NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Bipolar disorder, psychosis and schizophrenia in children and young people

Output: Prioritised quality improvement areas for development.

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1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for bipolar disorder, psychosis and schizophrenia in children and young people. It provides the Committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the Committee in considering potential statements and measures.

1.2 Development source

The key development sources referenced in this briefing paper are:

<u>Bipolar disorder: the assessment and management of bipolar disorder in adults,</u> <u>children and young people in primary and secondary care</u> (2014) NICE clinical guideline 185.

This is an updated guideline that replaces NICE clinical guideline 38 (2006).

<u>Psychosis and schizophrenia in children and young people</u> (2013) NICE clinical guideline 155.

Update not yet scheduled.

2 Overview

2.1 Focus of quality standard

This quality standard will cover the recognition, early intervention and management of bipolar disorder, psychosis and schizophrenia '(including related psychotic disorders such as schizoaffective disorder, schizophreniform disorder and delusional disorder) in children and young people up to the age of 18. It will also include children and young people considered to be at high risk or experiencing early symptoms of bipolar disorder, psychosis or schizophrenia.

2.2 Definition

Bipolar disorder is a potentially lifelong and disabling condition characterised by episodes of mania (abnormally elevated mood or irritability and related symptoms with severe functional impairment or psychotic symptoms for 7 days or more) or hypomania (abnormally elevated mood or irritability and related symptoms with decreased or increased function for 4 days or more) and episodes of depressed mood. It is often comorbid with other disorders such as anxiety disorders, substance misuse, personality disorders and attention deficit hyperactivity disorder (ADHD).

Psychosis and the specific diagnosis of schizophrenia in children and young people represent a major psychiatric disorder, or cluster of disorders that alters a person's perception, thoughts, mood and behaviour. The symptoms of psychosis are usually divided into 'positive symptoms', including hallucinations (perception in the absence of any stimulus) and delusions (fixed or falsely held beliefs), and 'negative symptoms' (such as emotional apathy, lack of drive, poverty of speech, social withdrawal and self-neglect). Children and young people who develop psychosis will have their own unique combination of symptoms and experiences, the precise pattern of which will be influenced by their circumstances and stage of development.

Bipolar disorder, psychosis and schizophrenia are commonly preceded by a socalled prodromal period, in which the child or young person's behaviour and experience are altered. It is important to recognise children and young people at risk of early-onset bipolar, particularly those with recurrent depression, treatmentresistant depression and those with family histories or a hypomanic response to antidepressant treatment. Changes associated with psychosis and schizophrenia in the prodromal period include the emergence of transient and/or attenuated psychotic symptoms, such as hallucinations and/or delusions with associated impaired functioning. More subtly, the child or young person may become socially withdrawn or suspicious, with alterations in expressed feeling. It is important to note that most children and young people with transient or attenuated psychotic symptoms do not go on to develop psychosis or schizophrenia, although those with such symptoms do appear to be at higher risk than other children and young people of developing psychosis and schizophrenia up to 10 years after onset of symptoms.

2.3 Incidence and prevalence

Bipolar disorder in children and young people can be difficult to diagnose because of the nature of its presentation and complex comorbidities, for example, with attention deficit hyperactivity disorder. Data is limited but one study in the USA found the combined prevalence of bipolar I and II disorder in 13- to 18-year- olds to be 2.9%. The peak age of onset of bipolar disorder is 15–19 years, and there is often a substantial delay between onset and first contact with mental health services. Bipolar disorder in children under 12 years is very rare.

Bipolar disorder is associated with very high levels of need for mental health and physical health services, personal social, educational and occupational impairment and a high risk of suicide.

The prevalence of psychotic disorders in children aged between 5 and 18 years has been estimated to be 0.4% (the figure across all ages and populations in the UK is 0.7%). Schizophrenia accounts for 24.5% of all psychiatric admissions in young people aged 10–18 years (the overall admission rate is 0.46 per 1000 for this age range), with an exponential rise across the adolescent years. The rise in incidence increases most from age 15 onwards.

There is a worse prognosis for psychosis and schizophrenia when onset is in childhood or adolescence. Although about one-fifth of children and young people with schizophrenia have a good outcome with only mild impairment, one-third have severe impairment that needs intensive social and psychiatric support.

Psychosis and schizophrenia are associated with disabling psychotic symptoms, adverse effects of drug treatments, including poor physical health, and stigma. Impairment can affect a child or young person's psychological, social and educational development and functioning, placing a heavy burden on them and their parents and carers.

2.4 Management

The process of care and provision of treatment for children and young people with bipolar disorder, psychosis and schizophrenia in England and Wales is through the four-tier model of child and adolescent mental health services (CAMHS). Tier 1 and 2 are primarily community-based and are likely to be the first point of contact with the child or young person presenting with a mental health problem. An important role at this level is to detect those at high risk. Children and young people suspected of developing, or having, bipolar disorder, psychosis or schizophrenia are usually referred for a diagnostic evaluation and treatment in CAMHS tier 3, specialist secondary care services. If children and young people are at risk of harm to themselves or others they may be referred to highly specialised tier 4 CAMHS inpatient, day patient or outpatient settings. Following tier 4 intervention, young people are usually discharged to tier 3 CAMHS.

Early intervention in psychosis services provide people aged 14–35 years with a more intensive therapeutic service than traditional community services. They are designed to intervene early, and deliver support and evidence-based interventions in a 'normalising' environment for the first 3 years after onset of psychosis.

There is geographical variation in the configuration and integration of CAMHS and early intervention in psychosis services, and in the provision and integration of other services for children and young people with severe mental illness, including education, employment and rehabilitation, and social services. In particular, provision for the needs of 16- and 17-year-olds can be fragmented and inadequate and they can experience difficulties in gaining access to appropriate accommodation and vocational or occupational support and rehabilitation.

Antipsychotic medication may be used for a limited period during episodes of mania or hypomania in young people with bipolar disorder and psychological interventions are offered to those with bipolar depression. If the young person's bipolar depression is moderate or severe, a pharmacological intervention may also be used.

Although the mainstay of treatment for psychosis and schizophrenia has been antipsychotic medication, there is limited evidence of its efficacy in children and young people. There are also concerns that children and young people are more sensitive than adults to the potential adverse effects of antipsychotics, including weight gain, metabolic effects and movement disorders. A number of psychological interventions, including family intervention, cognitive behavioural therapy (CBT) and arts therapies, have been used but evidence of efficacy is currently unavailable in children and young people and provision of these therapies for children and young people and for adults is variable.

2.5 National Outcome Frameworks

Tables 1 and 2 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

Domain	Overarching indicators and improvement areas
1 Preventing people from	Overarching indicator
dying prematurely	1a Potential Years of Life Lost (PYLL) from causes considered amenable to healthcare
	i Adults ii Children and young people
	Improvement areas
	Reducing premature death in people with serious mental illness
	1.5i Excess under 75 mortality rate in adults with serious mental illness* (PHOF 4.9)
	iii Suicide and mortality from injury of undetermined intent among people with recent contact from NHS services (PHOF 4.10**)
2 Enhancing quality of life for	Improvement areas
people with long-term	Enhancing quality of life for carers
conditions	2.4 Health-related quality of life for carers*** (ASCOF 1D)
	Enhancing quality of life for people with mental illness
	2.5i Employment of people with mental illness**** (ASCOF 1F & PHOF 1.8)
	<i>ii Health-related quality of life for people with mental illness****</i> (ASCOF 1A & PHOF 1.6)
3 Helping people to recover	Improvement area
from episodes of ill health or	Improving outcomes from planned treatments
following injury	3.1 Total health gain as assessed by patients for elective procedures
	ii Psychological therapies
	iii recovery in quality of life for patients with mental illness

Table 1 NHS Outcomes Framework 2015–16

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**** Indicator complementary with Adult Social Care Outcomes Framework (ASCOF) and Public Health Outcomes Framework (PHOF)			
Indicators in italics are in development			

Domain	Objectives and indicators	
1 Improving the wider	Objective	
	Improvements against wider factors which affect health and wellbeing and health inequalities	
	Indicators	
	1.3 Pupil absence	
	1.5 16-18 year olds not in education, employment or training	
2 Health improvement	Objective	
	People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities	
	Indicators	
	2.9 Smoking prevalence – 15 year olds (Placeholder)	
	2.10 Self-harm	
4 Healthcare public health and	Objective	
preventing premature mortality	Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities	
	Indicators	
	4.3 Mortality rate from causes considered preventable** (NHSOF 1a)	
	4.9 Excess under 75 mortality rate in adults with serious mental illness* (NHSOF 1.5)	
	4.10 Suicide rate	
Alignment across the health and social care system		
* Indicator shared with NHS Outcomes Framework (NHSOF)		
** Indicator complementary with NHS Outcomes Framework (NHSOF)		
Indicator in italics is in development		

Table 2 Public health outcomes framework for England, 2013–2016

3 Summary of suggestions

3.1 Responses

In total 7 stakeholders and 3 Specialist Committee Members responded to the 2week engagement exercise 15/12/2014 to 8/1/2015.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 3 for further consideration by the Committee.

NHS England's patient safety division did not submit any data for this topic.

Full details of all the suggestions provided are given in appendix 2 for information.

Suggested area for improvement	Stakeholders
 Possible bipolar disorder or psychosis Detection Early referral Children and young people with learning disabilities 	HDUHB HDUHB RCPCH
TreatmentPsychological and psychosocial interventionsMonitoring and review of pharmacological treatment	SCMs SCMs
 Hospital care Avoid hospital admissions Appropriate hospital environment 	SCM SCM, HDUHB
 Physical health Monitoring Physical health programmes 	SCMs, RCP SCM
 Promoting recovery Educational, training and occupational provision 	RCP, HDUHB, SCM
 General principles of care Care planning Support for carers 	SCM SCM
 Additional areas Tests for fatty acids & Vitamin D Reflect differences in treatment for bipolar disorder 	HQT LCNFT
HDUHB - Hywel Dda University Health Board HQT - HQT Diagnostics LCNFT - Lancashire Care NHS Foundation Trust RCP - Royal College of Psychiatrists RCPCH - Royal College of Paediatrics and Child Health SCM – Specialist Committee Member	

Table 3 Summary of suggested quality improvement areas

4 Suggested improvement areas

4.1 Possible bipolar disorder or psychosis

4.1.1 Summary of suggestions

Detection

The early detection of psychosis was highlighted as a priority as early intervention can improve a young person's prognosis and future outcomes. It was suggested that there needs to be a wider awareness of an At Risk Mental State (ARMS) and actions to take if there are concerns across a wide range of organisations including primary care, schools and the voluntary sector.

Early referral

Early referral of young people with possible bipolar disorder or psychosis to appropriate mental health services was highlighted as a priority to reduce the duration of untreated psychosis and improve prognosis and outcomes.

Early diagnosis of children and young people with learning disabilities

It was suggested that there should be more focus on the early diagnosis of psychosis in children and young people with a learning disability as it can be more difficult to recognise due to more limited communication skills.

4.1.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 4 to help inform the Committee's discussion.

Suggested quality improvement area	Suggested source guidance recommendations
Detection	Not directly covered in NICE CG155 or CG185 and no recommendations are presented.
Early referral	Possible psychosis
	NICE CG155 Recommendations 1.2.1 (KPI)
	First episode psychosis
	NICE CG155 Recommendations 1.3.1 (KPI)
	Recognising, diagnosing and managing

Table 4 Specific areas for quality improvement

	bipolar disorder in children and young people NICE CG185 Recommendations 1.11.2, and 1.11.3
Early diagnosis of children and young people with learning disabilities	Care for adults, children and young people across all phases of bipolar disorder NICE CG185 Recommendation 1.1.5

Possible psychosis

NICE CG155 - Recommendation 1.2.1 (KPI)

When a child or young person experiences transient or attenuated psychotic symptoms or other experiences suggestive of possible psychosis, refer for assessment without delay to a specialist mental health service such as CAMHS or an early intervention in psychosis service (14 years or over).

First episode psychosis

NICE CG155 - Recommendation 1.3.1 (KPI)

Urgently refer all children and young people with a first presentation of sustained psychotic symptoms (lasting 4 weeks or more) to a specialist mental health service, either CAMHS (up to 17 years) or an early intervention in psychosis service (14 years or over), which includes a consultant psychiatrist with training in child and adolescent mental health.

Recognising, diagnosing and managing bipolar disorder in children and young people

NICE CG185 - Recommendation 1.11.2

If bipolar disorder is suspected in primary care in children or young people aged under 14 years, refer them to child and adolescent mental health services (CAMHS).

NICE CG185 – Recommendation 1.11.3

If bipolar disorder is suspected in primary care in young people aged 14 years or over, refer them to a specialist early intervention in psychosis service or a CAMHS team with expertise in the assessment and management of bipolar disorder in line with the recommendations in this guideline. The service should be multidisciplinary and have:

- engagement or assertive outreach approaches
- family involvement and family intervention
- access to structured psychological interventions and psychologically informed care

- vocational and educational interventions
- access to pharmacological interventions
- professionals who are trained and competent in working with young people with bipolar disorder.

Care for adults, children and young people across all phases of bipolar disorder

NICE CG185 – Recommendation 1.1.5

Ensure that people with bipolar disorder and a coexisting learning disability are offered the same range of treatments and services as other people with bipolar disorder.

4.1.3 Current UK practice

Detection

A House of Commons Health Committee report on Children's and adolescents' mental health and CAMHS¹ concluded that despite evidence of the importance of early intervention services in preventing mental health problems from developing or escalating, there has been significant disinvestment in these services including those delivered by voluntary sector organisations. Where they have been able to sustain services, some voluntary sector organisations report very fragile funding arrangements and great uncertainty over their future sustainability, despite evidence of growing demand for their services.

The Health Committee report also concluded that while there are many examples of good practice, where schools are able to act as a central 'hub' for the wider community based mental health provision, as well as providing support themselves, this is not happening universally. Young people felt that although some teachers and schools provide excellent support, others seem less knowledgeable or well trained, and can even seem 'scared' of discussing mental health issues. The need for better support and training for teachers about mental health was raised by many of those who gave evidence to the inquiry.

Early referral

A qualitative study of experiences of the onset of psychosis² concluded that there are multiple barriers to prompt treatment which includes unhelpful service responses. Participants in this study typically reported significant service delays in pathways to care once help-seeking had been initiated. In this sample, these mostly related to the

¹ <u>Children's and adolescents' mental health and CAMHS</u>. House of Commons Health Committee. Third report of session 2014-15.

² Service user and carer experiences of seeking help for a first episode of psychosis: A UK qualitative study. Tanskanen et al. BMC Psychiatry 2011 11:57.

response of GPs and primary care, rather than secondary mental health services. It was acknowledged, however, that problems of recognition of psychosis can mean that GP's are presented with vague, or physical rather than mental symptoms which may illustrate why it is difficult for them to identify early psychosis.

The Health Committee inquiry report³ indicated that many GPs currently feel illequipped and lacking in confidence in dealing with children and young people's mental health problems, and that their current training does not prepare them adequately for this.

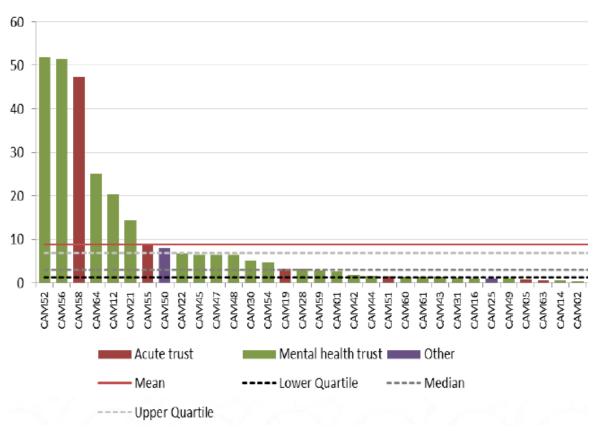
Analysis of data from a national cohort study site in Birmingham⁴ concluded that the greatest contribution to duration of untreated psychosis (DUP) came from delays experienced within mental health services. Care pathways which involved generic Community Mental Health Teams were associated with longer DUP due to inadequate engagement of young people with psychosis within services. Care pathways involving direct access to early intervention services led to much reduced DUP.

The Health Committee inquiry reported increased demand for CAMHS tier 3 outpatient specialist services which has led to increased referral thresholds in order to prioritise those with the highest level of need and long waits to access services. It is important to note that these findings apply generally across the CAMHS tier 3 services and there was no specific evidence in this report about referrals for children with possible bipolar disorder or psychosis.

The CAMHS benchmarking report 2013 indicated that maximum waiting time for emergency specialist CAMHS appointments averaged 3 weeks across participating providers with considerable variation from 0 to 50+ weeks. The report concluded that the 3-week median confirms that many CAMHS services can offer rapid access to appointments although 3 weeks waiting time for an emergency appointment is a lengthy wait for a service user with urgent needs. This information is not specific to children and young people with suspected bipolar disorder or psychosis.

³ <u>Children's and adolescents' mental health and CAMHS</u>. House of Commons Health Committee. Third report of session 2014-15.

⁴ <u>Reducing DUP in first-episode psychosis requires a detailed understanding of care pathways in community and mental health service settings: data from Birmingham, UK</u>. Connor et al. Early Intervention in Psychiatry 2012; 6 (Suppl.1): 1-19.



Maximum waiting time in weeks for emergency appointment

Early diagnosis of children and young people with learning disabilities

No published studies on current practice were highlighted for this suggested area for quality improvement. This area is based on stakeholder's knowledge and experience.

4.2 Treatment

4.2.1 Summary of suggestions

Psychological and psychosocial interventions

Stakeholders suggested that psychological and psychosocial interventions including cognitive behavioural therapy and family interventions should be offered to children and young people with bipolar disorder or psychosis in conjunction with antipsychotic medication as they can improve outcomes. It was suggested that these treatment options should be available from the onset of the illness as well as in the longer term. It was noted, however, that there is a current lack of evidence to support the use of these treatment options in children and young people.

Monitoring and review of pharmacological treatment

It was suggested there is a need to improve monitoring of the effects of antipsychotic medication, including both therapeutic effects and side effects. This will ensure medication is adjusted as required and will help to minimise side effects. As antipsychotic medication may exacerbate weight gain and metabolic disturbances, it is particularly important that physical health is monitored in young people who are taking medication for the first time.

4.2.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 5 to help inform the Committee's discussion.

Suggested quality improvement area	Selected source guidance recommendations
Psychological and psychosocial	Possible psychosis
interventions	NICE CG155 Recommendation 1.2.5 (KPI)
	First episode psychosis
	NICE CG155 Recommendations 1.3.11 and 1.3.12 (KPI)
	Subsequent acute episodes of psychosis or schizophrenia
	NICE CG155 Recommendations 1.4.1, 1.4.4 (KPI), and 1.4.5
	Promoting recovery and providing possible future care in secondary care
	NICE CG155 Recommendations 1.8.2, 1.8.3, and 1.8.4
	Recognising, diagnosing and managing bipolar disorder in children and young people
	NICE CG185 Recommendations 1.11.11 (KPI)
Monitoring and review of	First episode psychosis
pharmacological treatment	NICE CG155 Recommendation 1.3.15 (KPI), 1.3.16, 1.3.18 (KPI), and 1.3.25
	Subsequent acute episodes of psychosis or schizophrenia
	NICE CG155 Recommendation 1.4.2
	Recognising, diagnosing and managing bipolar disorder in children and young people
	NICE CG185 Recommendations 1.11.9 (KPI) and 1.11.15
	How to use medication
	NICE CG185 Recommendations 1.10.6, 1.10.8, 1.10.9, 1.10.10, and 1.10.11

Table 5 Specific areas for quality improvement

Psychological and psychosocial interventions

First episode psychosis

NICE CG155 Recommendation 1.3.11

For children and young people with first episode psychosis offer:

• oral antipsychotic medication(see recommendations 1.3.14–1.3.25) in conjunction with

• psychological interventions (family intervention with individual CBT, delivered as set out in recommendations 1.3.26–1.3.32).

NICE CG155 Recommendation 1.3.12 (KPI)

If the child or young person and their parents or carers wish to try psychological interventions (family intervention with individual CBT) alone without antipsychotic medication, advise that psychological interventions are more effective when delivered in conjunction with antipsychotic medication. If the child or young person and their parents or carers still wish to try psychological interventions alone, then offer family intervention with individual CBT. Agree a time limit (1 month or less) for reviewing treatment options, including introducing antipsychotic medication. Continue to monitor symptoms, level of distress, impairment and level of functioning, including educational engagement and achievement, regularly.

Subsequent acute episodes of psychosis or schizophrenia

NICE CG155 Recommendation 1.4.1

For children and young people with an acute exacerbation or recurrence of psychosis or schizophrenia offer:

- oral antipsychotic medication in conjunction with
- psychological interventions (family intervention with individual CBT).

NICE CG155 Recommendation 1.4.4 (KPI)

Offer family intervention (delivered as set out in recommendation 1.3.27) to all families of children and young people with psychosis or schizophrenia, particularly for preventing and reducing relapse. This can be started either during the acute phase or later, including in inpatient settings.

NICE CG155 Recommendation 1.4.5

Offer CBT (delivered as set out in recommendation 1.3.28) to all children and young people with psychosis or schizophrenia, particularly for symptom reduction. This can be started either during the acute phase or later, including in inpatient settings.

Promoting recovery and providing possible future care in secondary care

NICE CG155 Recommendation 1.8.2

Offer family intervention to families of children and young people with psychosis or schizophrenia to promote recovery. Deliver family intervention as described in recommendation 1.3.27.

NICE CG155 Recommendation 1.8.3

Consider family intervention particularly for families of children and young people with psychosis or schizophrenia who have:

- recently relapsed or are at risk of relapse
- persisting symptoms

NICE CG155 Recommendation 1.8.4

Offer CBT to assist in promoting recovery in children and young people with persisting positive and negative symptoms and for those in remission. Deliver CBT as described in recommendation 1.3.28.

Recognising, diagnosing and managing bipolar disorder in children and young people

NICE CG185 Recommendation 1.11.11 (KPI)

Offer a structured psychological intervention (individual cognitive behavioural therapy or interpersonal therapy) to young people with bipolar depression. The intervention should be of at least 3 months' duration and have a published evidence-based manual describing how it should be delivered.

Monitoring and review of pharmacological treatment

First episode psychosis

NICE CG155 Recommendation 1.3.15 (KPI)

Before starting antipsychotic medication, undertake and record the following baseline investigations:

- weight and height (both plotted on a growth chart)
- waist and hip circumference
- pulse and blood pressure
- fasting blood glucose, glycosylated haemoglobin (HbA1c), blood lipid profile and prolactin levels
- assessment of any movement disorders
- assessment of nutritional status, diet and level of physical activity.

NICE CG155 Recommendation 1.3.16

Before starting antipsychotic medication, offer the child or young person an electrocardiogram (ECG) if:

- specified in the SPC for adults and/or children
- a physical examination has identified specific cardiovascular risk (such as diagnosis of high blood pressure)

- there is a personal history of cardiovascular disease
- there is a family history of cardiovascular disease such as premature sudden cardiac death or prolonged QT interval, or the child or young person is being admitted as an inpatient.

NICE CG155 Recommendation 1.3.18 (KPI)

Monitor and record the following regularly and systematically throughout treatment, but especially during titration:

- efficacy, including changes in symptoms and behaviour
- side effects of treatment, taking into account overlap between certain side effects and clinical features of schizophrenia (for example, the overlap between akathisia and agitation or anxiety)
- the emergence of movement disorders
- weight, weekly for the first 6 weeks, then at 12 weeks and then every 6 months (plotted on a growth chart)
- height every 6 months (plotted on a growth chart)
- waist and hip circumference every 6 months (plotted on a percentile chart)
- pulse and blood pressure (plotted on a percentile chart) at 12 weeks and then every 6 months
- fasting blood glucose, HbA1c, blood lipid and prolactin levels at 12 weeks and then every 6 months
- adherence
- physical health.

The secondary care team should maintain responsibility for monitoring physical health and the effects of antipsychotic medication in children and young people for at least the first 12 months or until their condition has stabilised. Thereafter, the responsibility for this monitoring may be transferred to primary care under shared care arrangements.

NICE CG155 Recommendation 1.3.25

Review antipsychotic medication annually, including observed benefits and any side effects

Subsequent acute episodes of psychosis or schizophrenia

NICE CG155 Recommendation 1.4.2

For children or young people with an acute exacerbation or recurrence of psychosis or schizophrenia, offer oral antipsychotic medication or review existing medication. The choice of drug should be influenced by the same criteria recommended for starting treatment (see recommendations 1.3.14–1.3.25). Take into account the

clinical response to and side effects associated with current and previous medication, and monitor as described in recommendation 1.3.18.

Recognising, diagnosing and managing bipolar disorder in children and young people

NICE CG185 Recommendation 1.11.9 (KPI)

To treat mania or hypomania in young people see NICE's technology appraisal guidance on aripiprazole for treating moderate to severe manic episodes in adolescents with bipolar I disorder and also consider the recommendations for adults in section 1.5. Refer to the BNF for children to modify drug treatments, be aware of the increased potential for a range of side effects, and do not routinely continue antipsychotic treatment for longer than 12 weeks.

NICE CG185 Recommendation 1.11.15

If the young person's bipolar depression is moderate to severe, consider a pharmacological intervention in addition to a psychological intervention. Follow the recommendations for pharmacological interventions for adults in section 1.6 but refer to the BNF for children to modify drug treatments, and do not routinely continue antipsychotic treatment for longer than 12 weeks. At 12 weeks, carry out a full multidisciplinary review of mental and physical health, and consider further management of depression or long-term management.

How to use medication

NICE CG185 Recommendation 1.10.6

Before starting antipsychotic medication, offer the person an electrocardiogram (ECG) if:

- it is specified in the drug's summary of product characteristics (SPC) or
- a physical examination has identified a specific cardiovascular risk (such as hypertension) or
- there is a family history of cardiovascular disease, a history of sudden collapse, or other cardiovascular risk factors such as cardiac arrhythmia or
- the person is being admitted as an inpatient.

NICE CG185 Recommendation 1.10.8

Monitor and record the following during dose titration and then regularly and systematically throughout treatment:

- pulse and blood pressure after each dose change
- weight or BMI weekly for the first 6 weeks, then at 12 weeks

- blood glucose or HbA1c and blood lipid profile at 12 weeks
- response to treatment, including changes in symptoms and behaviour
- side effects and their impact on physical health and functioning
- the emergence of movement disorders
- adherence

NICE CG185 Recommendation 1.10.9

The secondary care team should maintain responsibility for monitoring the efficacy and tolerability of antipsychotic medication for at least the first 12 months or until the person's condition has stabilised, whichever is longer. Thereafter, the responsibility for this monitoring may be transferred to primary care under shared-care arrangements.

NICE CG185 Recommendation 1.10.10

If out-of-range test results are reported at any stage of treatment, the healthcare professional who ordered the tests should ensure that the person is offered further investigations and treatment as needed.

NICE CG185 Recommendation 1.10.11

'As required' (p.r.n.) prescriptions of antipsychotic medication should be made as described in recommendation 1.10.7. Review clinical indications, frequency of administration, therapeutic benefits and side effects each week or more often if needed. Ensure that p.r.n. prescriptions have not unintentionally led to a total antipsychotic dosage above the maximum specified in the BNF or SPC.

4.2.3 Current UK practice

Psychological and psychosocial interventions

The Children and Young People's Improving Access to Psychological Therapies programme (CYP IAPT) is a service transformation programme delivered by NHS England which began in 2011 and has a target to work with CAMHS that cover 60% of the 0-19 population by March 2015.

A report by the We need to talk coalition⁵ indicates that despite the progress of the children and young people's IAPT project, many children and young people are waiting for long periods to receive access to psychological therapy, citing evidence based on the escalation of calls to the Young Minds parents helpline since 2008. The report also raises concerns about the availability of psychological therapies for people with severe mental illness, although the evidence is based on a survey of adults and the National Audit of Schizophrenia (adults).

⁵ We still need to talk: a report on access to talking therapies. We need to talk coalition (2013).

Release of the Child and Adolescent Mental Health Services data⁶ has been delaved and therefore national data on access to psychological therapies is not currently available.

Monitoring and review of pharmacological treatment

An audit of physical health monitoring of young people on antipsychotic medication in the Newcastle early interventions service⁷ concluded that young people receiving antipsychotic medication were not being monitored in accordance with Trust's recommendations. Only 55% received baseline monitoring. During the treatment continuation phase, 82% adhered to the recommended annual blood tests, but physical examinations, drug screens and ECGs were not done. At the annual psychiatric reviews, only 64% of young people had physical monitoring requests sent to primary care. It is important to note that this study is based on a small sample of young people.

Further information is available in the confidential Prescribing Observatory for Mental Health 2014 audit report on 'Prescribing antipsychotics for children and adolescents' and will be shared with the Committee.

 ⁶ Child and Adolescent Mental Health Services Data Set, HSCIC
 ⁷ Physical health monitoring of young people on antipsychotic medication in the newcastle early interventions (EIP) service. George and Ward European Psychiatry vol 27, Sup 1 2012.

4.3 Hospital care

4.3.1 Summary of suggestions

Avoid hospital admissions

As hospital admissions are very traumatic for the child or young person and their family it was suggested that hospital admissions should be avoided by providing timely and cost-effective support.

Appropriate hospital environment

If a hospital admission is necessary it is important that care is provided in an environment that is suitable for children and young people. There was concern that some children and young people are being admitted to adult wards or to in-patient units a long way from their home. This can be a very traumatic experience.

4.3.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 6 to help inform the Committee's discussion.

Suggested quality improvement area	Selected source guidance recommendations
Avoid hospital admissions	Referral in crisis and challenging behaviour
	NICE CG155 Recommendations 1.5.2, and 1.5.7 (KPI)
Appropriate hospital environment	Referral in crisis and challenging behaviour
	NICE CG155 Recommendation 1.5.6

Table 6 Specific areas for quality improvement

Referral in crisis and challenging behaviour

NICE CG155 Recommendation 1.5.2

To avoid admission, aim to:

- explore with the child or young person and their parents or carers what support systems they have, including other family members and friends
- support a child or young person in crisis and their parents or carers in their home environment

• make early plans to help the child or young person maintain their day-to-day activities, including education, work, voluntary work, and other occupations and leisure activities, wherever possible.

NICE CG155 Recommendation 1.5.6

If a child or young person needs hospital care, this should be in a setting appropriate to their age and developmental level.

NICE CG155 Recommendation 1.5.7 (KPI)

Before referral for hospital care, think about the impact on the child or young person and their parents, carers and other family members, especially when the inpatient unit is a long way from where they live. Consider alternative care within the community wherever possible. If hospital admission is unavoidable, provide support for parents or carers when the child or young person is admitted.

4.3.3 Current UK practice

Avoid hospital admissions

The Health Committee inquiry into Children's and adolescents' mental health and CAMHS⁸ highlighted the importance of intensive services provided in the community that act as a bridge between inpatient services and community services, with the aim of preventing the need for an admission, or facilitating more swift discharge back to the community. The inquiry concluded, however, that the availability of such services is extremely variable and that the experience of care reported by young people suffering a mental health crisis remains extremely negative due to inadequate crisis support.

Appropriate hospital environment

The House of Commons Health Committee report concluded that it is clear that there are major problems with access to Tier 4 inpatient services, with children and young people's safety being compromised while they wait, suffering from severe mental health problems, for an inpatient bed to become available. In some cases they need to wait at home, in other cases in a general paediatric ward, or even in some instances in an adult psychiatric ward or a police cell. Often when beds are found they may be in distant parts of the country, making contact with family and friends difficult, and leading to longer stays. The Committee was particularly concerned about the practice of taking children and young people detained under s136 of the Mental Health Act to police cells, with very few mental health trusts providing a dedicated place of safety for children and young people.

⁸ <u>Children's and adolescents' mental health and CAMHS</u>. House of Commons Health Committee. Third report of session 2014-15.

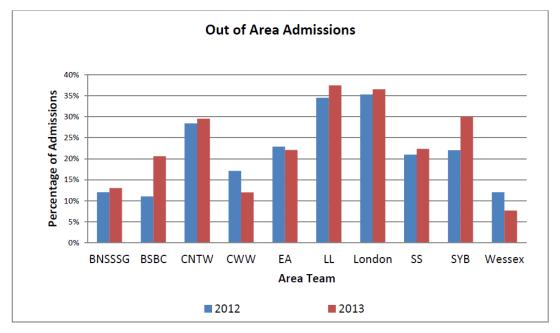
An NHS England report on CAMHS Tier 4⁹ inpatient provision concluded that there is a reasonable distribution of adolescent units around major centres of population but units for under 13's and sub speciality units are less evenly distributed. The map below shows there are areas of England without any local provision, notably the South West, as well as areas with a relative lack of capacity for example Yorkshire and Humber.



⁹ ⁹Child and Adolescent Mental Health Services (CAMHS) Tier 4 Report. NHS England. July 2014

The Health Committee report¹⁰ also indicated concerns relating to quality in some inpatient services including evidence from NHS England that over the previous year some inpatient services were closed owing to quality concerns.

A survey of CAMHS Tier 4 inpatient providers¹¹ asked them to identify for 2012 and 2013 the number of admissions out- of -area, defined as "admissions deemed to be placements where young people are harmed by the distance and disconnection from local services, family and friends". The chart below shows an increasing and high proportion of out of area admissions in some areas in England.



Key

Area Team	Abbreviation
Bristol, North Somerset, Somerset and South Gloucestershire	BNSSSG
Birmingham, Solihull and Black Country	BSBC
Cumbria, Northumberland, Tyne & Wear	CNTW
Cheshire, Warrington & Wirral	CWW
East Anglia	EA
Leicestershire and Lincolnshire	LL
Surrey and Sussex	SS
South Yorkshire and Bassetlaw	SYB

¹⁰ <u>Children's and adolescents' mental health and CAMHS</u>. House of Commons Health Committee. Third report of session 2014-15.

¹¹ Child and Adolescent Mental Health Services (CAMHS) Tier 4 Report. NHS England. July 2014

4.4 Physical health

4.4.1 Summary of suggestions

Monitoring physical health

Stakeholders suggested that physical health monitoring is important to identify and treat at the earliest opportunity those at high cardiovascular and metabolic risk. There was a concern that the responsibility for monitoring physical health can get lost between primary and secondary care.

Physical health programmes

It was suggested that there should be a more proactive approach to promoting good physical health in children and young people with bipolar disorder or psychosis including combined healthy eating and physical activity programmes, and help to stop smoking.

4.4.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 7 to help inform the Committee's discussion.

Suggested quality improvement area	Selected source guidance recommendations
Monitoring physical health	First episode psychosis
	NICE CG155 Recommendation 1.3.4
	Promoting recovery and providing possible future care in primary care
	NICE CG155 Recommendations 1.7.1, 1.7.2, 1.7.3, and 1.7.5
	Monitoring physical health in secondary care
	NICE CG185 Recommendation 1.8.4
Physical health programmes	First episode psychosis
	NICE CG155 Recommendation 1.3.6
	Referral in crisis and challenging behaviour
	NICE CG155 Recommendation 1.5.13
	Monitoring physical health in secondary care
	NICE CG185 Recommendations 1.8.2

Table 7 Specific areas for quality improvement

First episode psychosis

NICE CG155 Recommendation 1.3.4

Ensure that children and young people with first episode psychosis receive a comprehensive multidisciplinary assessment. The assessment should address the following domains:

• physical health and wellbeing (including weight and height, and information about smoking, diet and exercise, and sexual health).

NICE CG155 Recommendation 1.3.6

Develop a care plan with the parents or carers of younger children, or jointly with the young person and their parents or carers, as soon as possible, and:

• include activities that promote physical health and social inclusion, especially education, but also employment, volunteering and other occupations such as leisure activities.

Referral in crisis and challenging behaviour

NICE CG155 Recommendation 1.5.13

Promote good physical health, including healthy eating, exercise and smoking cessation.

Promoting recovery and providing possible future care in primary care

NICE CG155 Recommendation 1.7.1

Develop and use practice case registers to monitor the physical and mental health of children and young people with psychosis or schizophrenia in primary care.

NICE CG155 Recommendation 1.7.2

GPs and other primary healthcare professionals should monitor the physical health of children and young people with psychosis or schizophrenia at least once a year. They should bear in mind that people with schizophrenia are at higher risk of cardiovascular disease than the general population.

NICE CG155 Recommendation 1.7.3

Identify children and young people with psychosis or schizophrenia who smoke or who have high blood pressure, raised lipid levels or increased waist measurement at the earliest opportunity and monitor for the emergence of cardiovascular disease and diabetes.

NICE CG155 Recommendation 1.7.5

Healthcare professionals in secondary care should ensure, as part of the care programme approach (CPA) in England and care and treatment plans in Wales, that children and young people with psychosis or schizophrenia receive physical healthcare from primary care as described in recommendations 1.7.2–1.7.4. Healthcare professionals in secondary care should continue to maintain responsibility for monitoring and managing any side effects of antipsychotic medication.

Monitoring physical health in secondary care

NICE CG185 Recommendation 1.8.2

People with bipolar disorder, especially those taking antipsychotics and long-term medication, should be offered a combined healthy eating and physical activity programme by their mental healthcare provider.

NICE CG185 Recommendation 1.8.4

Routinely monitor weight and cardiovascular and metabolic indicators of morbidity in people with bipolar disorder. These should be audited in the annual team report.

4.4.3 Current UK practice

Monitoring physical health

A longitudinal qualitative study of young people's views of moving on from early intervention services for psychosis at 5 sites across England¹² found that most young people had not then seen their GP or used primary care during the 3 years they were in contact with the early intervention service. This appeared to be related to the intensity of support from early intervention services, which meant that service users felt little need to use primary care. Even though some young people in the sample had experienced significant physical health comorbidities such as obesity, diabetes, or heart disease there was little recognition from the majority of service users of the potential physical health problems in store or of the need to actively address them with their GP. Discussions about physical health were noticeably absent both during contact with early intervention services and after discharge.

Physical health programmes

No published studies on current practice were highlighted for this suggested area for quality improvement. This area is based on stakeholder's knowledge and experience.

¹² <u>Service users' views of moving on from early intervention services for psychosis: a longitudinal gualitative study in primary care.</u> Lester et al. British Journal of General Practice (March, 2012).

4.5 Promoting recovery

4.5.1 Summary of suggestions

Educational, training and occupational provision

Stakeholders suggested that there is currently inconsistent educational /training /occupational provision for children and young people with psychosis, schizophrenia or bipolar disorder, with a more joined up approach across key organisations needed. This is a priority because it will improve academic and social development and overall life chances.

4.5.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 8 to help inform the Committee's discussion.

Suggested quality improvement area	Selected source guidance recommendations
Educational, training and occupational	General principles of care
provision	NICE CG155 Recommendation 1.1.5
	First episode psychosis
	NICE CG155 Recommendation 1.3.9
	Referral in crisis and challenging behaviour
	NICE CG155 Recommendation 1.5.10
	Promoting recovery and providing possible future care in secondary care
	NICE CG155 Recommendations 1.8.11 (KPI), 1.8.12, 1.8.13, 1.8.14 and 1.8.15
	Promoting recovery and return to primary care
	NICE CG185 Recommendation 1.9.6

Table 8 Specific areas for quality improvement

General principles of care

NICE CG155 Recommendation 1.1.5

Help the child or young person to continue their education. Contact the school or college, subject to consent, to ask for additional educational support if their performance has been affected by their condition.

First episode psychosis

NICE CG155 Recommendation 1.3.9

For children and young people with first episode psychosis who are unable to attend mainstream school or college, facilitate alternative educational input in line with their capacity to engage with educational activity and according to their individual needs, with an ultimate goal of returning to mainstream education, training or employment.

Referral in crisis and challenging behaviour

NICE CG155 Recommendation 1.5.10

Ensure that children and young people of compulsory school age have access to a full educational programme while in hospital. The programme should meet the National Curriculum, be matched to the child or young person's developmental level and educational attainment, and should take account of their illness and degree of impairment.

Promoting recovery and providing possible future care in secondary care

NICE CG155 Recommendation 1.8.11 (KPI)

For children and young people of compulsory school age, liaise with the child or young person's school and educational authority, subject to consent, to ensure that ongoing education is provided.

NICE CG155 Recommendation 1.8.12

Liaise with the child or young person's school and with their parents or carers, subject to consent, to determine whether a special educational needs assessment is necessary. If it is agreed that this is needed, explain to parents or carers how to apply for an assessment and offer support throughout the process.

NICE CG155 Recommendation 1.8.13

Provide supported employment programmes for those young people with psychosis or schizophrenia above compulsory school age who wish to return to work or find employment. Consider other work-related activities and programmes when individuals are unable to work or are unsuccessful in their attempts to find employment.

NICE CG155 Recommendation 1.8.14

Mental health services should work in partnership with local stakeholders, including those representing black and minority ethnic groups, to enable young people with psychosis or schizophrenia to access local employment and educational opportunities. This should be sensitive to the young person's needs and skill level and is likely to involve working with agencies such as Jobcentre Plus, disability employment advisers and non-statutory providers.

NICE CG155 Recommendation 1.8.15

Routinely record the daytime activities of children and young people with psychosis or schizophrenia in their care plans, including educational and occupational outcomes.

Promoting recovery and return to primary care

NICE CG185 Recommendation 1.9.6

Offer supported employment programmes to people with bipolar disorder in primary or secondary care who wish to find or return to work. Consider other occupational or educational activities, including pre-vocational training, for people who are unable to work or unsuccessful in finding employment.

4.5.3 Current UK practice

Educational, training and occupational provision

The Health Committee report on CAMHS¹³ highlighted poor educational provision in Tier 4 services as a particular concern. Young people indicated that there was not enough time spent on education in Tier 4 inpatient units, and also that the quality of it was poor.

An OFSTED report¹⁴ of an inspection of education provision for children and young people who do not, or cannot, attend full-time school education in the usual way, including, amongst other groups, those who have mental health needs concluded that (based on a sample of 15 local authorities):

"In too many of the local areas visited, provision was not flexible enough so that some children and young people had only a few hours of education each week. For example, those with the most significant mental health needs frequently had effective, full-time education in hospital or healthcare settings, but such provision was less frequent for those using community mental health services. Ofsted does not routinely inspect some of the education provision visited for this survey, because it is run as a local authority service or a health service rather than as a school."

¹³ <u>Children's and adolescents' mental health and CAMHS</u>. House of Commons Health Committee. Third report of session 2014-15.

¹⁴ <u>Pupils missing out on education: low aspirations, little access, limited achievement</u>. OFSTED November 2013

4.6 General principles of care

4.6.1 Summary of suggestions

Care planning

It was highlighted that it is important for the child/adolescent and family to contribute to and have a copy of the care plan including a crisis plan in order to increase compliance.

Support for carers

It was suggested that carers are often undervalued and poorly supported and there is a need to improve the provision of appropriate information and support for carers to help the child or young person with psychosis or bipolar disorder. Support for carers when a child or young person is in hospital was highlighted as a particular concern.

4.6.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development sources that may support potential statement development. These are presented in full after table 9 to help inform the Committee's discussion.

Suggested quality improvement area	Selected source guidance recommendations
Care planning	First episode psychosis
	NICE CG155 Recommendations 1.3.6, 1.3.7 and 1.3.8
	Promoting recovery and return to primary care
	NICE CG185 Recommendation 1.9.4
Support for carers	General principles of care
	NICE CG155 Recommendation 1.1.10
	Referral in crisis and challenging behaviour
	NICE CG155 Recommendation 1.5.4
	Care for adults, children and young people across all phases of bipolar disorder
	NICE CG185 Recommendations 1.1.12, 1.1.13 and 1.1.18

Table 9 Specific areas for quality improvement

First episode psychosis

NICE CG155 Recommendation 1.3.6

Develop a care plan with the parents or carers of younger children, or jointly with the young person and their parents or carers, as soon as possible, and:

- include activities that promote physical health and social inclusion, especially education, but also employment, volunteering and other occupations such as leisure activities
- provide support to help the child or young person and their parents or carers realise the plan
- give an up-to-date written copy of the care plan to the young person and their parents or carers if the young person agrees to this; give a copy of the care plan to the parents or carers of younger children; agree a suitable time to review it
- send a copy to the primary healthcare professional who made the referral.

NICE CG155 Recommendation 1.3.7

Support children and young people to develop strategies, including risk- and selfmanagement plans, to promote and maintain independence and self-efficacy, wherever possible. Incorporate these strategies into the care plan.

NICE CG155 Recommendation 1.3.8

If the child or young person is at risk of crisis, develop a crisis plan with the parents or carers of younger children, or jointly with the young person and their parents or carers, and with their care coordinator. The plan should be respected and implemented, incorporated into the care plan and include:

- possible early warning signs of a crisis and coping strategies
- support available to help prevent hospitalisation
- where the child or young person would like to be admitted in the event of hospitalisation
- definitions of the roles of primary and secondary care professionals and the degree to which parents or carers are involved
- information about 24-hour access to services
- the names of key clinical contacts.

Promoting recovery and return to primary care

NICE CG185 Recommendation 1.9.4

When making transfer arrangements for a return to primary care, agree a care plan with the person, which includes:

- clear, individualised social and emotional recovery goals
- a crisis plan indicating early warning symptoms and triggers of both mania and depression relapse and preferred response during relapse, including liaison and referral pathways

- an assessment of the person's mental state
- a medication plan with a date for review by primary care, frequency and nature of monitoring for effectiveness and adverse effects, and what should happen in the event of a relapse.

Give the person and their GP a copy of the plan, and encourage the person to share it with their carers

General principles of care

NICE CG155 Recommendation 1.1.10

Advise parents and carers about their right to a formal carer's assessment of their own physical and mental health needs, and explain how to access this.

Referral in crisis and challenging behaviour

NICE CG155 Recommendation 1.5.4

Consider the support and care needs of parents or carers of children or young people in crisis. Where needs are identified, ensure they are met when it is safe and practicable to do so.

Care for adults, children and young people across all phases of bipolar disorder

NICE CG185 Recommendation 1.1.12

Offer carers of people with bipolar disorder an assessment (provided by mental health services) of their own needs and discuss with them their strengths and views. Develop a care plan to address any identified needs, give a copy to the carer and their GP and ensure it is reviewed annually.

NICE CG185 Recommendation 1.1.13

Advise carers about their statutory right to a formal carer's assessment provided by social care services and explain how to access this.

NICE CG185 Recommendation 1.1.18

Offer a carer-focused education and support programme, which may be part of a family intervention for bipolar disorder, as early as possible to all carers. The intervention should:

- be available as needed
- have a positive message about recovery.

4.6.3 Current UK practice

Care planning

No published studies on current practice were highlighted for this suggested area for quality improvement. This area is based on stakeholder's knowledge and experience.

Support for carers

A 2012 report by the Schizophrenia Commission, 'The Abandoned Illness'¹⁵, heard from over 1,000 families (including friends and significant others) who are carers. The feedback showed that carers need better support to enable them to care effectively, this should include the provision of information, support groups, respite care and family education.

¹⁵ The Schizophrenia Commission. <u>The Abandoned Illness</u>. 2012

4.7 Additional areas

4.7.1 Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise, however they were felt to be either outside the remit of the quality standard referral and the development sources, covered by an existing quality standard or require further discussion by the Committee to establish potential for statement development.

There will be an opportunity for the QSAC to discuss these areas at the end of the session on 18 February 2015.

Tests for fatty acids & Vitamin D

Stakeholder suggested there can be major improvements in mental health within 3 months of supplementing levels of Omega-3 Fatty Acids & Vitamin D. It was suggested that it is better to make improvements in diet & lifestyle before prescribing prescription drugs.

Reflect differences in treatment for bipolar disorder

As bipolar is not a subtype of psychosis it was suggested that the quality standard should reflect that care and treatment for bipolar is different for care and treatment for schizophrenia.

Appendix 1: Key priorities for implementation (CG155)

Recommendations that are key priorities for implementation in the source guideline and that have been referred to in the main body of this report are highlighted in grey.

Referral from primary care for possible psychosis

 When a child or young person experiences transient or attenuated psychotic symptoms or other experiences suggestive of possible psychosis, refer for assessment without delay to a specialist mental health service such as CAMHS or an early intervention in psychosis service (14 years or over).

Treatment options for symptoms not sufficient for a diagnosis of psychosis or schizophrenia

- When transient or attenuated psychotic symptoms or other mental state changes associated with distress, impairment or help-seeking behaviour are not sufficient for a diagnosis of psychosis or schizophrenia:
 - consider individual cognitive behavioural therapy (CBT) (delivered as set out in recommendation 1.3.28) with or without family intervention (delivered as set out in recommendation 1.3.27), and
 - offer treatments recommended in NICE guidance for children and young people with any of the anxiety disorders, depression, emerging personality disorder or substance misuse.
- Do not offer antipsychotic medication:
 - for psychotic symptoms or mental state changes that are not sufficient for a diagnosis of psychosis or schizophrenia, or
 - \circ $\;$ with the aim of decreasing the risk of psychosis.

Referral from primary care for first episode psychosis

 Urgently refer all children and young people with a first presentation of sustained psychotic symptoms (lasting 4 weeks or more) to a specialist mental health service, either CAMHS (up to 17 years) or an early intervention in psychosis service (14 years or over), which includes a consultant psychiatrist with training in child and adolescent mental health.

Treatment options for first episode psychosis

 If the child or young person and their parents or carers wish to try psychological interventions (family intervention with individual CBT) alone without antipsychotic medication, advise that psychological interventions are more effective when delivered in conjunction with antipsychotic medication. If the child or young person and their parents or carers still wish to try psychological interventions alone, then offer family intervention with individual CBT. Agree a time limit (1 month or less) for reviewing treatment options, including introducing antipsychotic medication. Continue to monitor symptoms, level of distress, impairment and level of functioning, including educational engagement and achievement, regularly.

How to use oral antipsychotic medication

- Before starting antipsychotic medication, undertake and record the following baseline investigations:
- weight and height (both plotted on a growth chart)
- waist and hip circumference
- pulse and blood pressure
- fasting blood glucose, glycosylated haemoglobin (HbA1c), blood lipid profile and prolactin levels
- assessment of any movement disorders
- assessment of nutritional status, diet and level of physical activity.
- Monitor and record the following regularly and systematically throughout treatment, but especially during titration:
- efficacy, including changes in symptoms and behaviour
- side effects of treatment, taking into account overlap between certain side effects and clinical features of schizophrenia (for example, the overlap between akathisia and agitation or anxiety)
- the emergence of movement disorders
- weight, weekly for the first 6 weeks, then at 12 weeks and then every 6 months (plotted on a growth chart)
- height every 6 months (plotted on a growth chart)
- waist and hip circumference every 6 months (plotted on a percentile chart)
- pulse and blood pressure (plotted on a percentile chart) at 12 weeks and then every 6 months
- fasting blood glucose, HbA1c, blood lipid and prolactin levels at 12 weeks and then every 6 months
- adherence
- physical health.

The secondary care team should maintain responsibility for monitoring physical health and the effects of antipsychotic medication in children and young people for at least the first 12 months or until their condition has stabilised. Thereafter, the responsibility for this monitoring may be transferred to primary care under shared care arrangements.

Treatment of subsequent acute episodes of psychosis or schizophrenia

 Offer family intervention (delivered as set out in recommendation 1.3.27) to all families of children and young people with psychosis or schizophrenia, particularly for preventing and reducing relapse. This can be started either during the acute phase or later, including in inpatient settings. Before referral for hospital care, think about the impact on the child or young
person and their parents, carers and other family members, especially when the
inpatient unit is a long way from where they live. Consider alternative care within
the community wherever possible. If hospital admission is unavoidable, provide
support for parents or carers when the child or young person is admitted.

Education, employment and occupational activities for children and young people with psychosis and schizophrenia

• For children and young people of compulsory school age, liaise with the child or young person's school and educational authority, subject to consent, to ensure that ongoing education is provided.

Appendix 2: Key priorities for implementation (CG185)

Recommendations that are key priorities for implementation in the source guideline that apply to children and young people and that have been referred to in the main body of this report are highlighted in grey.

Care for adults, children and young people across all phases of bipolar disorder

Support for carers of people with bipolar disorder

• As early as possible negotiate with the person with bipolar disorder and their carers about how information about the person will be shared. When discussing rights to confidentiality, emphasise the importance of sharing information about risks and the need for carers to understand the person's perspective. Foster a collaborative approach that supports both people with bipolar disorder and their carers, and respects their individual needs and interdependence.

Recognising, diagnosing and managing bipolar disorder in children and young people

Recognition and referral

Diagnosis and assessment

• Diagnosis of bipolar disorder in children or young people should be made only after a period of intensive, prospective longitudinal monitoring by a healthcare professional or multidisciplinary team trained and experienced in the assessment, diagnosis and management of bipolar disorder in children and young people, and in collaboration with the child or young person's parents or carers.

Management in young people

Mania

- To treat mania or hypomania in young people see NICE's technology appraisal guidance on aripiprazole for treating moderate to severe manic episodes in adolescents with bipolar I disorder and also consider the recommendations for adults in section 1.5. Refer to the BNF for children to modify drug treatments, be aware of the increased potential for a range of side effects, and do not routinely continue antipsychotic treatment for longer than 12 weeks.
- Do not offer valproate to girls or young women of childbearing potential.

Bipolar depression

• Offer a structured psychological intervention (individual cognitive behavioural therapy or interpersonal therapy) to young people with bipolar depression. The intervention should be of at least 3 months' duration and have a published evidence-based manual describing how it should be delivered.

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
01		Hywel Dda University Health Board	Key area for quality improvement 1	Early and age appropriate detection and assessment		NICE, 2014. Morrison et al 2013. Welsh, Tiffin, 2014.
02		Hywel Dda University Health Board	Key area for quality improvement 2	Focus on At Risk Mental States	services + PC services) and able to action a response if concerns are raised, then there is a greater chance of intervening earlier and again altering the young person's prognosis and future outcomes.	NICE, 2014. Phillips, Addington & Morrison, 2009. Rory & Morrison, 2013 Morroson et al, 2004, 2012. Young, McGorry, 2011. Addington et al, 2010 EPPIC, 2014 Welsh, Tiffin, 2014. IRIS
03		Hywel Dda University Health Board	Key area for quality improvement 3	Reduction in Duration of Untreated Psychosis (DUP) to <three months.<br="">Will affect later physical health issues of individual.</three>		NICE, 2009, 2014. Phillips, Addington & Morrison, 2009. Morrison et al, 2004, 2012

Appendix 3: Suggestions from stakeholder engagement exercise

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					problems people with these disorders develop at later life + the differences in morbidity age.	
04		Royal College of Paediatrics and Child Health	Key area for quality improvement 1	Psychosis, like other mental health problems, can be more difficult to recognise (hence diagnosis delayed), in children and young people with learning disabilities who have limited communication skills and a more limited range of ways to express their emotions and feelings.		No additional information provided by stakeholder.
05	4.2	SCM1	Key area for quality improvement 3 A child or young person experiencing psychosis, bipolar disease or schizophrenia is offered psychological and psychosocial interventions. These should include CBT and family interventions and should be available from the onset of illness as well	in conjunction with antipsychotic medication improve outcomes such as psychotic symptoms, social functioning, quality of life and coping skills. Furthermore these interventions, unlike antipsychotic medications,	5	include CBT and family interventions are shared by all three

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			as in the longer term.	cause service users to seek treatments free from these potential difficulties. Thus psychological interventions should form part of a broadly-based	However the Schizophrenia Commission (2011) highlighted lack of access to appropriate psychological interventions and the recent National Audit of Schizophrenia 2nd round (2014) confirmed problematic access with Mental Health Trusts reporting that 19% of service users received CBT and 8% received family interventions.	 NICE CG 178 Rec 1.3.1.3, 1.3.4.1, 1.4.4.1, 1.4.4.2, 1.5.4.1, 1.5.4.2, and 1.5.4.3 NICE CG 185 Rec 1.7.2, 1.7.3, and 1.7.4. NAS AUDIT – section on psychological therapies plus recommendations - download report from http://rcpsych.ac.uk/worki npsychiatry/qualityimprov ement/nationalclinicalaudit s/schizophrenia/nationalsc hizophreniaaudit/reports.a spx
06	4.2	SCM3	Key area for quality improvement 1	Psychological Family Intervention. Recommended by NICE for children/young people (CYP) with psychosis, schizophrenia and bipolar disorder (BD), but with only poor or moderate quality evidence available	Family Interventions have been shown to be effective for adults with psychosis/schizophrenia, and may be more acceptable to children/young people, as well as conferring fewer adverse effects, than medication, or even individual psychological therapy.	NICE Guideline 185 (Bipolar Disorder) NICE Guideline 178 (Psychosis & Schizophrenia in adults) NICE Guideline 155 (Psychosis & Schizophrenia in children/young people)

ID	Report section	Stakeholder	Suggested key area for quality improvement		Why is this a key area for quality improvement?	Supporting information
				to date.		
07	4.2	SCM3	Key area for quality improvement 2	Therapy (eg. CBT). Individual CBT is recommended by NICE for CYP with psychosis/schizophrenia/B D, but the evidence to date for it's effectiveness could be stronger. It is also important to consider evidence for talking	Other than antipsychotic medication, individual CBT is the most frequently endorsed treatment for psychosis/schizophrenia. There is a clear lack of evidence for the use of CBT with CYP with BD; however given the evidence supporting CBT for unipolar depression in CYP, it seems imperative to investigate it's use (among other talking therapies) in CYP with BD too.	NICE Guideline 185 (Bipolar Disorder) NICE Guideline 178 (Psychosis & Schizophrenia in adults) NICE Guideline 155 (Psychosis & Schizophrenia in children/young people)
08	4.2	SCM1	Key area for quality improvement 1. Children and young people with psychosis, bipolar disorder or schizophrenia are systematically monitored to identify and treat at the earliest opportunity those at high cardiovascular and metabolic risk.	experiencing psychosis face a future compromised by poor physical health and premature death – some 15 to 20 years earlier than their peers without psychosis. The majority of premature deaths are explained by cardiovascular disorders such as myocardial infarction and stroke. Many are linked to severe weight gain, high rates of smoking and metabolic		appearing in the equivalent section on physical healthcare in both guidelines (Section 2.1.6 in both). These considerations are especially relevant to younger patients whose vulnerability to weight gain and metabolic disturbances may be

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				(and on top of a mental illness) to these young people. Antipsychotic medications may exacerbate weight gain and metabolic disturbances, particularly in young people and particularly for those taking these medicines for the first time as when experiencing their first episode of psychosis. Of particular note these adverse effects accelerate within weeks of	and secondary care over the results of monitoring. While the NAS audits were directed at adults there is no reason to believe younger patients fare better. A focus on quality improvement to prevent accumulation of cardiovascular and metabolic risk in	Chapter 2 – section 2.1.6 Physical healthcare (pp 19- 23) • NICE CG 155 Chapter 2 – section 2.1.6 Physical healthcare (pp 19- 21) Specific NICE recommendations: <u>A. Before starting antipsychotic medication undertake and record the following baseline investigations</u>

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					providing the basis for assessing a quality standard.	 B. Monitor and record the following regularly and systematically throughout treatment, but especially during titration(specified list of CVD and metabolic indices) See NICE CG 155 Rec 1.3.18 // NICE CG 178 Rec 1.3.6.4 // NICE CG188 Rec 1.10.9. C. Offer interventions in line with relevant NICE guidance at the earliest opportunity (of
						specified CVD and metabolic abnormalities) See NICE CG 178 Rec 1.3.2. // NICE CG 185 Rec 1.2.13
						D. The secondary

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
						care team should maintain responsibility for monitoring physical health and the effects of antipsychotic medication in children and young people for at least the first 12 months or until their condition has
						National Audit of Schizophrenia (NAS) report from

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
						http://rcpsych.ac.uk/wor kinpsychiatry/qualityimp rovement/nationalclinic alaudits/schizophrenia/ nationalschizophreniaa udit/reports.aspx Additional supporting publication for NAS: Crawford M , Jayakumar S, Lemmey S, Zalewska K, Patel M, Cooper S, et al. Assessment and treatment of physical health problems among people with schizophrenia: national cross- sectional study <i>Br J</i> <i>Psychiatry</i> 2014; 205: 473-477

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
09	4.2	SCM2	Ensuring there is robust monitoring of medication effects including both therapeutic effects and unwanted side effects.		The RCPsych POMH audit on the monitoring of antipsychotic medication has benchmarked participating organisations. Results in the repeated audit did not provide reassurance that such monitoring has improved.	See RCPSYCH POMH
10	4.3	SCM1	Key area for quality improvement 4 A child or young person experiencing psychosis, bipolar disease or schizophrenia can expect to be treated in a way that minimises the likelihood of hospital admission, but if unavoidable can be confident this will be to a setting suited to their age, gender and developmental level, and that their parents or carers will be provided support.	traumatic to patient and family, and which can store an experience that makes people reluctant to engage with services again. Of particular concern, children and young people continue to be admitted to adult wards or to in-patient	Many admissions to hospital can be potentially avoided by timely and cost-effective support (compare the effectiveness of EIP services versus standard community mental health services on reduced likelihood of hospital admission) and effective crisis & home treatment response. Hospital in- patient care is also highly expensive. Thus inappropriate admissions are not only highly distressing to service users and their families, but they are also a waste of valuable resources. Measuring use of hospital beds would be straightforward to measure and allow a simple comparison between areas and organisations – for example a	 Specific NICE recommendations: NICE CG 155 Rec 1.5.6: if a child or young person needs hospital care, this should be in a setting appropriate to their age and developmental level. NICE CG 155 Rec 1.5.7: before referral for hospital care, think about the impact on the child or young person and their parents, carers and other

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				educational development.	measure of days admitted within the first 12 months of treatment. To this could be added number of days under coercion (Mental Health Act). Out-of-area placements offers another way of assessing local provision – this method assesses geographical distance and is a recognised aspect of the national commissioning tier 4 CAMHS – again a very expensive provision which reflects local failure to prevent admission or provide adequate CAMHS in-patient capacity. See the Child and Adolescent Mental Health Services (CAMHS) tier 4 report commissioned by NHSE – published July 2014 http://www.england.nhs.uk/wp- content/uploads/2014/07/camhs- tier-4-rep.pdf) In terms of admissions to adult wards – this should be extremely rare, if at all. Moreover there may be situations which contravene the 2004 Children's Act (UK) as well as the UN Convention on the Rights of the Child. Each case could be treated as a significant event with	

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					lessons to be learnt by clinicians and by organisations.	 is unavoidable, ensure that the setting is suitable for the person's age, gender and level of vulnerability, support their carers and follow the recommendations in <u>Service user</u> experience in adult mental health (NICE clinical guidance 136). NICE CG 185 Rec 1.4.2: offer crisis services to support people with bipolar disorder who are in crisis, in line with recommendatio ns 1.4.1.1–1.4.1.4 in the NICE clinical guideline on psychosis and schizophrenia in adults.
						Child and Adolescent Mental Health Services (CAMHS) tier 4 report

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this a key area for quality improvement?	Supporting information
					commissioned by NHSE. (published July 2014
					http://www.england.nhs. uk/wp- content/uploads/2014/0 7/camhs-tier-4-rep.pdf

ID	Report section	Stakeholder	Suggested key area for quality improvement		Why is this a key area for quality improvement?	Supporting information
11	4.3	Hywel Dda University Health Board	Key area for quality improvement 4	appropriate treatment that takes into consideration the transition to adult services.	Adult services are not designed to cater for this population, research has shown that young people often get traumatised when admitted to an adult acute unit and the treatments available too are not specifically designed for young people.	NICE, 2007, 2006, 2009, 2014
12	4.4	The Royal College of Psychiatrists	Key area for quality improvement 2: Physical health monitoring of children and young people receiving treatment for severe mental illness (psychosis, bipolar disorder	are receiving medication and make lifestyle choices that can have adverse effects on their physical health and well being.	There seems to be big variation across the UK in the physical health monitoring of children receiving psychotropic medication. The links between primary and secondary care are not perhaps as well established as in adults with severe mental illness and commissioning does always support that. CAMHS do not always have the facilities or the capacity to conduct or monitor appropriate investigations.	Quality standards need to be in line with NICE guidelines on physical health monitoring of children and young people with psychosis and bipolar disorder
13	4.4	SCM2	Physical Health Care Monitoring for Children & Adolescents with BPD or Childhood Schizophrenia	ensure best life chances physical health care	Physical health care advice and monitoring can fall between two stools, primary care and specialist mental health care. It is important that responsibility for such care is an integral part of the care plan.	No additional information provided by stakeholder.
14	4.4	SCM1	Key area for quality improvement 2	to my Key Area 1	Health services hold unjustifiably pessimistic views about this population's regard for their	The considerations that underpin this area of quality improvement are

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			A child or young person experiencing psychosis, bipolar disease or schizophrenia is offered a combined healthy eating and physical activity programme, and help to stop smoking (where appropriate).	a positive health promoting approach (to synergise with improved physical health monitoring of Key area 1)	avoidable physical illness. Despite this evidence of inadequate attention to physical health alongside an ethical responsibility to use treatments in a way that minimise harm, practitioner nihilism and clinical inertia remain a major challenge. And yet many of the potentially helpful interventions are not technically difficult and can be dramatically effective as the Worcestershire SHAPE programme currently demonstrates in promoting healthy lifestyles to people experiencing their first episode of psychosis (SHAPE is an	 amenable to health promoting interventions. Specific NICE recommendations: NICE CG 155 Rec 1.3.6: recommends that care planning includes activities that promote physical health NICE CG 185 Rec 1.82 and NICE CG 178 Rec 1.1.3:

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				are often compounded by illness factors such as poor motivation or untoward effects of medication on concentration or appetite.	preventive approach to issues like weight gain and physical inactivity from the onset of treatment means it is far easier to prevent weight gain than it is to remove weight, once gained. Moreover it is not technically difficult to identify the population at risk and measure access to health promotion or indeed the impact of interventions on for instance smoking rates or weight change, thus providing the basis for assessing a quality standard.	antipsychotics, should be offered a combined healthy eating and physical activity programme by their mental healthcare provider As an example of service led interventions the SHAPE programme for people with a first episode of psychosis (treated by Worcestershire's El service) is currently being evaluated by NHS IQ Early results look extremely encouraging for the two cohorts of young people who have now been through the 3 month programme Download details of SHAPE from: http://www.nhsiq.nhs.uk /improvement- programmes/living-

Report section	Suggested key area for quality improvement	-	Why is this a key area for quality improvement?	Supporting information
				longer- lives/cardiovascular- disease-outcomes- strategy/cvd-case- studies.aspx

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?		Supporting information
15	4.5	The Royal College of Psychiatrists	Key area for quality improvement 1: Educational /training /occupational provision for children and young people with severe mental illness (psychosis, bipolar disorder)	limited knowledge base in how to support children and young people with severe mental illness. This is an area of paramount importance for their social	educational provision for children and young people in Tier 4 services (many of whom have psychosis and bipolar disorder) has been highlighted in the Health Select Committee report on child mental health services published in	Health Committee - Third Report Children's and adolescents' mental health and CAMHS <u>http://www.publications.</u> <u>parliament.uk/pa/cm201</u> <u>415/cmselect/cmhealth/</u> <u>342/34202.htm</u>
16		Hywel Dda University Health Board	Key area for quality improvement 5	Focus on continuance in school, education and training + keeping access to peer group.	specific and specialist services designed to focus on their specific	NICE, 2005, 2006, 2007, 2009, 2011, 2013, 2014. RCP.

Report section	Suggested key area for quality improvement		Supporting information
		and youth related clubs and activities. FEP/EIP service must in- reach into these areas.	

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
17	4.5	SCM2	Ensure planning is in place for continued educational provision.	Planning for ongoing education is a critical part of a treatment regimen.	Ensuring a child/adolescents educational and social needs are met is important and special educational provision may be warranted. Enhancement of social inclusion is also important. This will improve life chances.	No additional information provided by stakeholder.
18	4.6	SCM2	Ensure robust care planning with an identified case co- ordinator and a clear crisis plan	It is important the child/adolescent and family have a copy of the care plan including a crisis plan and that they have contributed to the plan. This will increase compliance.	shared crisis plan.	No additional information provided by stakeholder.
19	4.6	SCM1	Key area for quality improvement 5 Carers of adults with psychosis or schizophrenia are offered a carer-focused education and support programme as early as possible.	Carers (usually family members – parents and siblings) play a frequently critical role in supporting the successful delivery of treatment to children and young people with psychosis - for instance: • first recognising something is wrong, • initiating health service contact • supporting service engagement	Despite carers having a critical role, the NAS audits and the Schizophrenia Commission reported that carers were often undervalued and poorly supported; these reports recommended that health services should improve their provision of appropriate information and support for carers to help their relative with psychosis.	Specific NICE recommendations: NICE CG 155 Rec 1.1.10, and 1.5.4. NICE CG 178 Rec Section 1.1.5 and its component recommendations NICE CG 185 Rec 1.1.12, 1.1.13, 1.1.14, and 1.1.18 NAS AUDIT – section on carers survey plus recommendations -

ID	Report section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				 in relapse prevention - spotting when things may be going wrong again Moreover they are in it for the long term – negotiating and advocating for young people through often problematic transitions to adult services, as well as many other problematic interfaces with social care, welfare, education, probation and many others. 		download report from http://rcpsych.ac.uk/wor kinpsychiatry/qualityimp rovement/nationalclinic alaudits/schizophrenia/ nationalschizophreniaa udit/reports.aspx
20	4.7	HQT Diagnostics	Many mental problems have an underlying physical cause. Before talking therapies and pharmaceutical drugs are used, physical tests should be done by GPs. These should include tests for Fatty Acids		It is better to make improvements in diet & lifestyle before prescribing prescription drugs	Sources: <u>www.expertomega3.co</u> <u>m/omega-3-</u> <u>study.asp?id=38</u> <u>www.hqt-</u> <u>diagnostics.com/Produc</u> <u>ts/HQT-Analysis</u>

ID	Report section	Stakeholder	Suggested key area for quality improvement			Supporting information
21	4.7	HQT Diagnostics	Many mental problems have an underlying physical cause Before talking therapies and pharmaceutical drugs are used, physical tests should be done by GPs. These should include tests for Vitamin D	Major improvements in mental health have been seen within 3 months of supplementing levels of Vitamin D so that 25(OH)D is between 100-150 nmol/L		Sources: <u>www.vitamindwiki.com/</u> <u>Depression</u>
22	4.7	Lancashire Care NHS Foundation Trust	Key area for quality improvement 1 Ensure bipolar disorder is treated separately from psychosis and schizophrenia	disadvantaged if treatment for bipolar was marginalised / not given equal prioritisation in this	psychosis. If bipolar is included in this quality standard that must be made clear, and standards should	Children are included in the bipolar clinical guideline and there is a separate guideline for children with psychosis.