NICE National Institute for Health and Care Excellence

2022 surveillance of psychosis and schizophrenia in children and young people: recognition and management (NICE guideline CG155)

Surveillance report

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Contents

Surveillance decision

We will not update the NICE guideline on psychosis and schizophrenia in children and young people. We will monitor the evidence base for new evidence in the following areas and assess its impact as it publishes:

- The effectiveness of antipsychotics for preventing transition to full psychosis in children and young people with psychotic symptoms or mental state changes insufficient for a diagnosis of psychosis or schizophrenia.
- Lurasidone for treating first episode and subsequent acute episodes of schizophrenia.
- The benefit of adding cognitive behavioural therapy (CBT) to standard care including antipsychotics.
- Weight management interventions for children, young people and adults receiving antipsychotics for psychosis and schizophrenia and bipolar disorder; and for children and young people receiving them for antisocial behaviour and conduct disorders.

Reasons for the decision

The evidence we identified is either equivocal, supports recommendations, or is not considered enough on its own to change them. We identified new evidence that indicated practice in some areas was developing rapidly and we propose actively monitoring those areas for new evidence that may impact recommendations.

For further details and a summary of all evidence identified in surveillance, see appendix A.

Overview of 2022 surveillance methods

NICE's surveillance team checked whether recommendations in NICE's guideline on psychosis and schizophrenia in children and young people remain up to date.

The surveillance process consisted of the following:

Intelligence gathering

Initial intelligence gathering (IIG) was used to gather new evidence relevant to all sections of the guideline, this comprised of:

- Feedback from topic experts via a questionnaire.
- A search for new or updated Cochrane reviews and national policy.
- Consideration of evidence from previous surveillance.
- Examining related NICE guidance and quality standards and NIHR signals.
- A search for ongoing research.
- Examining the NICE event tracker for relevant ongoing and published events.
- Assessing the new evidence against current recommendations to determine whether or not to update sections of the guideline.
- Consulting on the proposal with stakeholders, except if we propose to update and replace the whole guideline.

For further details about the process and the possible update proposals that are available, see ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual.

Evidence considered in surveillance

IIG was used to gather new evidence relevant to all sections of the guideline. For most areas sufficient evidence was identified through IIG to enable us to make a proposal about

the need to update guideline sections without the need for literature searches. Intelligence gathering included new evidence published or updated between 1 June 2016 and 31 October 2021. We included:

- 10 relevant studies from a total of 25 identified by topic experts
- 13 studies from trials that have now completed that were identified as ongoing during the previous surveillance review in 2016.

IIG suggested searches for more evidence about weight management interventions for children and young people using antipsychotics were warranted and we carried out focused literature searches in this area. We found 2 studies in a search for randomised controlled trials and systematic reviews.

From all sources, we considered 25 studies in total to be relevant to the guideline.

See appendix A for details of all evidence considered, and references.

Selecting relevant studies

Studies were considered for inclusion using criteria defined by the guideline review protocols contained in the full guideline. Evidence from populations of children and young people (less than 18 years) was prioritised for inclusion. Where this was not possible, studies that included people under and over 18 years, but with a mean age of under 25 are used, as per the guideline review protocols (pages 163 and 219 of the full guideline). The original guideline contains recommendations adapted from adult populations (pages 79 and 101 of the full guideline). Where we have included studies with data exclusively from adults, this is clearly stated in the evidence summary.

Ongoing research

We checked for relevant ongoing research; of the ongoing studies identified, 3 studies were assessed as having the potential to change recommendations. Therefore, we plan to regularly check whether these studies have published results and evaluate the impact of them on current recommendations as quickly as possible. These studies are:

- Early youth engagement in first episode psychosis (EYE-2) randomised controlled trial

- ECLIPSE study 9: Building resilience and recovery through enhancing cognition and quality
- CLEAR: (clozapine in early psychosis) a multi-centre, randomised controlled trial of clozapine for young people with treatment resistant psychosis in real world settings

Intelligence gathered during surveillance

Views of topic experts

We considered the views of topic experts who were recruited to the NICE Centre for Guidelines Expert Advisers Panel to represent their specialty. For this surveillance review, topic experts completed a questionnaire about developments in evidence, policy and services related to the guideline.

We received 6 questionnaire responses from topic experts, including: a general practitioner with a special interest in children and young people's health and mental health commissioning in primary care; an academic with a special interest in psychological interventions and schizophrenia spectrum disorders; a consultant psychiatrist and associate medical director; a professor of child and adolescent psychiatry; an academic and health economist with a special interest in children and young people's mental health; and a consultant mental health pharmacist.

Four topic experts thought guideline recommendations reflected current practice; 3 highlighted that ensuring the currency of recommendations about suspected psychosis remaining up to date was a high priority. One topic expert noted that in some circumstances antipsychotics can reduce symptom severity in some children at high risk of transition when psychological therapies have failed. Topic experts raised issues about principles of practice including strengthening recommendations about supporting patient decision making to better enable shared decision making. Topic experts also raised several equalities issues which are discussed in the equalities section of this report. Topic experts also highlighted new evidence about individual cognitive behavioural therapy (CBT) versus group CBT; brief versus longer duration CBT; and the antipsychotics lurasidone, quetiapine and aripiprazole.

Implementation of the guideline

We identified the Royal College of Psychiatrists and the Healthcare Quality Improvement Partnership's National Clinical Audit of Psychosis (NCAP), which includes data about children and young people. It concludes that there is 'pervasive evidence of wide variations and inequities in provision…and wait times, early intervention programmes (EIP), in provision for children and young people under 18 and…at-risk mental state service provision across England.…There is also wide variation in offer, take-up and refusal rates of NICE interventions across EIP teams nationally.'

We did not identify any evidence that recommendations in the NICE guideline are contributing to this implementation issue and page 56 of the NCAP states: 'more needs to be done to ensure equitable…provision of evidence-based EIP care across England in line with NICE quality standards.' NHS England and NICE have produced guidance on Implementing the early intervention in psychosis access and waiting time standard, which is based on recommendations and metrics in the NICE guidelines and quality standards about psychosis and schizophrenia. Those include NICE's guidelines on psychosis and schizophrenia in children and young people (the subject of this review), and psychosis and schizophrenia in adults, as well as NICE's quality standards on bipolar disorder, psychosis and schizophrenia in children and young people and psychosis and schizophrenia in adults.

Views of stakeholders

Stakeholders are consulted on all surveillance reviews except if the whole guideline will be updated and replaced. Because the surveillance proposal was to not update the guideline, we consulted with stakeholders.

We received responses from 2 stakeholders: the Royal College of Paediatrics and Child Health (RCPCH), who agreed with the decision not to update and the Royal College of Nursing who had no comments. The RCPCH commented that deaf children and young people are more at risk of mental health problems than their hearing peers and the recommendations in the NICE guideline should be strengthened to reflect the specific issues faced by deaf children with schizophrenia. They also highlighted the impact of COVID-19 and the barriers to communication involved in the wearing of personal protective equipment (PPE) and remote consultations can present for all children but particularly those who are deaf. Their comments are summarised in the equalities section of this report.

See appendix B for full details of stakeholders' comments and our responses.

See ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual for more details on our consultation processes.

Equalities

One topic expert commented that there is stigma attached to the recognition of serious mental illness and that most screening tools are devised for the 'western' British patient. Recommendation 1.1.18 in the NICE guideline recommends people working with those with schizophrenia should take into account the stigma associated with schizophrenia and recommendation 1.1.20 recommends that health and social care professionals should be competent to assess people from diverse backgrounds.

Another topic expert commented there are inequalities around deprivation, and stigma about recognising mental health problems in some groups of people leading to delays in engaging with talking therapies. The guideline's equality impact assessment (EIA) notes: 'The scope identified that children, young people and adults with schizophrenia from black and minority ethnic (BAME) backgrounds tend to present late to services.' Recommendations 1.1.18 to 1.1.23 encourage services to work collaboratively with BAME and other minority groups, to ensure culturally appropriate psychosocial interventions. Recommendation 1.1.18 encourages practitioners working with children with psychosis to respect their socioeconomic status.

Responding as a stakeholder the RCPCH commented that the NICE guideline should acknowledge that there is a higher prevalence of mental health problems in deaf children. The equality impact assessment acknowledges this group and the importance of relaying information to people with hearing problems in an individually appropriate manner.

The stakeholder added that the NICE guideline should specify the use of British Sign Language (BSL) trained interpreters. Recommendation 1.1.13 recommends adapting communication with children and young people with sight or hearing problems, or delays in language development and recommends using sign language if needed. The recommendation does not specify BSL-trained interpreters as this may act to exclude groups who do not use BSL, however it does accommodate their use when it is appropriate. When implementing this recommendation providers of healthcare services should have due regard to the need to eliminate unlawful discrimination and to advance equality of opportunity and as such should commission suitably qualified interpreters.

The stakeholder also noted that the use PPE to mitigate COVID-19 risk can particularly impact communication with all children and young people but particularly deaf children and young people. The recommendations on principles of care in the NICE guideline including those about communication and information also apply to situations when PPE is being worn. Their implementation may involve adaptation of PPE as required, for example, the use of transparent face masks or visors to enable lip reading or the use of communication aids as per recommendation 1.1.13.

Overall decision

After considering all evidence, stakeholder comments and other intelligence and the impact on current recommendations, we decided that no update is necessary at this time. We identified 4 areas described in the surveillance decision section of this report, where evidence and practice are developing at a rate that suggests recommendations may need amending in the near future. We will monitor these areas for new evidence to assess its impact on recommendations as it publishes.

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