4-year surveillance (2016)

Psychosis and schizophrenia in children and young people: recognition and management (2013) NICE guideline CG155

Appendix A: Summary of new evidence from surveillance

Access to and the delivery of services, and the experience of care

155 – 01 **For children and young people with psychosis and schizophrenia (particularly from black and minority ethnic groups), do specialised intensive services (EIP services; specialist CAMHS) improve access and engagement with mental health services?**

155 – 02 **For children and young people with psychosis and schizophrenia, what can be done to improve their experience of care?**

Recommendations derived from this question

General principles of care – Working safely and effectively with children and young people

1.1.1 Health and social care professionals working with children and young people with psychosis or schizophrenia should be trained and competent to work with children and young people with mental health problems of all levels of learning ability, cognitive capacity, emotional maturity and development.

1.1.2 Health and social care professionals should ensure that they:

- can assess capacity and competence, including 'Gillick competence', in children and young people of all ages, and
- understand how to apply legislation, including the Children Act (1989; amended 2004), the Mental Health Act (1983; amended 1995 and 2007*) and the Mental Capacity Act (2005), in the care and treatment of children and young people.

1.1.3 Consider children and young people with psychosis or schizophrenia for assessment according to local safeguarding procedures if there are concerns regarding exploitation or self-care, or if they have been in contact with the criminal justice system**.

1.1.4 Health and social care providers should ensure that children and young people with psychosis or schizophrenia:

- can routinely receive care and treatment from a single multidisciplinary community team
- are not passed from one team to another unnecessarily
- do not undergo multiple assessments unnecessarily**.

General principles of care – Establishing relationships with children and young people and their parents or carers

1.1.6 Work in partnership with children and young people with psychosis or schizophrenia of an appropriate developmental level, emotional maturity and cognitive capacity and parents or carers. Offer help, treatment and care in an atmosphere of hope and optimism. Take time to build trusting, supportive, empathic and non-judgemental relationships as an essential part of care**.

1.1.7 When working with children and young people with psychosis or schizophrenia:

- aim to foster autonomy, promote active participation in treatment decisions, and support self-management and access to peer support in children and young people of an appropriate developmental level, emotional maturity and cognitive capacity
- maintain continuity of individual therapeutic relationships wherever possible
- offer access to a trained advocate**.

1.1.8 When working with children and young people with psychosis or schizophrenia and their parents or carers:

- make sure that discussions take place in settings in which confidentiality, privacy and dignity are respected
- be clear with the child or young person and their parents or carers about limits of confidentiality (that is, which health and social care professionals have access to information about their diagnosis and its treatment and in what circumstances this may be shared with others)**.

1.1.9 Discuss with young people with psychosis or schizophrenia of an appropriate developmental level, emotional maturity and cognitive capacity how they want their parents or carers to be involved in their care. Such discussions should take place at intervals to take account of any changes in circumstances, including developmental level, and should not happen only once**.

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.

General principles of care – Communication and information

1.1.11 Health and social care professionals working with children and young people with psychosis or schizophrenia should be trained and skilled in:

- negotiating and working with parents and carers, and
- managing issues relating to information sharing and confidentiality as these apply to children and young people.

1.1.12 If a young person is 'Gillick competent' ask them what information can be shared before discussing their condition and treatment with their parents or carers.

1.1.13 When communicating with children and young people with psychosis or schizophrenia and their parents or carers:

- take into account the child or young person's developmental level, emotional maturity and cognitive capacity including any learning disabilities, sight or hearing problems or delays in language development
- use plain language where possible and clearly explain any clinical language
- check that the child or young person and their parents or carers understand what is being said
- use communication aids (such as pictures, symbols, large print, braille, different languages or sign language) if needed.

1.1.14 Provide children and young people with psychosis or schizophrenia and their parents or carers, comprehensive written information about:

- the nature of, and interventions for, psychosis and schizophrenia (including biomedical and psychosocial perspectives on causes and treatment) in an appropriate language or format, including any relevant 'Information for the public' booklets
- support groups, such as third sector, including voluntary, organisations**.

1.1.15 Ensure that you are:

- familiar with local and national sources (organisations and websites) of information and/or support for children and young people with psychosis or schizophrenia and their parents or carers
- able to discuss and advise how to access these resources

- able to discuss and actively support children and young people and their parents or carers to engage with these resources**.

1.1.16 When communicating with a child or young person with psychosis or schizophrenia, use diverse media, including letters, phone calls, emails or text messages, according to their preference**.

1.1.17 Copy all written communications with other health or social care professionals to the child or young person and/or their parents or carers at the address of their choice, unless this is declined**.

General principles of care – Culture, ethnicity and social inclusion

1.1.18 When working with children and young people with psychosis or schizophrenia and their parents or carers:

- take into account that stigma and discrimination are often associated with using mental health services
- be respectful of and sensitive to children and young people's gender, sexual orientation, socioeconomic status, age, background (including cultural, ethnic and religious background) and any disability
- be aware of possible variations in the presentation of mental health problems in children and young people of different genders, ages, cultural, ethnic, religious or other diverse backgrounds**.

1.1.19 When working with children and young people and their parents or carers who have difficulties speaking or reading English:

- provide and work proficiently with interpreters if needed
- offer a list of local education providers who can provide English language teaching.

1.1.20 Health and social care professionals working with children and young people with psychosis or schizophrenia and their parents or carers should have competence in:

- assessment skills for people from diverse ethnic and cultural backgrounds
- using explanatory models of illness for people from diverse ethnic and cultural backgrounds
- explaining the possible causes of psychosis and schizophrenia and treatment options
- addressing cultural and ethnic differences in treatment expectations and adherence
- addressing cultural and ethnic differences in beliefs regarding biological, social and family influences on the possible causes of mental health problems
- conflict management and conflict resolution†.

1.1.21 Health and social care professionals inexperienced in working with children and young people with psychosis or schizophrenia from diverse ethnic and cultural backgrounds, and their parents or carers, should seek advice and supervision from healthcare professionals who are experienced in working transculturally†.

1.1.22 Local mental health services should work with primary care, other secondary care and local third sector, including voluntary, organisations to ensure that:

- all children and young people with psychosis or schizophrenia have equal access to services based on clinical need and irrespective of gender, sexual orientation, socioeconomic status, age, background (including cultural, ethnic and religious background) and any disability
- services are culturally appropriate**.

1.1.23 Mental health services should work with local voluntary black and minority ethnic groups to jointly ensure that culturally appropriate psychological and psychosocial treatment, consistent with this guideline and delivered by competent practitioners, is provided to children and young people from diverse ethnic and cultural backgrounds†.

General principles of care – Transfer and discharge

1.1.24 Anticipate that withdrawal and ending of treatments or services, and transition from one service to another, may evoke strong emotions and reactions in children and young people with psychosis or schizophrenia and their parents or carers. Ensure that:

- such changes, especially discharge and transfer from CAMHS to adult services, or to primary care, are discussed and planned carefully beforehand with the child or young person and their parents or carers, and are structured and phased
- the care plan supports effective collaboration with social care and other care providers during endings and transitions, and includes details of how to access services in times of crisis
- when referring a child or young person for an assessment in other services (including for psychological interventions), they are supported during the referral period and arrangements for support are agreed beforehand with them**.

First episode psychosis – Referral from primary care

1.3.1 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.

1.3.3 When carrying out an assessment:

- ensure there is enough time for:
  - the child or young person and their parents or carers to describe and discuss their problems
  - summarising the conclusions of the assessment and for discussion, with questions and answers
- explain and give written material in an accessible format about any diagnosis given
- give information about different treatment options, including pharmacological and psychological interventions, and their benefits and side effects, to promote discussion and shared understanding
- offer support after the assessment, particularly if sensitive issues, such as childhood trauma, have been discussed**.

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:

- psychiatric (mental health problems, risk of harm to self or others, alcohol consumption and prescribed and non-prescribed drug history)
- medical, including medical history and full physical examination to identify physical illness (including organic brain disorders) and prescribed drug treatments that may result in psychosis
- psychological and psychosocial, including social networks, relationships and history of trauma
- developmental (social, cognitive and motor development and skills, including coexisting neurodevelopmental conditions)
- physical health and wellbeing (including weight and height, and information about smoking, diet and exercise, and sexual health)
- social (accommodation, culture and ethnicity, leisure activities and recreation, carer responsibilities [for example, of parents or siblings])
- educational and occupational (attendance at school or college, educational attainment, employment and functional activity)
- economic (family's economic status).

1.3.5 Routinely monitor for other coexisting mental health problems, including depression and anxiety, and substance misuse, particularly in the early phases of treatment†.

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**.

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

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**.

1.3.10 If the child or young person and/or their parent or carer is unhappy about the assessment, diagnosis or care plan, give them time to discuss this and offer them the opportunity for a second opinion**.

First episode psychosis – Treatment options for first episode psychosis

1.3.13 If the child or young person shows symptoms and behaviour sufficient for a diagnosis of an affective psychosis or disorder, including bipolar disorder and unipolar psychotic depression, follow the recommendations in bipolar disorder: assessment and management (NICE guideline CG185) or depression in children and young people: identification and management (NICE guideline CG28).

Referral in crisis and challenging behaviour

1.5.1 When a child or young person is referred in crisis they should be seen by specialist mental health secondary care services within 4 hours of referral**.

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**.

1.5.3 At the end of a crisis assessment, ensure that the decision to start home treatment depends not on the diagnosis, but on:

- the level of distress

- the severity of the problems
- the vulnerability of the child or young person and issues of safety and support at home
- the child or young person's cooperation with treatment**.

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**.

1.5.5 Follow the recommendations in self-harm in over 8s: short-term management and prevention of recurrence (NICE guideline CG16) when managing acts of self-harm in children and young people with psychosis or schizophrenia who are 8 years or over†.

Referral in crisis and challenging behaviour – Hospital care

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.

1.5.7 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.

1.5.8 Give verbal and written information to children and young people with psychosis or schizophrenia admitted to hospital, and their parents or carers, about:

- the hospital and the ward in which the child or young person will stay
- treatments, activities and services available
- expected contact from health and social care professionals
- rules of the ward (including substance misuse policy)
- their rights, responsibilities and freedom to move around the ward and outside
- meal times
- visiting arrangements.

Make sure there is enough time for the child or young person and their parents or carers to ask questions**.

1.5.9 Undertake shared decision-making routinely with children or young people in hospital who are of an appropriate developmental level, emotional maturity and cognitive capacity, including, whenever possible, those who are subject to the Mental Health Act (1983; amended 1995 and 2007). Include their parents or carers if appropriate**.

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.

1.5.11 Ensure that children and young people in hospital continue to have access to a wide range of meaningful and culturally appropriate occupations and activities 7 days per week, and not restricted to 9am to 5pm. These should include creative and leisure activities, exercise, self-care and community access activities (where appropriate). Activities should be facilitated by appropriately trained educational, health or social care professionals**.

1.5.12 Children and young people receiving community care before hospital admission should be routinely visited while in hospital by the health and social care professionals responsible for their community care**.

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

Early post-acute period

1.6.1 In the early period of recovery following an acute episode, reflect upon the episode and its impact with the child or young person and their parents or carers, and make plans for recovery and possible future care.

Promoting recovery and providing possible future care in primary care

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†.

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.

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.

1.7.4 Treat children and young people with psychosis or schizophrenia who have diabetes and/or cardiovascular disease in primary care. Use the appropriate NICE guidance for children and young people where available† (see NICE guideline NG18 diabetes (type 1 and type 2) in children and young people: diagnosis and management).

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†.

1.7.6 When a child or young person with a diagnosis of psychosis or schizophrenia presents with a suspected relapse (for example, with increased psychotic symptoms or a significant increase in the use of alcohol or other substances) and is still receiving treatment, primary healthcare professionals should refer to the crisis section of the care plan. Consider referral to the key clinician or care coordinator identified in the crisis plan†.

1.7.7 For a child or young person with psychosis or schizophrenia being cared for in primary care, consider referral to secondary care again if there is:

- poor response to treatment
- non-adherence to medication
- intolerable side effects from medication or the child or young person or their parents or carers request a review of side effects
- the child or young person or their parents or carers request psychological interventions not available in primary care
- comorbid substance misuse
- risk to self or others†.

Promoting recovery and providing possible future care in secondary care

1.8.1 Children and young people with psychosis or schizophrenia who are being treated in an early intervention in psychosis service should have access to that service for up to 3 years (or until their 18th birthday, whichever is longer) whatever the age of onset of psychosis or schizophrenia.

* Including the Code of Practice: Mental Health Act 1983

** Adapted from service user experience in adult mental health (NICE guideline CG136)

† Adapted from psychosis and schizophrenia: management (NICE guideline CG82)

Surveillance decision

This review question should not be updated.

General principles of care

2-year Evidence Update summary
A systematic review and meta-analysis[1] combining 21 studies (n=716) found that early onset of schizophrenia in children and young people appears to be associated with poor long-term outcomes.

The Evidence Update concluded that this evidence was consistent with recommendations on long-term care strategies in NICE guideline CG155.

4-year surveillance summary
A systematic review and meta-analysis[2] combining 15 studies found that early intervention programmes reduced the use of inpatient services with fewer people hospitalised and lower bed usage compared with standard treatment for psychosis.

Topic expert feedback
There is new national (English) guidance on Early Intervention Services to see all cases of prodromal psychosis.

There is a major policy initiative to improve access for people with their first episode of psychosis (all ages and therefore including young people) to NICE-concordant treatment (Achieving Better Access to MH services by 2020 – NHSE)

More limited treatment options for those with learning disabilities, and very much more limited research (LD persons often excluded), consequently more limited evidence base.

Impact statement
Evidence from the 2-year Evidence Update, 4-year surveillance review and topic expert feedback is consistent with recommendations to urgently refer children and young people with psychotic symptoms to specialist mental health services including early intervention services.

New evidence is unlikely to change guideline recommendations.

At risk mental states for psychosis and schizophrenia in children and young people: recognition and management

155 – 03 **In children and young people, what are the specific behaviours and symptoms that are associated with an increased risk of developing psychosis and schizophrenia (at risk mental state)?**

155 – 04 **For children and young people who are at risk of developing psychosis and schizophrenia (at risk mental state), does the provision of pharmacological, psychological or psychosocial and/or dietary interventions improve outcomes?**

Subquestions

What is the course of these behaviours and symptoms?

What are the specific behaviours and symptoms that prompt initial recognition of psychosis or prompt diagnosis of schizophrenia?

Recommendations derived from this question

Possible psychosis – Referral from primary care

1.2.1 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).

Possible psychosis – Assessment in specialist mental health services

1.2.2 Carry out an assessment of the child or young person with possible psychosis, ensuring that:

- assessments in CAMHS include a consultant psychiatrist
- assessments in early intervention in psychosis services are multidisciplinary
- where there is considerable uncertainty about the diagnosis, or concern about underlying neurological illness, there is an assessment by a consultant psychiatrist with training in child and adolescent mental health.

1.2.3 If a clear diagnosis of psychosis cannot be made, monitor regularly for further changes in symptoms and functioning for up to 3 years. Determine the frequency and duration of monitoring by:

- the severity and frequency of symptoms
- the level of impairment and/or distress in the child or young person, and
- the degree of family disruption or concern.

1.2.4 If discharge from the service is requested, offer follow-up appointments and the option to self-refer at a later date. Ask the GP to continue monitoring changes in mental state.

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

1.2.5 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 1.3.29) with or without family intervention (delivered as set out in recommendation 1.3.28), 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.

1.2.6 Do not offer antipsychotic medication:

- for psychotic symptoms or mental state changes that are not sufficient for a diagnosis of psychosis or schizophrenia, or
- with the aim of decreasing the risk of psychosis.

Surveillance decision

This review question should not be updated.

Possible psychosis - assessment

2-year Evidence Update summary

A systematic review and meta-analysis[3] combining 44 studies (n=3861) found that cognitive deficits appear to be evident in people at familial or clinical risk of psychosis. The level of deficit also appears to have some correlation with eventual transition to psychosis.

The Evidence Update concluded that the recommendations for cognitive assessments of children and young people with first episode psychosis could also be applied to those with possible psychosis.

4-year surveillance summary

A systematic review and meta-analysis combining 47 studies[4] found that young people at ultra-high risk for psychosis had increased cardiometabolic risk factors (low physical activity, smoking and alcohol abuse) compared with controls.

A systematic review[5] combining 35 studies (n=1506; mean age <19) found auditory hallucinations, delusions, thought disorder, bizarre/disorganised behaviour, and flat or blunted affect to be the most frequent psychotic symptoms of early onset schizophrenia in children and adolescents. Poor illness outcome was found to be associated with longer

duration of untreated psychosis and poor premorbid adjustment.

Topic expert feedback
There can be a lack of clarity in practice in the interpretation of how much of this guideline applies to those with 'possible psychosis' (e.g. is it 'CBTp' or 'CBT'), and how much this presentation would need to trigger other guidelines such as Depression in Children and Young People.

The phrase in Appendix 1 (4.1.2) of the full guideline that states it does not cover "Children and young people with psychotic disorders other than schizophrenia [but including psychosis or possible psychosis as per 4.1.1 b], might introduce confusion, bearing in mind how the guideline recognises diagnostic instability.

Impact statement
Evidence from the 2-year Evidence Update and 4-year surveillance review is consistent with recommendations to assess the frequency and duration of symptoms, specifically cognitive and behavioural, in children and young people at risk for psychosis.

Intelligence from topic experts suggests there is a lack of clarity for the diagnostic thresholds for psychosis in CG155. No new evidence was identified at the 4-year surveillance review to specify diagnostic criteria or change recommendations.

New evidence is unlikely to change guideline recommendations.

Possible psychosis - treatment

2-year Evidence Update summary
An RCT[6] (n=288) of people at high risk of psychosis found the addition of CBT to treatment as usual did not reduce transition to psychosis or distress from symptoms of psychosis compared with treatment as usual only. However, severity of psychotic symptoms was found to reduce with the addition of CBT treatment.

An RCT[7] (n=115) of people at high risk of psychosis found no difference in rates of transition to psychosis between CBT with or without risperidone and supportive therapy.

The Evidence Update concluded that the evidence was consistent with recommendations to consider CBT and not to offer antipsychotic medication when symptoms are not sufficient for diagnosis of psychosis or schizophrenia.

4-year surveillance summary
A four-year follow-up study[8] (n=113; aged 14-35) of the EDIE-NL trial found that CBT for ultra-high risk of psychosis combined with treatment as usual maintained a clinically important and significant reduced incidence rate for transition to psychosis compared with treatment as usual alone.

Topic expert feedback
No topic expert feedback was relevant to this evidence.

Impact statement
Evidence from the 2-year Evidence Update and 4-year surveillance review is consistent with recommendations to consider CBT and not to offer antipsychotic medication when symptoms are not sufficient for diagnosis of psychosis or schizophrenia.

New evidence is unlikely to change guideline recommendations.

Psychological and psychosocial interventions

155 – 05 **Do the advantages and disadvantages of psychological or psychosocial interventions, compared with alternative management, differ between children/young people and adults with psychosis and schizophrenia?**

155 – 06 **Are the advantages and disadvantages of combining particular psychological/ psychosocial interventions with an antipsychotic, either concurrently or sequentially, different for children and young people with psychosis and schizophrenia compared with adults with psychosis and schizophrenia?**

155 – 07 **Should the duration (and, where relevant, frequency) of an initial psychological/ psychosocial intervention be different in children and young people with psychosis and schizophrenia compared with adults with psychosis and schizophrenia?**

155 – 08 **Is the most effective format for particular psychological/ psychosocial interventions (for example, group or individual) the same for children and young people with psychosis and schizophrenia compared with adults with psychosis and schizophrenia?**

Subquestions

Do the competencies or training requirements for practitioners to be able to deliver psychological/psychosocial interventions differ for those working with children and young people with psychosis and schizophrenia compared with those working with adults with psychosis and schizophrenia?*

Are there any different factors (including patient population, age, and so on) that predict the nature and degree of response to psychological/psychosocial interventions, which should be considered in children and young people with psychosis and schizophrenia that it is not necessary to consider in adults with psychosis and schizophrenia?*

* This review question was posed for GDG consideration and not answered via systematic review.

Recommendations derived from this question

First episode psychosis – Treatment options

1.3.11 For children and young people with first episode psychosis offer:

- oral antipsychotic medication†† (see recommendations 1.3.14–1.3.26) in conjunction with
- psychological interventions (family intervention with individual CBT, delivered as set out in recommendations 1.3.27–1.3.33).

1.3.12 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.

First episode psychosis – How to deliver psychological interventions

1.3.27 When delivering psychological interventions for children and young people with psychosis or schizophrenia, take into account their developmental level, emotional maturity and cognitive capacity, including any learning disabilities, sight or hearing problems or delays in language development.

1.3.28 Family intervention should:

- include the child or young person with psychosis or schizophrenia if practical
- be carried out for between 3 months and 1 year
- include at least 10 planned sessions
- take account of the whole family's preference for either single-family intervention or multi-family group intervention
- take account of the relationship between the parent or carer and the child or young person with psychosis or schizophrenia
- have a specific supportive, educational or treatment function and include negotiated problem solving or crisis management work†.

1.3.29 CBT should be delivered on a one-to-one basis over at least 16 planned sessions (although longer may be needed) and:

- follow a treatment manual§ so that:
  - children and young people can establish links between their thoughts, feelings or actions and their current or past symptoms, and/or functioning
  - the re-evaluation of the child or young person's perceptions, beliefs or reasoning relates to the target symptoms
- also include at least one of the following components:
  - normalising, leading to understanding and acceptability of their experience
  - children and young people monitoring their own thoughts, feelings or behaviours with respect to their symptoms or recurrence of symptoms
  - promoting alternative ways of coping with the target symptom
  - reducing distress
- improving functioning†.

First episode psychosis – Monitoring and reviewing psychological interventions

1.3.30 When providing psychological interventions, routinely and systematically monitor a range of outcomes across relevant areas, including the child or young person's satisfaction and, if appropriate, parents' or carers' satisfaction†.

1.3.31 Healthcare teams working with children and young people with psychosis or schizophrenia should identify a lead healthcare professional within the team whose responsibility is to monitor and review:

- access to and engagement with psychological interventions
- decisions to offer psychological interventions and equality of access across different ethnic groups†.

First episode psychosis – Competencies for delivering psychological interventions

1.3.32 Healthcare professionals delivering psychological interventions should:

- have an appropriate level of competence in delivering the intervention to children and young people with psychosis or schizophrenia
- be regularly supervised during psychological therapy by a competent therapist and supervisor†.

1.3.33 Trusts should provide access to training that equips healthcare professionals with the competencies required to deliver the psychological interventions for children and young people recommended in this guideline†.

Subsequent acute episodes of psychosis or schizophrenia

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).

Subsequent acute episodes of psychosis or schizophrenia – Psychological and psychosocial interventions

1.4.4 Offer family intervention (delivered as set out in recommendation 1.3.28) 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†.

1.4.5 Offer CBT (delivered as set out in recommendation 1.3.29) 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†.

1.4.6 Consider arts therapies (for example, dance movement, drama, music or art therapy) for all children and young people with psychosis or schizophrenia, particularly for the alleviation of negative symptoms. This can be started either during the acute phase or later, including in inpatient settings†.

1.4.7 If arts therapies are considered, they should be provided by Health Professions Council (HPC) registered arts therapists, with experience of working with children and young people with psychosis or schizophrenia. The intervention should be provided in groups unless difficulties with acceptability and access and engagement indicate otherwise. Arts therapies should combine psychotherapeutic techniques with activity aimed at promoting creative expression, which is often unstructured and led by the child or young person. Aims of arts therapies should include:

- enabling children and young people with psychosis or schizophrenia to experience themselves differently and to develop new ways of relating to others
- helping children and young people to express themselves and to organise their experience into a satisfying aesthetic form
- helping children and young people to accept and understand feelings that may have emerged during the creative process (including, in some cases, how they came to have these feelings) at a pace suited to them†.

1.4.8 Do not routinely offer counselling and supportive psychotherapy (as specific interventions) to children and young people with psychosis or schizophrenia. However, take the child or young person's and their parents' or carers' preferences into account, especially if other more efficacious psychological interventions, such as CBT, family intervention and arts therapies, are not available locally†.

1.4.9 Do not offer adherence therapy (as a specific intervention) to children and young people with psychosis or schizophrenia†.

1.4.10 Do not routinely offer social skills training (as a specific intervention) to children and young people with psychosis or schizophrenia†.

1.4.11 When psychological interventions, including arts therapies, are started in the acute phase (including in inpatient settings), the full course should be continued after discharge without unnecessary interruption†.

Promoting recovery and providing possible future care in secondary care – Psychological interventions

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 1.3.28†.

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†.

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 1.3.29†.

1.8.5 Consider arts therapies (see recommendation 1.4.7) to assist in promoting recovery, particularly in children and young people with negative symptoms†.

Promoting recovery and providing possible future care in secondary care – Interventions for children and young people whose illness has not responded adequately to treatment

1.8.8 For children and young people with psychosis or schizophrenia whose illness has not responded adequately to pharmacological or psychological interventions:

- review the diagnosis
- establish that there has been adherence to antipsychotic medication††, prescribed at an adequate dose and for the correct duration
- review engagement with and use of psychological interventions and ensure that these have been offered according to this guideline; if family intervention has been undertaken suggest CBT; if CBT has been undertaken suggest family intervention for children and young people in close contact with their families
- consider other causes of non-response, such as comorbid substance misuse (including alcohol), the concurrent use of other prescribed medication or physical illness†.

† Adapted from psychosis and schizophrenia: management (NICE guideline CG82)

†† At the time of publication (January 2013), most antipsychotic medication did not have a UK marketing authorisation specifically for children and young people. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines and 0-18 years: guidance for all doctors for further information.

§ Treatment manuals that have evidence for their efficacy from clinical trials are preferred. If developed for adults, the approach should be adapted to suit the age and developmental level of the child or young person.

Surveillance decision

This review question should not be updated.

Group psychoeducation

2-year Evidence Update summary

An RCT[9] (n=55) found that a structured psychoeducational group intervention for young people with psychosis and their parents or carers appears to reduce visits to the emergency department compared with a non-structured group intervention.

The Evidence Update concluded that this evidence was consistent with recommendations for family-based psychological interventions for young people with psychosis.

4-year surveillance summary

A 2-year follow-up study[10] of the RCT identified at the Evidence Update found that visits to the emergency department remained reduced amongst the psychoeducational group 2 years after the intervention compared with the non-structured group intervention.

A randomised trial[11] (n=102; mean age 17.4) found that 18 sessions of family-focussed therapy reduced positive symptoms compared with 3 sessions of family psychoeducation over 6 months in individuals at high risk for psychosis.

Topic expert feedback
Topic expert highlighted the ongoing IFCBT trial that combines individual and family therapy for people at risk of psychosis.

Topic expert highlighted the ongoing COMPARE trial of antipsychotic medication in comparison to CBT or combination of both in adults with psychosis.

Impact statement
Evidence from the 2-year Evidence Update and the 4-year surveillance review is consistent with recommendations to offer structured family-based group interventions with at least 10 planned sessions to children and young people with psychosis.

Topic experts highlighted ongoing trials which may be of relevance to research recommendations 3 and 4. These trials will be monitored and considered at the next surveillance review when results publish.

New evidence is unlikely to change guideline recommendations.

Individual therapy

2-year Evidence Update summary
No relevant evidence was identified.

4-year surveillance summary
No relevant evidence was identified.

Topic expert feedback
Topic experts highlighted Open Dialogue and Voice Dialogue as gaining ground in clinical practice. However, experts were not aware of accompanying research that would be robust enough to support their inclusion yet.

Impact statement
Intelligence from topic experts highlights the emergence of Open Dialogue and Voice Dialogue treatment in clinical practice.

However, there is currently a paucity of evidence for these treatments and it is unlikely to affect recommendations at this time.

New evidence is unlikely to change guideline recommendations.

Pharmacological interventions

155 – 09 **Does the efficacy profile of continuous antipsychotic drug treatment, compared with alternative management strategies (placebo, another drug treatment, psychological interventions, psychosocial interventions) differ between children/young people and adults with psychosis and schizophrenia?**

155 – 10 **Are children and young people with psychosis and schizophrenia more susceptible to side effects of antipsychotic medication, compared with adults with psychosis and schizophrenia (in particular, metabolic, neurological and cognitive impairments)?**

155 – 11 **For initial treatment in children and young people with psychosis and schizophrenia: Should the dose/duration (and, where relevant, frequency) be different compared with adults?**

155 – 12 **For children and young people whose illness has not responded to pharmacological treatment, what is the next most effective treatment strategy and when do you decide to change treatment? Does this differ from adults with psychosis and schizophrenia?**

155 – 13 **Does the most appropriate treatment strategy in people where antipsychotic medication is effective but not tolerated differ between children and young people with psychosis and schizophrenia compared with adults with psychosis and schizophrenia?**

Subquestions

Do clinicians manage and monitor side effects of antipsychotic treatment differently in children and young people with psychosis and schizophrenia compared with adults with psychosis and schizophrenia?*

Are there any different factors (including patient population, age, and so on) that predict the nature and degree of response to medication, which should be considered in children and young people with psychosis and schizophrenia that it is not necessary to consider in adults with psychosis and schizophrenia?*

Are the same baseline measurements/ monitoring procedures undertaken before initiating antipsychotic medication used in children and young people with psychosis and schizophrenia compared with adults with psychosis and schizophrenia?*

Does the length of antipsychotic medication that is continued for prevention of relapse (maintaining and promoting recovery) differ between children and young people with psychosis and schizophrenia and adults with psychosis and schizophrenia?*

Does the risk of adverse effects associated with antipsychotic augmentation differ between children/young people and adults with psychosis and schizophrenia that is in remission?*

What is the adverse effects profile of olanzapine compared to other ‘second generation’ antipsychotics (SGAs) for treating children and young people with psychosis and schizophrenia?**

* This review question was posed for GDG consideration and not answered via systematic review.

** This review question was considered by the committee following the 2-year Evidence Update (2015).

Recommendations derived from this question

First episode psychosis – Referral from primary care

1.3.2 Antipsychotic medication in children and young people with a first presentation of sustained psychotic symptoms should not be started in primary care unless it is done in consultation with a consultant psychiatrist with training in child and adolescent mental health.

First episode psychosis – Treatment options

1.3.11 For children and young people with first episode psychosis offer:

- oral antipsychotic medication[††] (see recommendations 1.3.14–1.3.26) in conjunction with
- psychological interventions (family intervention with individual CBT, delivered as set out in recommendations 1.3.27–1.3.33).

First episode psychosis – Choice of antipsychotic medication

1.3.14 The choice of antipsychotic medication[‡] should be made by the parents or carers of younger children, or jointly with the young person and their parents or carers, and healthcare professionals. Provide age-appropriate information and discuss the likely benefits and possible side effects of each drug including:

- metabolic (including weight gain and diabetes)
- extrapyramidal (including akathisia, dyskinesia and dystonia)
- cardiovascular (including prolonging the QT interval)
- hormonal (including increasing plasma prolactin)
- other (including unpleasant subjective experiences).

1.3.15 When choosing between olanzapine and other 'second generation' antipsychotic medications[‡], discuss with the young person and their parents or carers the increased likelihood of greater weight gain with olanzapine.
Inform them that this effect is likely to happen soon after starting treatment. [new 2016]

First episode psychosis – How to use oral antipsychotic medication

1.3.16 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.

1.3.17 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[†].

1.3.18 Treatment with antipsychotic medication[††] should be considered an explicit individual therapeutic trial. Include the following:

- From a discussion with the child or young person and their parent or carer, record the side effects the child or young person is most and least willing to tolerate.
- Record the indications and expected benefits and risks of oral antipsychotic medication, and the expected time for a change in symptoms and appearance of side effects.
- At the start of treatment give a dose below the lower end of the licensed range for adults if the drug is not licensed for children and young people and at the lower end of the licensed range if the drug is licensed for children and young people; slowly titrate upwards within the dose range given in the British national formulary (BNF), the British national formulary for children (BNFC) or the SPC.
- Justify and record reasons for dosages above the range given in the BNF, BNFC or SPC.
- Record the rationale for continuing, changing or stopping medication, and the effects of such changes.
- Carry out a trial of the medication at optimum dosage for 4–6 weeks[†].

1.3.19 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.

1.3.20 Discuss any non-prescribed therapies that children or young people, or their parents or carers, wish to use (including complementary therapies) with them. Discuss the safety and efficacy of the therapies, and possible interference with the therapeutic effects of prescribed medication and psychological interventions[†].

1.3.21 Discuss the use of alcohol, tobacco, prescription and non-prescription medication and illicit drugs with the child or young person, and their parents or carers where this has been agreed. Discuss their possible interference with the therapeutic effects of prescribed medication and psychological interventions and the potential of illicit drugs to exacerbate psychotic symptoms[†].

1.3.22 'As required' (p.r.n.) prescriptions of antipsychotic medication should be made as described in recommendation 1.3.18. Review clinical indications, frequency of administration, therapeutic benefits and side effects at least weekly. Check whether 'p.r.n.' prescriptions have led to a dosage above the maximum specified in the BNF, BNFC or SPC[†].

1.3.23 Do not use a loading dose of antipsychotic medication (often referred to as 'rapid neuroleptisation') [†].

1.3.24 Do not initiate regular combined antipsychotic medication, except for short periods (for example, when changing medication) †.

1.3.25 If prescribing chlorpromazine, warn of its potential to cause skin photosensitivity. Advise using sunscreen if necessary†.

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

Subsequent acute episodes of psychosis or schizophrenia

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).

Subsequent acute episodes of psychosis or schizophrenia – Pharmacological interventions

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 1.3.14–1.3.26). Take into account the clinical response to and side effects associated with current and previous medication, and monitor as described in recommendation 1.3.19†.

1.4.3 Aripiprazole is recommended as an option for the treatment of schizophrenia in people aged 15 to 17 years who are intolerant of risperidone, or for whom risperidone is contraindicated, or whose schizophrenia has not been adequately controlled with risperidone. [This recommendation is from Aripiprazole for the treatment of schizophrenia in people aged 15 to 17 years (NICE technology appraisal guidance 213).]

Referral in crisis and challenging behaviour – Rapid tranquillisation and restraint

1.5.14 Healthcare professionals undertaking rapid tranquillisation and/or restraint in children and young people with psychosis or schizophrenia should be trained and competent in undertaking these procedures in children and young people.

1.5.15 Occasionally children and young people with psychosis or schizophrenia pose an immediate risk to themselves or others during an acute episode and may need rapid tranquillisation. Be particularly cautious when considering high-potency antipsychotic medication (such as haloperidol) in children and young people, especially those who have not taken antipsychotic medication before, because of the increased risk of acute dystonic reactions in that age group†.

1.5.16 After rapid tranquillisation, offer the child or young person the opportunity to discuss their experiences. Provide them with a clear explanation of the decision to use urgent sedation. Record this in their notes†.

Early post-acute period

1.6.2 Inform the child or young person and their parents or carers that there is a high risk of relapse if medication is stopped in the 1–2 years following an acute episode†.

1.6.3 If withdrawing antipsychotic medication, undertake gradually and monitor regularly for signs and symptoms of relapse†.

1.6.4 After withdrawal from antipsychotic medication, continue monitoring for signs and symptoms of relapse for at least 2 years†.

Promoting recovery and providing possible future care in secondary care – Pharmacological interventions

1.8.6 The choice of drug†† should be influenced by the same criteria recommended for starting treatment (see recommendations 1.3.14–1.3.26)†.

1.8.7 Do not use targeted, intermittent dosage maintenance strategies¶ routinely. However, consider them for children and young people with psychosis or schizophrenia who are unwilling to accept a continuous maintenance regimen or if there is another contraindication to maintenance therapy, such as side-effect sensitivity†.

Promoting recovery and providing possible future care in secondary care – Interventions for children and young people whose illness has not responded adequately to treatment

1.8.8 For children and young people with psychosis or schizophrenia whose illness has not responded adequately to pharmacological or psychological interventions:

- review the diagnosis
- establish that there has been adherence to antipsychotic medication[††], prescribed at an adequate dose and for the correct duration
- review engagement with and use of psychological interventions and ensure that these have been offered according to this guideline; if family intervention has been undertaken suggest CBT; if CBT has been undertaken suggest family intervention for children and young people in close contact with their families
- consider other causes of non-response, such as comorbid substance misuse (including alcohol), the concurrent use of other prescribed medication or physical illness[†].

1.8.9 Offer clozapine[††] to children and young people with schizophrenia whose illness has not responded adequately to pharmacological treatment despite the sequential use of adequate doses of at least two different antipsychotic drugs each used for 6–8 weeks[†].

1.8.10 For children and young people whose illness has not responded adequately to clozapine[††] at an optimised dose, consider a multidisciplinary review, and recommendation 1.8.8 (including measuring therapeutic drug levels) before adding a second antipsychotic to augment treatment with clozapine. An adequate trial of such an augmentation may need to be up to 8–10 weeks. Choose a drug that does not compound the common side effects of clozapine[†].

[†] Adapted from psychosis and schizophrenia: management (NICE guideline CG82)

[††] At the time of publication (January 2013), most antipsychotic medication did not have a UK marketing authorisation specifically for children and young people. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines and 0-18 years: guidance for all doctors for further information.

[‡] At the time of publication (May 2016), most antipsychotic medication did not have a UK marketing authorisation specifically for children and young people. The prescriber should follow relevant professional guidance, taking full responsibility for the decision. Informed consent should be obtained and documented. See the General Medical Council's Prescribing guidance: prescribing unlicensed medicines and 0-18 years: guidance for all doctors for further information.

[‡‡] See supplementary information for a table of baseline investigations and monitoring for children and young people who are prescribed antipsychotic medication (read in conjunction with the BNF, BNFC and SPC).

[¶] Defined as the use of antipsychotic medication only during periods of incipient relapse or symptom exacerbation rather than continuously.

Surveillance decision

This review question should not be updated.

Antipsychotic medication for first episode psychosis

2-year Evidence Update summary

An RCT[12] (n=222) found that 6 week use of quetiapine improved schizophrenia symptoms compared to placebo in young people and had a safety profile similar to that of adult populations.

An open-label continuation study[13] (n=381) found that safety and tolerability of quetiapine over 26 weeks can be limited by a number of adverse effects in children and young people.

A cohort study[14] (n=179 young people; n=4280 adults), found that the magnitude of metabolic changes such as body weight appear to be greater in young people than adults following long-term treatment with olanzapine.

A retrospective case-control study[15] (n=43,287) found that treatment with antipsychotics appear to increase the risk of type 2 diabetes in children and young people.

A cross-sectional study[16] (n=404) found that people with first episode schizophrenia with a mean lifetime antipsychotic treatment duration

of less than 7 weeks appear to have higher rates of smoking, metabolic syndrome, dyslipidemia and prehypertension than the general population.

The Evidence Update concluded that this evidence was consistent with NICE guideline CG155 recommendations to regularly monitor weight, blood pressure, fasting glucose, HbA1c and blood lipids throughout antipsychotic treatment, and to provide information about smoking, diet and exercise to children and young people with first episode psychosis.

The evidence is also consistent with recommendations to discuss possible side effects, including metabolic issues such as diabetes, when choosing an antipsychotic drug and that certain antipsychotic medications may cause greater metabolic disturbance than others.

The Evidence Update also concluded that the magnitude of metabolic effects caused by olanzapine means that this drug may not be suitable for first-line treatment in children and young people with first episode psychosis.

The Addendum (2016) added new recommendations (1.3.14 – 1.3.15) on providing information about olanzapine when choosing antipsychotic medication.

The Addendum (2016) included the following additional studies:

A prospective cohort study[17] (n=279; aged 4-17) found that body weight increased with olanzapine, quetiapine and risperidone compared with a non-medicated healthy control group. The antipsychotics were also found to have different cardiometabolic and temporal side effects when compared with each other.

The SATIETY[18] prospective cohort study (n=342, mean age 13.6) found that antipsychotic type, dose, age, ethnicity and baseline functioning were significantly associated with increased neuromotor adverse effects.

A cohort study[19] (n=182) found that olanzapine was associated with significantly lower rates of extrapyramidal side effects compared with risperidone and conventional antipsychotics.

A longitudinal study[20] (n=110, aged 9-17) found that olanzapine was associated with significant increases in body mass index at 6 months compared with other second generation antipsychotics.

4-year surveillance summary

A systematic review and network meta-analysis[21] combining 11 studies (n=1714) found antipsychotic medications reduced overall symptoms as measured using the positive and negative syndrome scale (PANSS) compared to placebo in children and adolescents with early onset schizophrenia. However, significant reduction in total PANSS score was found only for molindone, olanzapine and risperidone compared to placebo.

A randomised study[22] (n=174; aged 12-17) found no differences in efficacy or safety between paliperidone and aripiprazole in adolescents with schizophrenia.

An RCT[23] found no significant differences in safety or efficacy between asenapine and placebo for the treatment of schizophrenia in adolescents. Asenapine does not currently have a license in the UK for this indication.

Topic expert feedback

Topic experts identified antipsychotic-induced weight gain as an issue for patients. A study investigating options to mitigate weight gain identified as currently ongoing:

The IMPACT randomised controlled trial will compare healthy lifestyle education against two pharmacological strategies for management of antipsychotic-induced weight gain in young people aged 8-19.

Impact statement

Evidence from the 2-year Evidence Update and 4-year surveillance review is consistent with recommendations to offer antipsychotic medications for first episode psychosis, regularly monitor metabolic changes, and to discuss possible side effects when choosing an antipsychotic drug.

The evidence is also consistent with the Addendum (2016) recommendations to provide information on the increased likelihood of greater weight gain with olanzapine.

Intelligence from topic experts identified the IMPACT study in progress which investigates weight gain in antipsychotic treatment. As results are currently unavailable, the study will be monitored for completion and considered again at the next surveillance review.

New evidence is unlikely to impact on the guideline.

Interventions when illness has not responded adequately to treatment

2-year Evidence Update summary
A retrospective cohort study[24] (n=87) found an increased risk of neutropenia in children and young people treated with clozapine than adult populations. It was also found that younger, male, and African-American children appear to be at greater risk of neutropenia.

The Evidence Update concluded that this evidence was consistent with NICE guideline CG155 recommendations to offer clozapine to children and young people with schizophrenia whose illness has not responded adequately to pharmacological treatment and reinforces the need for long-term monitoring of blood counts.

4-year surveillance summary
No relevant evidence was identified.

Topic expert feedback
Intelligence identified information from the summary of product characteristics (SPC) of clozapine. The SPC states that clozapine should not be used in children and adolescents under the age of 16. This is because safety and efficacy is yet to be established in this population.

Further intelligence found age-specific license indications for perphenazine (14 years and over only), pimozide (over 12 years), sulpiride (14 years and over), and aripiprazole (15 years and over).

Impact statement
Evidence from the 2-year Evidence Update suggests an increased risk of adverse effects of clozapine in children and young people with schizophrenia whose illness has not responded adequately to pharmacological treatment and reinforces the need for long-term monitoring of blood counts.

Intelligence found age-specific license indications for antipsychotic medications for use in children and young people. However, the guideline already includes footnotes highlighting the lack of UK marketing authorisation of antipsychotic medications in children and young people. Also, the guideline includes warnings for clinicians to refer to the SPCs.

New evidence is unlikely to impact on the guideline.

Cognition, employment and education

155 – 14 **For children and young people with psychosis and schizophrenia: a) Are there any psychological or psychosocial interventions (CRT) that enhance cognition and/or improve engagement with education/occupational activities?**

Subquestions

b) What are the competencies or training requirements for practitioners to be able to deliver such interventions?*

What is the best way of providing educational opportunities to integrate/coordinate access to education/employment opportunities for children and young people with schizophrenia: school, or a classroom in a CAMHS unit?*

* This review question was posed for GDG consideration and not answered via systematic review.

Recommendations derived from this question

General principles of care – Working safely and effectively with children and young people

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 – Assessment and care planning in secondary care

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.

Promoting recovery and providing possible future care in secondary care – Education, employment and occupational activities

1.8.11 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.

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.

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†.

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†.

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†.

† Adapted from psychosis and schizophrenia: management (NICE guideline CG82)

Surveillance decision

No new information was identified at any surveillance review.

NQ – 01 Genetic basis of weight gain associated with antipsychotic drugs

This question was not addressed by the guideline.

New evidence has subsequently been identified and considered for possible addition to the guideline as a new question.

Surveillance decision

This question should not be added.

Genetic testing

2-year Evidence Update summary
A cohort study[25] (n=139 discovery cohort; n=205 validation cohorts) found that a genetic locus near the melanocortin 4 receptor gene appears to be associated with weight gain and other adverse metabolic effects in response to antipsychotic drugs.

The Evidence Update concluded that the preliminary nature of the evidence and its limitations of small sample size and results not widely replicated mean that this data were unlikely to affect the guideline.

4-year surveillance summary
No relevant evidence was identified.

Topic expert feedback
No topic expert feedback was relevant to this evidence.

Impact statement
Evidence from the 2-year Evidence Update suggests a genetic basis of adverse metabolic effects associated with antipsychotic medication.

However, the preliminary nature of the evidence and paucity of further supporting evidence mean it is unlikely to impact the guideline at this time.

New evidence is unlikely to impact on the guideline.

NQ – 02 What is the clinical and cost effectiveness of omega-3 fatty acids in the treatment of children and young people considered to be at high risk of developing psychosis?

This is a research recommendation not addressed by any review question above.

2-year Evidence Update summary
No relevant evidence was identified.

4-year surveillance summary
No relevant evidence was identified.

Topic expert feedback
An ongoing RCT (NEURAPRO-E study) was identified during stakeholder consultation which considers omega-3 fatty acids and cognitive-behavioural case management for patients at ultra-high risk of schizophrenia and other psychotic disorders.

Impact statement
The ongoing trial will be considered at the next surveillance review once results publish. There is currently a paucity of evidence to change recommendations at this time.

The research recommendation will be retained.

Research recommendations

Prioritised research recommendations

At 4-year and 8-year surveillance reviews of guidelines published after 2011, we assess progress made against prioritised research recommendations. We may then propose to remove research recommendations from the NICE version of the guideline and the NICE database for research recommendations. The research recommendations will remain in the full versions of the guideline. See NICE's research recommendations process and methods guide 2015 for more information.

These research recommendations were deemed priority areas for research by the Guideline Committee; therefore, at this 4-year surveillance review time point a decision **will** be taken on whether to retain the research recommendations or stand them down.

We applied the following approach:

- New evidence relevant to the research recommendation was found and an update of the related review question is planned.
  - The research recommendation will be removed from the NICE version of the guideline and the NICE research recommendations database. If needed, a new research recommendation may be made as part of the update process.
- New evidence relevant to the research recommendation was found but an update of the related review question is not planned because the new evidence is insufficient to trigger an update.
  - The research recommendation will be retained because there is evidence of research activity in this area.
- New evidence relevant to the research recommendation was found but an update of the related review question is not planned because evidence supports current recommendations.
  - The research recommendation will be removed from the NICE version of the guideline and the NICE research recommendations database because further research is unlikely to impact on the guideline.
- Ongoing research relevant to the research recommendation was found.
  - The research recommendation will be retained and evidence from the ongoing research will be considered when results are published.
- No new evidence relevant to the research recommendation was found and no ongoing studies were identified.
  - The research recommendation will be removed from the NICE version of guideline and the NICE research recommendations database because there is no evidence of research activity in this area.
- The research recommendation would be answered by a study design that was not included in the search (usually systematic reviews or randomised controlled trials).
  - The research recommendation will be retained in the NICE version of the guideline and the NICE research recommendations database.
- The new research recommendation was made during a recent update of the guideline.
  - The research recommendation will be retained in the NICE version of the guideline and the NICE research recommendations database.

RR – 01 What are the long-term outcomes, both psychotic and non-psychotic, for children and young people with attenuated or transient psychotic symptoms suggestive of a developing psychosis, and can the criteria for 'at risk states' be refined to better predict those who will and those who will not go on to develop psychosis?

See review questions 155-03 and 155-04 for new evidence.

Surveillance decision

New evidence relevant to the research recommendation was found but an update of the related review question is not planned because the new evidence is insufficient to trigger an update.

This research recommendation should be retained in the NICE version of the guideline and the NICE research recommendations database.

RR – 02 What is the clinical and cost effectiveness of omega-3 fatty acids in the treatment of children and young people considered to be at high risk of developing psychosis?

See NQ-02 for ongoing research.

Surveillance decision

Ongoing research relevant to the research recommendation was found.

The research recommendation will be retained and evidence from the ongoing research will be considered when results are published.

RR – 03 What is the clinical and cost effectiveness for family intervention combined with individual CBT in the treatment of children and young people considered to be at high risk of developing psychosis and their parents or carers?

See review questions 155-05 to 155-08 for new evidence.

Surveillance decision

Ongoing research relevant to the research recommendation was found.

The research recommendation will be retained and evidence from the ongoing research will be considered when results are published.

RR – 04 What is the clinical and cost effectiveness of psychological treatment alone, compared with antipsychotic medication and compared with psychological treatment and antipsychotic medication combined, for young people with first episode psychosis?

See review questions 155-05 to 155-08 for new evidence.

Surveillance decision

Ongoing research relevant to the research recommendation was found.

The research recommendation will be retained and evidence from the ongoing research will be considered when results are published.

RR – 05 What is the clinical effectiveness of clozapine for children and young people with schizophrenia with symptoms unresponsive to antipsychotic medication and psychological treatment combined?

See review questions 155-09 to 155-13 for new evidence.

Surveillance decision

New evidence relevant to the research recommendation was found but an update of the related review question is not planned because the new evidence is insufficient to trigger an update.

This research recommendation should be retained in the NICE version of the guideline and the NICE research recommendations database.

RR – 06 What is the most effective management strategy for preventing the development of excessive weight gain and metabolic syndrome associated with the use of antipsychotic medication in children and young people?

See review questions 155-09 to 155-13 for new evidence.

Surveillance decision

Ongoing research relevant to the research recommendation was found.

The research recommendation will be retained and evidence from the ongoing research will be considered when results are published.

Other research recommendations

The following research recommendations were not deemed as priority areas for research by the guideline committee. No decisions will be taken the status of these research recommendations.

RR – 07 An adequately powered RCT should be conducted to investigate the influence of sampling strategies on rates of transition to psychosis.

No new information was identified at any surveillance review.

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