National Institute for Health and Care Excellence

4-year surveillance (2016) – Psychosis and schizophrenia in children and young people (2013) NICE guideline CG155

Appendix B: stakeholder consultation comments table

Consultation dates: 01 to 14 September 2016

Do you agree with the proposal not to update the guideline?

Stakeholder	Overall response	Comments	NICE response
Association of School and College Leaders (ASCL)	Agree	None	Thank you for your response.
British Association for Psychopharmacology	Agree	Comments on proposal not to update the guideline As outlined in the Surveillance proposal document, a number of areas of research evidence should report in the coming 2-3 years. Thus a fuller review of the guidance would be achievable at this point. However, at present the guidance for the treatment of psychosis and schizophrenia in children and young people, similarly to the guidance for the treatment of psychosis and schizophrenia in adults does not give adequate attention to the difficulties of co-morbidities in this patient group (for example schizophrenia and depression, ASD and schizophrenia, anxiety and OCD and schizophrenia etc). This can lead to considerable uncertainty in pharmacological guidance or polypharmacy when following multiple guidelines. Likewise, within early intervention services, diagnostic uncertainty and accepting a dimensional approach to psychosis is accepted, yet prescribing guidelines do not currently reflect this sufficiently. This area does need to be considered in the future updated guidance.	Thank you for your comments. We have made note of the ongoing trials in this area. These trials will be considered at the next surveillance review once results publish. No evidence was found relating to comorbid disorders in this population therefore no impact on the guideline at this time.
NHS England	Agree	The Surveillance Review seemed to me to be thorough and identified all the studies I was aware of. I did not see coverage of Open Dialogue, a Finnish programme involving the family which seems to have some success. I expect that evidence favouring it is not yet substantial enough to modify recommendations. This situation should be monitored in relation to Voice Dialogue also.	Thank you for your comments. Information on Open Dialogue and Voice Dialogue treatments was noted in the surveillance review following topic expert comments. No evidence was found relating to these treatments therefore no impact on the guideline at this time.

Do you agree with the proposal to remove the research recommendation: 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?			
Association of School and College Leaders (ASCL)	None	None	Thank you for your response.
British Association for Psychopharmacology	Disagree	Some recent evidence suggests this may be effective in UHR adults and young people. Papers that may have not been seen are listed below, which should be reviewed for the age of participants included. For example, Amminger et al 2015 studied young people age 13-25. As the majority of UHR evidence is in young adults and omega-3 fatty acids are generally low risk, a recommendation could be made, or indeed if there remains insufficient evidence then what is present suggests this would warrant further investigation. Indeed Ammingers original study in 2010 (Amminger et al. Long-chain omega-3 fatty acids for indicated prevention of psychotic disorders: a randomized, placebo-controlled trial. Arch Gen Psychiatry. 2010; 67: 146–154) had some significant results and an average age in UHR of 16. We presume this was reviewed in the original guidance. There is also at least one study in process, also cited below Markulev, C., McGorry, P. D., Nelson, B., Yuen, H. P., Schaefer, M., Yung, A. R., ... & Smesny, S. (2015). NEURAPRO-E study protocol: a multicentre randomized controlled trial of omega-3 fatty acids and cognitive-behavioural case management for patients at ultra high risk of schizophrenia and other psychotic disorders. Early intervention in psychiatry. Amminger, G. P., Mechelli, A., Rice, S., Kim, S. W., Klier, C. M., McNamara, R. K., ... & Schäfer, M. R. (2015). Predictors of treatment response in young people at ultra-high risk for psychosis who received long-chain omega-3 fatty acids. Translational psychiatry, 5(1), e495. Mechelli, A., Prata, D., Kefford, C., & Kapur, S. (2015). Predicting clinical response in people at ultra-high risk of psychosis: a systematic and quantitative review. Drug discovery today, 20(8), 924-927.	Thank you for your comments. We have considered the studies highlighted and changed the research recommendation proposal. This recommendation will now be retained. Amminger (2010) has not been included as it was published before the search dates of the surveillance review and would have been considered during guideline development. Markulev (2015) has been noted as an ongoing study and will be considered at the next surveillance review when results publish. Amminger (2015) has not been included as there is insufficient statistical and results data in the abstract for review. Mechelli (2015) has not been included as there is insufficient statistical and results data in the abstract for review.
NHS England	Agree	Agree to remove this. Not sufficient preliminary data.	Thank you for your comments. New evidence has been highlighted relevant to this research recommendation. We have changed the proposal to now retain this recommendation.

Do you agree with the proposal to remove the research recommendation:

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?

Stakeholder	Overall response	Comments	NICE response
Association of School and College Leaders (ASCL)	None	None	Thank you for your response.
British Association for Psychopharmacology	Agree	No comment, this appears sensible and covered in current evidence	Thank you for your comments. New evidence has been highlighted relevant to this research recommendation. We have changed the proposal to now retain this recommendation.
NHS England	Disagree	Already recommended. More definitive trials are needed in this area	Thank you for your comments. New evidence has been highlighted relevant to this research recommendation. We have changed the proposal to now retain this recommendation.

Do you agree with the proposal to remove the research recommendation:

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?

Stakeholder	Overall response	Comments	NICE response
Association of School and College Leaders (ASCL)	None	None	Thank you for your response.
British Association for Psychopharmacology	Agree	In addition, there is clear evidence that the duration of untreated psychosis is a robust and significant predictor of poor functional recovery and remission. There is an ethical point of encouraging or facilitating the withholding of the most effective treatment of psychosis and schizophrenia for children and young people (medication). This is a separate issue from the UHR population, and if a young person meets threshold for psychosis, or diagnostic criteria for schizophrenia they should be offered the treatment with best	Thank you for your comments. New evidence has been highlighted relevant to this research recommendation. We have changed the proposal to now retain this recommendation.

		evidence base.	
NHS England	Disagree	Already part of practice. More definitive trials are needed in this area	Thank you for your comments. New evidence has been highlighted relevant to this research recommendation. We have changed the proposal to now retain this recommendation.

Do you have any comments on areas excluded from the scope of the guideline?

Stakeholder	Overall response	Comments	NICE response
Association of School and College Leaders (ASCL)	None	None	Thank you for your response.
British Association for Psychopharmacology	Yes	No comment on equality issues but please see comment above concerning co-morbidities. In children and young people, presenting with emerging disorders at a time of developmental change and diagnostic uncertainty, attention to this is needed.	Thank you for your comments. No evidence was found relating to comorbid disorders in this population therefore no impact on the guideline at this time.
NHS England	None	None	Thank you for your response.

Do you have any comments on equalities issues?

Stakeholder	Overall response	Comments	NICE response
Association of School and College Leaders (ASCL)	None	None	Thank you for your response.
British Association for Psychopharmacology	Yes	No comment on equality issues but please see comment above concerning co-morbidities. In children and young people, presenting with emerging disorders at a time of developmental change and diagnostic uncertainty, attention to this is needed.	Thank you for your comments. No evidence was found relating to comorbid disorders in this population therefore no impact on the guideline at this time.
NHS England	None	None	Thank you for your response.

No comments from the Royal College of Nursing – thank you for your response
No comments from Royal College of Paediatrics and Child Health – thank you for your response