviours and question prompts can help to identify possible bipolar disorder.

Consultation question 5

Stakeholders made the following comments in relation to consultation question 5: 'Would it be possible to measure whether children and young people presenting in primary care with symptoms of possible bipolar disorder or psychosis are referred to a specialist mental health service?'

- Some stakeholders felt this should be possible through service audit within primary care services or a specific search of GP databases.
- There was concern that it may be difficult to measure possible symptoms consistently as definitions are so broad and coding of symptoms will vary.
- Other stakeholders felt this would be more challenging due to the small numbers in individual practices and existing IT systems.

5.2 Draft statement 2

Children and young people with a first episode of psychosis start treatment in a specialist mental health service within 2 weeks of referral.

Consultation comments

Stakeholders made the following comments in relation to draft statement 2:

- The statement needs to be more specific so that it is clear if this is 2 weeks from referral from the GP or 2 weeks following assessment.
- There was some concern that if the assessment period is included within the timescale this will be unrealistic as time is needed to engage, monitor and assess young people who may present with vague symptoms.
- It was suggested that there is a need to define 'treatment'.
- There was support for increasing the speed of response to children and young people but also concern that it may be difficult to achieve the standard due to current waiting times.

5.3 Draft statement 3

Children and young people newly diagnosed with bipolar depression or a first episode of psychosis are offered a psychological intervention.

Consultation comments

Stakeholders made the following comments in relation to draft statement 3:

- It was suggested that the statement wording should highlight the importance of a full psychological assessment in order to determine the approach.
- Stakeholders suggested it needs to be clearer which psychological interventions should be used.
- The wording in the rationale that suggests 'psychological therapy works better with antipsychotic medication' was felt to be an overstatement based on the evidence in the guideline.
- Do we need to be clearer that the expected level of achievement for the process measures is not 100% as patients may choose not to have psychological therapy?
- There was support for this statement but a concern that it will require investment in psychological interventions as these are not always available currently.

5.4 Draft statement 4

Family members of children and young people with a first episode of psychosis are offered family intervention.

Consultation comments

Stakeholders made the following comments in relation to draft statement 4:

- There was support for this statement but a concern that it will require investment at a local level to improve availability.
- It was suggested that family intervention should focus on the needs of families and carers as well as those of the child or young person and that this should be reflected in the outcomes.

5.5 Draft statement 5

Children and young people with bipolar disorder, psychosis or schizophrenia have comprehensive physical health assessments that include advice on healthy eating, physical activity and smoking.

Consultation comments

Stakeholders made the following comments in relation to draft statement 5:

- It was queried whether the statement should focus on an annual assessment.
- It was suggested that the definition of comprehensive physical health assessment should also include 'weight for height or BMI, assessment for movement disorders, blood glucose/HbA1c and prolactin' as well as advice on drugs and alcohol and sleep hygiene.
- There is a need to be realistic about the expected level of achievement as some children and young people will refuse consent, particularly for blood tests.
- It is important to highlight the need for a local agreement on how this will be delivered either by GP's or specialist mental health teams.

5.6 Draft statement 6

Children and young people with bipolar disorder, psychosis or schizophrenia prescribed antipsychotic medication have side effects monitored throughout treatment.

Consultation comments

Stakeholders made the following comments in relation to draft statement 6:

- It was suggested that the statement should include an indication of frequency such as "regularly in line with clinical guidelines".
- It was questioned whether it is necessary to include clarification that antipsychotics should not be prescribed routinely beyond 12 weeks for bipolar within the rationale as it may or may not be appropriate for individual children or young people.
- Stakeholders suggested that there should be more emphasis on the wider potential side effects of antipsychotic medication such as sleep disturbance and cognitive development.
- Stakeholders indicated that it is important to emphasise that mental health professionals are responsible for ensuring this is happening even if GP's or

paediatricians actually carry it out. The lack of expertise of GP's in this area was highlighted.

Consultation question 6

Stakeholders made the following comments in relation to consultation question 6: 'Are children and young people with bipolar disorder prescribed antipsychotics for longer than 12 weeks? If so, is this a rare or frequent occurrence?

- Stakeholders indicated that antipsychotics may be prescribed for longer than 12 weeks for a child or young person with any long term mental health condition.
- There was concern that the inconsistencies between recommendations for bipolar disorder and psychosis and schizophrenia could discriminate against young people with bipolar disorder.

5.7 Draft statement 7

Children and young people with bipolar disorder, psychosis or schizophrenia in crisis are assessed for home treatment.

Consultation comments

Stakeholders made the following comments in relation to draft statement 7:

- Some stakeholders supported this statement but were concerned that home treatment services are not always available.
- It was emphasised that hospital treatment will also still be needed for some children and young people.
- Should this be considered as a developmental statement based on potential cost impact?

5.8 Draft statement 8

Children and young people with bipolar disorder, psychosis and schizophrenia have the arrangements for accessing education or employment-related training outlined in their care plan.

Consultation comments

Stakeholders made the following comments in relation to draft statement 8:

- There was strong support for this statement.
- There was a concern that it may be difficult for some services to comply with this, particularly where other statutory agencies are taking a lead on the education provision or where vocational and medical educational services have been recently scaled back.

Consultation question 8

Stakeholders made the following comments in relation to consultation question 8: 'What is the key area for quality improvement for education and training provision for children and young people with bipolar disorder, psychosis or schizophrenia?'

- Priorities for improvement were suggested as follows:
 - Ensuring equal access so that children and young people are not discriminated or excluded because of their mental health condition.
 - Retaining existing links so that children and young people can return to their ordinary lives.
 - Role of care co-ordinator in maintaining previous links and aiding transitions.
 - Access to a vocational worker, occupational therapist or individual placement support worker is highly variable currently.

5.9 Draft statement 9

Parents and carers of children and young people with bipolar disorder, psychosis or schizophrenia are offered a carer-focused education and support programme.

Consultation comments

Stakeholders made the following comments in relation to draft statement 9:

- There was support for this statement.
- It is important to ensure that young carers such as siblings also receive this support.

 It was emphasised that this should not be the only support provided to families and carers who should have ongoing information and support and referral to carers' services for information and advice in their own right.

6 Suggestions for additional statements

The following is a summary of stakeholder suggestions for additional statements.

- Assessment for diagnosis including:
 - Accurate diagnostic assessments as many CAMHS do not use diagnostic assessment tools routinely.
 - A wider multi-professional assessment process to ensure social and personal perspectives are taken into account as part of the assessment process. This was felt to be important to ameliorate the current trend of increasing diagnosis rates.
- Increasing the availability of psychological interventions with a particular focus on the efficacy of group interventions.
- Clarification of referral thresholds between educational psychology and CAMHS services because GPs and families struggle to get either service to engage with a young person and their family.
- Communication and sharing of information about current treatment and care plans from CAMHS/EIP to GP's.
- Support for young people in the criminal justice system is important because this
 can be the first time a young person comes into contact with a health care
 professional. More emphasis is needed on liaison and diversion in the pathway.
- Developing collaborative formulations with service users and their families.
- Mental health promotion.

Appendix 1: Quality standard consultation comments table – registered stakeholders

ID	Stakeholder	Statement number	Comments ¹
1	British Medical Association	General	We broadly welcome the guideline. It provides a structure and systematic approach to this small cohort of patients who often require a large amount of input.
2	British Medical Association	General	We believe the guideline will put the onus on Health Boards in Scotland and CCGs in England to review current organisational practice and we hope that this will lead to significant redesign of services to patients.
3	Association of School and College Leaders	General	ASCL welcomes the draft quality standards.
4	Department of Health	General	What is the rationale for putting these three items together as one guideline? Psychosis is a set of symptoms rather than a long term condition like the other two, and can be symptom of both the long term conditions and other mental health issues. What is the perceived benefit of doing this?
5	Department of Health	General	Policy-related comments overall - Press release could link or should refer to the local transformation guidance as this will be relevant. We could provide a paragraph but it would be useful to make the link, as it will remind service providers and deliverers of best practice through the new/updated guidance.
			Prevalence survey – the guidance refers to the data being limited. Is it worth them incorporating either through the briefing and guidance, or at least we should let them know, about the new prevalence survey so they can update their guidance and briefing accordingly?
			Early Intervention in Psychosis (EIP) waiting standard is not explicitly referred to. There is something about an intervention being delivered within two weeks, but is it worth making this clearer as assuming any adult standards will reflect this policy development?
6	The British Psychological Society	General	The inclusion of equality and diversity considerations for each statement is welcomed, especially as it highlights cultural differences, social factors, cognitive impairments and communication needs.
			The quality standard suggests that the majority of children and young people will not make a good recovery from bipolar disorder or psychosis. However, in practice based evidence terms this is not the case, it is hugely beneficial if services retain optimism and hopefulness about the recovery the young person can make and actively de-stigmatise

¹PLEASE NOTE: Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how quality standards are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its staff or its advisory committees.

ID	Stakeholder	Statement number	Comments ¹
			mental health problems. Especially with the appropriate MDT interventions and support from a bio-psycho-social model and it would be helpful to see this emphasised more explicitly in the quality standard.
			Finally we believe that it would be useful if the guidelines were able to emphasise the importance of training for teachers and non-specialist staff with respect to relatively rare states of psychological distress / defined psychiatric conditions. This would particularly be the case for those working in specialist provisions where there are likely to be a far higher incidence of pupils who may exhibit or develop symptoms, such as PRUs, SEBD and other special schools, units for pupils with ASC etc. School staff may be the first professionals to notice changes in behaviour that may be indicating (for example) the onset of a psychotic episode and therefore be in a position to do something about it, but in our experience many school based staff still feel uninformed and as a result lack confidence in making professional judgements and decisions in this area. This would also extend to planning and implementing interventions etc. once a diagnosis has been made.
7	Royal College of Paediatrics and Child Health	General	Thank you for inviting the Royal College of Paediatrics and Child Health to comment on the draft bipolar disorder, psychosis and schizophrenia in children quality standard. We have not received any responses for this consultation.
8	Digital Assessment Service, NHS Choices	General	The Digital Assessment Service welcome the guidance and have no comments as part of the consultation.
9	The Royal College of Surgeons of England	General	The RCS will not be sending a response to this consultation.
10	NHS England	General	Thank you for the opportunity to comment on the above Quality Standard. I wish to confirm that NHS England has no substantive comments to make regarding this consultation.
11	Department of Health	General – Briefing paper	(Briefing paper page 25): there is a map of CAMHS tier four beds from July 2014, which probably came from the NHS E review. It mentions that SW and YH do not have any provision. This is no longer the case, after NHS England spent on extra tier four beds.
12	The Royal College of Psychiatrists	Introduction	It is unclear how the quoted prevalence of psychotic disorders in under 18s was derived, and definitions involved. Although there is no total clarity about this, it is probably 5-15% of all cases of psychosis (figure usually given for schizophrenia; there is a lack of clarity regarding the precise figure for psychosis). Psychotic symptoms (e.g. hallucinations) are much higher than 0.4% though (in the region of 5-15% depending on the study). Similarly, it would be helpful to understand how the figure of ~25% for admissions for schizophrenia (vs psychotic symptoms) was derived, as this does appear high from clinical experience.
13	The Royal College of Psychiatrists	Introduction	The evidence for the efficacy of antipsychotics in children and young people is not that limited but what is limited is our knowledge about long term side-effects.
14	The Royal College of Psychiatrists	Introduction	Table 1 domain 2 - Education not mentioned.

Stakeholder	Statement number	Comments ¹
The Royal College of Psychiatrists	Introduction	Pages 6-7 - Education needs to be explicitly mentioned. Education staff need to receive training as well.
The British Psychological Society	Introduction	The Society believes that the introduction would benefit from highlighting the term at risk mental state for those at risk of psychosis as that is outlined in the full guideline.
Carers Trust	Introduction	Comment about "Role of Family and Carers" – Carers Trust welcomes the recognition of the role carers play in supporting young people with mental health problems. However, it is important not only to recognise the role carers play but the impact on their own health and wellbeing as outlined in "Psychological Distress in Carers of People with Mental Disorders", Shah A, Wadoo O, Latoo J (BJMP 2010).
Carers Trust	Introduction	Comment about "Role of Family and Carers" – Carers Trust welcomes the recognition of the role carers play in supporting young people with mental health problems. It is important to recognise that by stating "where appropriatecarersinvolved in decision making". This guidance should recognise the new Mental Health Act Code of Practice 2015 that recognises the need to give carers information and support in their own right. Where young people are being supported by mental health services, it is important for them to manage the rights of the young person but also the role their carers are playing in supporting them. Whether services like it or not carers are involved.
British Medical Association	Questions for consultation – Question 1	Probably yes
The Royal College of Psychiatrists	Questions for consultation – Question 1	Generally yes, but no statement on accurate diagnostic assessments - this appears to be a gap between statements 1 and 2. It should be noted that many CAMHS do not use diagnostic assessment tools routinely and this should be considered as a standard.
The British Psychological Society	Questions for consultation – Question 1	The Society welcomes the highlighting of many of the key areas including the need for early intervention and quicker access to mental health input for these young people. We welcome that the standard also highlights the need for support for the family/carers, access to education and employment, covers psycho social and health care factors and furthermore input within the home if need be. However, it would be helpful if the draft could do more to accurately reflect a number of other areas which are also key for quality improvement. It would benefit from more standards regarding: 1. Mental health promotion (Early Psychosis Declaration, 2002; French and Morrison, 2004), 2. Developing collaborative formulations with service users and their families (Johnstone and Dallos, 2006; Tarrier et al., 2006), 3. More information on assessment and
	The Royal College of Psychiatrists The British Psychological Society Carers Trust Carers Trust British Medical Association The Royal College of Psychiatrists The British Psychological	The Royal College of Psychiatrists The British Psychological Society Carers Trust British Medical Association The Royal College of Psychiatrists The Royal College of Psychiatrists The British Psychological Society Psychological Society Introduction Questions for consultation — Question 1 Questions for consultation — Question 1 The British Psychological Society

ID	Stakeholder	Statement number	Comments ¹
			4. In increasing the availability of psychological interventions (NICE 2014; The Schizophrenia Commission, 2012) particularly a focus on the efficacy of group interventions.
22	The Royal College of General Practitioners	Questions for consultation – Question 1	The College feels that this statement only partially reflects the areas for quality improvement. There are issues of referral thresholds and boundary disputes between educational psychology and CAMHS services where GPs and families struggle to get either service to engage with a young person and their family.
			There is nothing in the standards about how services should support young people in the criminal justice system – many end up being arrested and this can be the first time they have seen a health care professional. Can we consider thinking about liaison and diversion in the pathway?
			Should there be a standard around communication and information sharing? It is rare to get a letter from EIS outlining current treatment and care plans or bloods etc.
23	British Medical Association	Questions for consultation – Question 2	Probably yes
24	Betsi Cadwaladr University Health Board	Questions for consultation – Question 2	Statistics related to number of young people with possible psychotic symptoms or possible bipolar disorder would not be meaningful as the definitions are so broad, statistics related to admission rates are also unhelpful as this so rarely happens in adolescents
25	The Royal College of Psychiatrists	Questions for consultation – Question 2	Largely dependent on adequacy of systems and structures.
26	The British Psychological Society	Questions for consultation – Question 2	The Society believes that collecting the data for the quality standards will considerably challenge the existent resources within many CAMHS and EI teams, particularly those where interface is limited and where transition guidelines are still in development. These reports come from CAMHS services across the country including the devolved nations.
27	The Royal College of General Practitioners	Questions for consultation – Question 2	This will depend on appropriate data linkage between GP IT systems and CAMHS secondary care health systems as well as using a standard CAHMS system nationally.
			System and structures are not available at present and would take a significant amount of time to develop effective accurate IT systems that can find this data. Have electronic data in primary care but secondary care children's service data poor generally.
28	British Medical Association	Questions for consultation – Question 3	For most of the quality statements significant local redesign and new resources will need to be found. General practice has no capacity nor has the critical mass to provide the type of systematic care that this small but important group of patients need.

ID	Stakeholder	Statement number	Comments ¹
29	The Royal College of Psychiatrists	Questions for consultation – Question 3	Statement 1: needs time frame and training for GPs. Statements 2-5: training and adequate clinical staff required, including nursing staff for physical health care. Statement 6: frequency needs to be mentioned, even if vague (e.g. "regularly in line with clinical guidelines") Statement 7: home treatment is not available in all areas – is there sufficiently good evidence to suggest that this should be a quality standard? Statements 8: training for teachers and trainers required.
30	The British Psychological Society	Questions for consultation – Question 3	An overarching barrier for all of the quality statements comes down to access to specialist mental health services and resources, while clinicians want to be able to provide quick access for the most vulnerable of young people especially those with conditions such as bipolar and psychosis which could have a lifelong impact on their quality of life they are not able to as is highlighted so well in the following article: http://www.theguardian.com/society/2015/may/02/crisis-in-childrens-mental-health-nhs-insider-speaks
			In order to support this and overcome the barriers specialist services need further investment if the young people are to get the care and input they need. Furthermore, in order for them to not be discriminated against and have equal access to education and employment training and awareness would be beneficial for our education and recruitment colleagues.
			In addition as regards barriers specific to each individual quality statement:
			Statement 1: There needs to be increased training for primary mental health care professions on the prodrome of bipolar and at risk mental state presentations as well as a published flow chart or diagrammatic representation of the referral pathway.
			Statement 2: Due to interface issues and difficulty in engaging young people with BPD, ARMS or first episode of psychosis there will inevitably be delays in assessment which will consequently cause a breach of the treatment target. Furthermore in cases of diagnostic uncertainty there should be specialist assessment using measures such as the Structured Interview for Prodromal Syndromes (SIPS), the Comprehensive Assessment of At Risk Mental States (CAARMS) or the Positive and Negative Syndrome Scale (PANSS) (French and Morrison, 2004) to provide clarity and inform the care pathway.
			Statement 3: should be achievable for some teams/trusts if there are sufficient numbers of appropriately trained staff to deliver CBT and family interventions, however, others will not have sufficient staff numbers to accommodate this standard and extra training and supervisory support may also need to be increased substantially.

ID	Stakeholder	Statement number	Comments ¹
			Statement 4: This should be both possible and best practice within CAMHS and EI teams.
			Statement 5: This should be routine practice and should be offered at baseline assessments. Some children and young people will invariably refuse consent, particularly for bloods, for several clinical and non-reason reasons, so the target needs to be realistic.
			Statement 6: Again, this should be routinely monitored within either primary care or the specialist team and is a paramount standard.
			Statement 7: Where services are provided and are accessible, however coverage for 3.5/HT teams for children and young people remain inconsistent nationally.
			Statement 8: This is another essential standard; however it will be very difficult for some services to fully comply with this, particularly where other statutory agencies are taking a lead on the education provision or where vocational and medical educational services have been recently scaled back.
			Statement 9: In CAMHS and EI teams this should be routine practice.
31	The Royal College of General Practitioners	Questions for consultation – Question 3	Family therapy is important to help improve family communication (statement 4) but this is a very limited resource and requires families to come together during working hours in a secondary care setting. Locally based services or this service at home would help as well as flexibility on hours.
			Better definition – Statement 1 – need to clearly define symptoms and signs or unfair to measure time to referral. If someone with vague symptoms referred, then an EIS would not have time to observe the person before treatment (depending on what is defined as treatment).
32	British Medical Association	Statement 1	It is clearly important patients are referred early. However, there can be issues in determining an exact diagnosis, so specialist teams need to understand that patients present with symptoms and not a diagnosis will be referred to them. Therefore, the specialist mental health service must be flexible in accepting referrals (and not refer them back to practices if they do not initially meet certain diagnostic criteria).
33	Association of School and College Leaders	Statement 1	Education professionals in schools and colleges often become aware of, or are more willing to take note of, symptoms earlier than families and carers. It can be difficult for them to help young people to get the help they need if families are resistant or in denial. It would be helpful to give some thought to and make an explicit statement about referral from education professionals.

ID	Stakeholder	Statement number	Comments ¹
34	The Royal College of Psychiatrists	Statement 1	P12 - Schizotypal personality disorder is not in ICD-10 and is rarely diagnosed in CAMHS, if at all. Most children and young people with the symptoms of schizotypal disorder are probably rightly diagnosed with ASD.
35	The British Psychological Society	Statement 1	The Society believes that there should be an inclusion of a wider multi-professional assessment process to be considered within this quality statement. This concept has been successfully used and dramatically improved the holistic nature of the assessment, included social dimensions of the genesis of the condition more effectively and led to a move away from a totally 'Medical Model,' 'within child' view of the onset of the condition (Read et al., 2001; The Schizophrenia Commission, 2012). It has been suggested that conditions like Juvenile Bipolar Disorder which have been impacted upon adversely by the publication of DSM-5 in May 2013 when much more inclusive and 'catch all' definitions of a number of conditions were created. It is possible that this will result in many 'false positive' diagnoses being issued unless wider social and personal perspectives are taken into account as part of the assessment process and that this may ameliorate the current trend of increasing diagnosis rates significantly. Consideration of this within the quality standard would be useful. These points and concerns were elaborated on in,'DSM-5: The future of psychiatric diagnosis,' (2012 – final consultation) British Psychological Society response to the American Psychiatric Association, June 2012.
36	The International Society for Psychological and Social Approaches to Psychosis- UK	Statement 1 – Question 3	The Quality Statement seems concerned only with the process following referral from primary care. However, interventions could in many cases be earlier – and therefore stand a significantly increased chance of being effective – if referrals could be fielded from any direction (with a positive and responsive attitude) and if efforts were made to inform the community widely about possible indications of psychosis (for example, by contacts with schools and colleges). This has been the approach of many Early Intervention in Psychosis teams.
37	British Medical Association	Statement 1 – Question 4	Symptoms of possible bipolar disorder in children and young people vary significantly from patient to patient. Therefore, specialist teams must be flexible in ensuring acceptance of referrals from GPs, particularly when there is diagnostic doubt.
38	The Royal College of Psychiatrists	Statement 1 – Question 4	Similar to adults. Elation, grandiosity and episodicity are most important. Sexual disinhibition needs to be assessed depending on the age of the young person as in children and younger adolescents may indicate sexual abuse. Irritability on its own will not be enough to warrant diagnosis. Increased activity needs to be considered in light of preexisting ADHD, which may also be comorbid and complicate diagnostic assessments.
39	The British Psychological Society	Statement 1 – Question 4	The Society recommends that diagnostic criteria should be considered routinely following clinical interview, accompanied by a personal social and medical history alongside longitudinal monitoring of mood and symptoms; in addition psychometric measures should be carried out if necessary to provide further information for a psychological formulation.
			We also would like to highlight the importance of differentiation between the symptoms as younger people may switch between moods more frequently than adults do. Ideally parents/carers should be encouraged to notice changes in their child's behaviours that is out with the norm;

ID	Stakeholder	Statement number	Comments ¹
			 Is their mood dropping more frequently with no apparent trigger, are they having periods of hyperness and silliness? Is their mood going up and down regularly which is not like the usual up and downs of childhood and adolescence? Are they falling out with friends regularly? Are they finding it difficult to concentrate and focus in school? Experiencing racing thoughts? Talking really quickly? Jumping from tasks to task at home and school without properly completing? Engaging in promiscuous and risky behaviours? Are they trying to harm themselves or experiencing suicidal ideation? Changes in appetite and sleep? Complaining about stomach and headaches? No energy? Parents/carers should ideally monitor how often their mood is fluctuating during the day/week? How long do the periods last? It is also important to recognise and record that bipolar disorder can occur alongside other difficulties such as anxiety and depression, ADHD, substance misuse and it is also vitally important that these are assessed simultaneously as discussed in previous NICE guidance (NICE, 2014). NICE (2014) Bipolar disorder: the assessment and management of bipolar disorder in adults, children and young people in primary and secondary care: Guideline 185. London: NICE.
40	Department of Health	Statement 1 – Question 4	Defining symptoms of bipolar disorder – severe depression that affects cognitive function and speech, which may be coupled with mania or hypomania triggered by anti-depressants;
41	The Royal College of General Practitioners	Statement 1 – Question 4	This remains a challenging issue for children suspected of possible bipolar disorder as rapid mood swings appear to be common in children and young people. If these symptoms are causing problems at school particularly in boys, there can be diagnostic uncertainty with ADHD. A family history of bipolar is likely in children and young people with bipolar disorder. There is potential for misdiagnosis and overdiagnosis with considerable pressure on specialist CAMHS services to provide an early diagnosis that may require observation over a period of time.
42	British Medical	Statement 1	This would be quite challenging for GPs, primarily due to the small numbers in individual practices. It would be time-

ID	Stakeholder	Statement number	Comments ¹
	Association	- Question 5	consuming and the IT systems are probably not robust enough to provide this information. A more systematic approach would be better.
43	Betsi Cadwaladr University Health Board	Statement 1 – Question 5	The definition of possible psychosis and possible bipolar disorder is very wide. Mood swings, irritability and even complaints of hearing voices are extremely common in young people in the community and in CAMHS referrals. It is our experience that these symptoms very rarely herald the onset of psychosis or bipolar disorder. Psychotic-like experience very commonly are associated with bullying and other forms of abuse is young people and this isn't covered. The presence of psychotic like symptoms should arguably prompt consideration of other explanations than bipolar disorder or psychosis. Lack of functioning in young people with a parent with psychosis doesn't immediately suggest psychosis and schizoptypal personality disorder is almost never diagnosed in young people. Much more common diagnostic dilemmas for child and adolescent psychiatrists related to ADHD and bipolar disorder, mood swings and emerging borderline personality disorder, trauma symptoms and hearing voices and Autism Spectrum Disorder (ASD) and odd beliefs / behaviour which can suggest psychosis.
44	The Royal College of Psychiatrists	Statement 1 – Question 5	Difficult to comment – needs primary care perspective.
45	The British Psychological Society	Statement 1 – Question 5	This should be possible through routine service audit within primary care services. Most CAMHS services tend to record stats and some can also record referral rates and reasons for referrals therefore it would be possible to measure how many young people are referred on due to these symptoms. However, it wouldn't capture those young people that may be missed and not referred on but it is likely that these individuals would present in the future. It is important to note that young people may be referred for many reasons and not necessarily termed as symptoms of Bipolar or Psychosis but following assessment are diagnosed with these disorders, therefore this would make it difficult to measure. It would be interesting to measure how many children are referred with symptoms of Bipolar and/or Psychosis and those that are not but then diagnosed as such.
46	The Royal College of General Practitioners	Statement 1 – Question 5	This would be difficult without a specific audit or a MIQUEST search as the coding is likely to be varied. Some of the GP databases including CPRD may be able to do this with a sophisticated search protocol. It is possible to do a search for children with a read code for symptoms of psychosis/bipolar (but these are quite broad so would likely call up quite a large number of people) and also a read code for referral to psychiatrist for example. The problem has always been that early psychosis can be very vague and difficult to pick up and differentiate between what is normal behaviour and what is pathological.

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47	British Medical Association	Statement 2	We agree it is important to start treatment of children and young children with a first episode of psychosis as early as possible. However, given current waiting times for child psychiatry, this will be a challenging target to meet.
48	Association of School and College Leaders	Statement 2	It is pleasing to see that there is an expectation of rapid assessment and start of treatment. The experience of schools and colleges is that mental health services for young people are often very slow to react and set unduly high thresholds for treatment.
49	Betsi Cadwaladr University Health Board	Statement 2	Starting treatment within 2 weeks. Psychosis is young people very often has an insidious onset and it time is need to monitor and assess. For very rare emergency presentations of florid psychosis a rapid response is needed but in the majority of cases the diagnosis takes some time to become clear. Is the 2 week response time for treatment evidence based or politically based?
50	The British Psychological Society	Statement 2	It is important to note that in Scotland, we are working towards the HEAT target which ensures faster access to mental health services by delivering 18 weeks referral to treatment for specialist Child and Adolescent Mental Health Services (CAMHS) services from December 2014; and 18 weeks referral to treatment for Psychological Therapies from December 2014 (http://www.gov.scot/About/Performance/scotPerforms/partnerstories/NHSScotlandperformance/CAMHS18weeks). Therefore, some consideration might be made to whether the 2 week goal would apply to those working in Scotland.
51	The British Psychological Society	Statement 2	We fully endorse the view that a broad multi-professional assessment needs to happen within two weeks for the first episodes of these conditions. This should include a systematic analysis of the support networks around a child in the run up to the episode and a creative consideration of the Circle of Support that may be put in place around the child or young person in the coming months as we strongly believe, along with clear research evidence, that this is the best way to minimise the harm of the current situation and to maximise the recovery phase thus reducing significantly the relapse rate and the length of interval and severity of future transient episodes. We strongly believe that all mental distress episodes are transient manifestations of the accumulated stress within a young person's life and can be largely addressed in more creative ways than reliance mainly on psycho-pharmaceutical interventions alone. (Hendryx, 2009)
52	British Medical Association	Statement 3	We believe offering children and young people newly diagnosed with bipolar depression or a first episode of psychosis a psychological intervention is very important. However, this will require investment as often these services are not available (or they are inadequately available) at a local level.
53	The International Society for Psychological and Social Approaches to Psychosis- UK	Statement 3	We wanted to check the wording of the statement "For children and young people with psychosis psychological therapy works better when they also take antipsychotic medication". From our reading of the Full Guideline it did not seem clear that this was the case – the sense we gained was that there was no satisfactory evidence specifically on this point in relation to under-18s, and that it was decided merely that there was no definite evidence to suggest that the situation for young people was different from the situation for adults. If that is so, then the wording is an overstatement.
54	The International Society	Statement 3	The Quality Statement refers to 'a psychological intervention', but the definition of terms is, we think, unfortunately

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	for Psychological and Social Approaches to Psychosis- UK		narrow and rigid. As the Full Guideline says "this is often a highly complex and co-morbid group" (p187), and among several areas of complexity is the incidence of adversity and trauma in the backgrounds of young people seeking help. A further element of complexity is the range of ages involved, where there is reason to suppose that this may also bear upon the suitability of style and approach (cf p178). It therefore seems of particular importance for the style and approach of therapeutic intervention to be determined by a full psychological assessment, capable of weighing up the individual and complex needs of the patient, and of discussing this fully with the patient in clear terms. For example, it would be necessary to take into account to the individual needs of a young person who may, for example, be trying to cope with both psychotic phenomena and traumatic experiences. We would favour measuring against the standard by specifying that "Children and young people with a first episode of psychosis should be offered a substantial, evidence-based psychological intervention over at least 16 sessions, following a full psychological assessment".
55	The British Psychological Society	Statement 3	The Society welcomes the proposal that a psychological intervention should be the first level response with newly appearing mental distress conditions such as Bipolar Disorder and Early Onset Psychosis. It may be useful for consideration to be given to recent research that highlights the association between people who are highly artistic and a pattern of bipolar disorder. It is important to recognise the huge benefits of such energy and indeed the link with the state of 'creative flow'. This is in line with our view of the importance of not presenting a solely negative picture of any prognosis following diagnosis in young people of these disorders. We would therefore recommend that consideration needs to be given to not medicating this creative life force away but helping the person to channel and focus it more effectively so that it does not disable them from living a normal life. (Power, 2015)
56	South London and Maudsley NHS Foundation Trust / King's College London	Statement 3	Rationale - There is very little evidence of this statement. This may divert resources away from those who are likely to benefit.
57	The Royal College of General Practitioners	Statement 3	Psychological therapies should be offered to the young person – which ones?
58	British Medical Association	Statement 4	As with statement 3, we believe this is a very important issue, which will require investment as often these services are not available (or they are inadequately available) at a local level.
59	Carers Trust	Statement 4	Comment about the benefits of family interventions – Carers Trust welcomes the promotion of family interventions however, it is important that the benefits must be for the whole family and not solely for the child with psychosis. The impact of caring for a child with a serious mental health problem has a significant impact on the whole family (parents and siblings) and the family intervention must show clear benefits for their health and wellbeing.
60	Carers Trust	Statement 4	Comment on family interventions – whilst Carers Trust welcomes the recognition of carers in CAMHS and EIT services it is important to ensure services do not only provide family interventions as their only means of support to

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			carers. The Triangle of Care makes clear that carers need to be included and supported in their own right as carers ensuring they have information and advice not only on mental health but also what is available to them as carers.
61	British Medical Association	Statement 5	There needs to be agreement at a local level who will deliver this. If general practice is expected to be involved, new resources will need to be provided to deliver this through an enhanced service. We believe it would be better organised by specialist mental health teams and provided as package to patient. This would enable the assessments to be organised on a systematic basis and the clinicians involved would become comfortable with the protocol set out.
62	The Royal College of Psychiatrists	Statement 5	P28 - In the last paragraph height, weight for height or BMI, assessment for movement disorders, blood glucose/HbA1c and prolactin need to be also mentioned (as presented in more detail later in the document).
63	The British Psychological Society	Statement 5	We welcome the inclusion of dietary and exercise considerations in a more holistic intervention plan agreed with the young people concerned. Dietary adaptations like using calming foods and aroma therapy oils have also been seen in this service to help settle children and promote better sleep which is hugely beneficial to increasing their general wellbeing. Milk is another example of a natural product that contains tryptophan with varying levels of naturally occurring melatonin both of which have calming properties. The high calcium level is also beneficial in converting tryptophan into more melatonin. Milk is also an excellent rehydrating fluid as proven by Loughborough University's Sport's Science team (Shirreffs et al, 2007). Rehydration in itself can, as we all know, benefit mood, behaviour and energy levels (Benton, 2011). A Scottish Education Department study (http://www.educationscotland.gov.uk/lmages/Water_is_cool_in_school_tcm4-663301.pdf) demonstrated that a 2% dehydration can lead to a 20% deterioration in behaviour and led to Scottish schools to promoting more water being made more readily available to children in the classroom. Mindfulness, yoga, peer massage and deep breathing training methods such as the "7:11 Technique" are also very effective for use in this area. (Shapiro et al, 2007) Although the inclusion of the above is positive we would also suggest that this should include drugs and alcohol advice and also sleep hygiene.
64	The Royal College of General Practitioners	Statement 5	There should be a standard around considering alcohol or substance misuse and appropriate referrals or services being in place? The prevalence of underage drinking among children in England is widespread; 43% of all 11 to 15 year-olds surveyed said they had drunk alcohol at least once in 2012. The number and proportion of those who had drunk alcohol at least once increases with age, rising from 12% of 11 year-old schoolchildren to almost 4 in every 5 (74%) by the age of 15 in 2012. There is an association between BPD and drug and alcohol misuse. There needs to be much greater emphasis on better measurement and management of this in the pathway. Also linked with forensic activity. Could this be possibly added in to statement five?

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65	British Medical Association	Statement 6	Similarly to statement 5, there is a need to ensure child psychiatry and the relevant mental health teams have enough capacity to cope with this specialist work. Again this would better be provided by specialist mental health teams, as it is unlikely that most GPs would see enough patients to build up the critical mass of knowledge needed.
66	The Royal College of Psychiatrists	Statement 6	P32 - Potentially the best way of ensuring that side effect monitoring is happening is that mental health professionals are leading on it. It may be that GPs/paediatricians do it but psychiatrists should be monitoring that it is happening.
67	The British Psychological Society	Statement 6	In regard to anti-psychotic medications we would recommend that not enough account has been taken of recent successful litigation in America against drugs companies for this category of psychotropic drug (http://www.nytimes.com/2013/11/05/business/johnson-johnson-to-settle-risperdal-improper-marketing-case.html). A stronger warning about the current reliance on strong psycho-pharmaceutical agents as the first response of choice is in our opinion definitely required. Many other side effects are of concern to us, the most common being that many of these psychotropic medications impact adversely on the quality of a child's and adult's sleep and even common sense dictates that a deterioration in the refreshing and healing effects of sleep may consequently impact on a person's mood and behaviour patterns. The unprecedented Department of Justice Press Release for this key ruling to Safeguard vulnerable groups was
			issued by the Office of Public Affairs on Monday, November 4, 2013 and is available online.
68	Tees ESK and Wear Valley NHS Foundation Trust	Statement 6	I am really concerned about that the standard that YP with Bipolar Disorder should not continue with medication for longer than 12 weeks. Where is the evidence to support this standard? It may or may not be appropriate. If a young person is seriously ill and has an extended period of hospitalisation the costs of relapse may be high and to withdraw well tolerated treatment may not be appropriate.
69	The Royal College of General Practitioners	Statement 6	Secondary care teams should assess the child or young person's physical health and the effects of antipsychotic medication for at least the first 12 months or until their condition has stabilised, whichever is longer. After this, assessments may be transferred to primary care under shared care arrangements and should take place at least annually. [Adapted from Psychosis and schizophrenia in children and young people (NICE guideline CG155) recommendation 1.3.18 (key priority for implementation and 1.7.5 and Bipolar disorder (NICE guideline CG185) recommendation 1.10.9] Most medications for children in this clinical situation are not licensed and therefore GPs wouldn't prescribe usually or have experience in long term monitoring, particularly antipsychotic medication. Even with a shared protocol in place GPs can decline to prescribe if they do not feel it is appropriate. The person prescribing should be ensuring they have access to monitoring this prescribing which may mean additional training. GPs don't usually do ECGs and BPs on children so interpretation of the results could be a problem.
70	The Royal College of General Practitioners	Statement 6	Should we be checking for side effects of medication such as possible impact on cognitive development?
71	The Royal College of	Statement 6	Our previous comments on these guidelines expressed our members' concerns regarding the inconsistent approach

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	Psychiatrists	- Question 6	adopted by the guidelines on psychosis and bipolar disorder in child and adolescent mental health, and we are concerned that there remains a distinction regarding the maintenance use of AAPs between these disorders. Overall, these severe mental illnesses will most likely require long-term treatment, particularly after several relapses. If the presentation completely improves with no residual symptoms after a period of significant stability, then after careful discussion with the family a gradual discontinuation with close monitoring of symptoms may take place. However, given the protracted course and prognosis of bipolar disorder, antipsychotic medication/mood stabilisers will need to be considered for long-term use. This will particularly be the case if the young person has had a number of admissions for bipolar disorder and the illness is associated with high risks which are outweighed by the potential risks of medication. It would be standard clinical practice to prescribe for >12 weeks even during the acute phase of the illness, as often a number of trials of medication are required in order to achieve stabilisation; if the illness has been this protracted, together with a number of relapses and high risks, then it would be negligent not to prescribe maintenance medication in terms of the risk/benefit ratio. Most young people admitted to inpatient units with bipolar disorder would fall into this category and therefore this NICE recommendation cannot be adhered to and the RCPsych cannot support this recommendation and cannot support this quality standard. In addition, this recommendation discriminates against young people with serious bipolar disorder, as treatment could potentially be withheld on the basis of this recommendation, unlike with adults. We are concerned that the guidance has not taken the risks of the illness into consideration when making this recommendation.
72	Department of Health	Statement 6 – Question 6	Prescription of anti-psychotics over the past 12 weeks – this would be a more frequent occurrence for a long term condition and it would last longer than 12 weeks for bipolar and schizophrenia.
73	The Royal College of General Practitioners	Statement 6 – Question 6	This data is not known and is more likely to be available from CAHMS.
74	British Medical Association	Statement 7	We strongly believe that home treatment is always preferable when appropriate and sufficient resources must be in place to ensure its success. However, hospital treatment should remain an available option for those whose condition warrants it or whose circumstances mean that providing care at home is not possible.
75	British Medical Association	Statement 8	We strongly agree with this statement.
76	The British Psychological Society	Statement 8	The Society welcomes the notion that educational plans are an integral part of a recovery phase in a programme of support and are firm believers that Medical Referral Units/Medical education teams in their various guises around the country can offer excellent support to children in crisis. Residential schools with a proven track record in this field can also be vital in offering a 'safe haven' in which a child can recover enough to return home successfully.
77	British Medical Association	Statement 8 – Question 8	A holistic plan must be provided to patients, with a more joined up approach between health and education.

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78	The British Psychological Society	Statement 8 – Question 8	The key area is access and making sure these young people are not discriminated or excluded just because of their mental health condition. Further awareness and training may be needed for education professionals in how best to work with young people with these types of difficulties. Service users need to be supported in retaining current links in education/vocational and occupational roles as much as possible, and returning to their ordinary lives, as identified in the international Early Psychosis declaration in 2002. Practicably the child or young person should be supported by their care coordinator to maintain their previous links and also have access to a vocational worker, occupational therapist or IPS worker, although this is likely to be highly inconsistent due to service changes and cuts. They need to be able to access education and employments as this will contribute to their overall well-being and quality of life (Early Psychosis Declaration, 2002; The Schizophrenia Commission, 2012). The introduction of the new children's act in Scotland should aid the transitions between education and health due to
70	The Devel College of	01-1	having a named person/lead professional to ensure the young person's needs are met.
79	The Royal College of General Practitioners	Statement 8 – Question 8	Support for families and the young person. Continuity of care in primary care, CAHMS services and pharmacy. Family therapy
80	British Medical Association	Statement 9	We agree with this statement.
81	The British Psychological Society	Statement 9	There is no doubt that the role of parents and carers is an essential part of any support package and that child and psychologists have a lot of professional skills to contribute to this therapeutic phase of young people's recovery from crisis. (J.W. Kaminski, et al, 2008)
82	Carers Trust	Statement 9	Comment on the provision of carer-focused education and support – Carers Trust welcomes the promotion of carer education and support, however, recommends that this is not the only means of information and support provided to carers. The Triangle of Care makes clear that information and support along the care pathway is vital as well as referral to independent carers' services to ensure carers are given information and advice on their own rights. Not only should adult carers receive this but young carers (siblings) require this too.
83	The British Psychological Society	References	Cooke, A. (Ed). (2014) <i>Understanding Psychosis and Schizophrenia</i> . Leicester: British Psychological Society
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			Shirreffs, S.M, et al (2007) <i>Milk as an effective post-exercise rehydration drink</i> . British Journal of Nutrition; 98(1) : 173-80.
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			Declaration: http://www.rethink.org/newcastledeclaration

Registered stakeholders who submitted comments at consultation

- Association of School and College Leaders
- Betsi Cadwaladr University Health Board
- British Medical Association
- Carers Trust
- Department of Health
- South London and Maudsley NHS Foundation Trust / King's College London
- Tees ESK and Wear Valley NHS Foundation Trust
- The British Psychological Society
- The International Society for Psychological and Social Approaches to Psychosis- UK
- The Royal College of General Practitioners
- The Royal College of Psychiatrists