Psychosis and Schizophrenia in children and young people
Consultation on draft guideline - Stakeholder comments table
28 January 2016 – 25 February 2016

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Stakeholder	Document	Page No	Line No	Comments Please insert each new comment in a new row	Developer's response Please respond to each comment
HQT Diagnostics	Addendum	general	general	This draft Guideline does not consider any non-drug treatments There is good evidence that testing and increasing the blood level of Vitamin D has a significant positive effect on Psychosis Suggest GP to test Vitamin D 25(OH)D and supplement to achieve 100-150 nmol/L Re-test after 3 months and review **Evidence:** http://www.vitamindwiki.com/tiki-index.php?page_id=1309 http://www.vitamindcouncil.org/?s=psychosis&submit=Submit http://www.sussexpartnership.nhs.uk/sites/default/files/documents/18._vitamin_d_deficiency_in_first_episode_psychosis.pdf http://dx.doi.org/10.1016/j.schres.2013.08.036	Thank you for your comment however non-drug treatments were outside the scope of this update. This update was limited to pharmacological treatments, specifically adverse effects of olanzapine compared to other second generation antipsychotics. We will however share the evidence suggested with the surveillance team for consideration when they review the guideline for future updates.
HQT Diagnostics	Addendum	general	general	This draft Guideline does not consider any non-drug treatments There is good evidence that adjusting the blood level of Fatty Acids has a significant positive effect on Psychosis Suggest GP to test Fatty Acids and advise diet and lifestyle changes plus supplements to achieve:	Thank you for your comment however non-drug treatments including dietary interventions such as fatty acids were outside the scope of this update and covered in section 5.5 of the original guideline. This update was limited to pharmacological treatments, specifically adverse effects of olanzapine compared to other second generation

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				BioMarker **Target** **Comment** **Omega-3 Index** **>8%** Increasing Omega-3 to this level improves mood and behaviour **Omega-6/3 ratio** **<3:1** Reducing Omega-6 to this level improves mood and behaviour Increasing Omega-3 is relatively easy Reducing Omega-6 requires advice about diet and lifestyle which is more difficult and requires expert help Refer to registered Dietitian (www.bda.uk.com) or Nutritional Therapist (http://bant.org.uk) Re-test after 3 months and review **Evidence:** http://www.expertomega3.com/omega-3-studies/psychiatry http://www.nimh.nih.gov/search.jsp?query=psychosis http://www.hqt-diagnostics.com/ http://www.sanomega.net/health-philosophy-2/ http://www.greenvits.eu/blogs/news/88500611-what-to-do-about-depression	antipsychotics. We will however share the evidence suggested with the surveillance team for consideration when they review the guideline for future updates.
South West Yorkshire Partnership NHS Foundation Trust	Addendum	General	General	The papers compare the effects of Olanzapine to other 'second generation antipsychotics', giving the potentially spurious impression that Olanzapine does not have any particular problems unique to itself. However this is in relation to the other antipsychotics, not in relation to a baseline of no antipsychotic drugs. Although it is acknowledged later in the document that all second generation drugs lead to problems like weight gain, I think	Thank you for your comment. The trigger for this update was new evidence relating to adverse effects of olanzapine which is considered a 'second generation' antipsychotic. The update therefore aimed to compare the relative side effects profile of olanzapine to other second generation antipsychotics as

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				this is minimised or misleading at the start of the document.	opposed to no antipsychotics at all. We note the fact that all second generation antipsychotics lead to problems like weight gain (as opposed to olanzapine only) and have now emphasised this is the case with all antipsychotics earlier in the document by adding to section 2.1 of the addendum. Please note this idea is also covered by a separate recommendation (1.3.14) which encourages healthcare professionals and young children to discuss the likely benefits and side effects of each drug.
South West Yorkshire Partnership NHS Foundation Trust	Addendum	General	General	It is openly acknowledged that the research is of limited quality, and yet recommendations are still made that Olanzapine could be used. This is particularly problematic with the next point…	Thank you for your comment. The committee as you point out noted that the evidence is of limited quality but nevertheless considered that there is clearly evidence of a greater and sudden weight gain with olanzapine which clinicians and patients ought to be aware of when considering which antipsychotic to use. Overall the committee agreed the evidence was not robust enough to suggest that olanzapine should not be used in any circumstances (please refer to section 2.6, trade-off between harms and benefits for a summary of this discussion). However, the wording in this section has been amended to emphasise both the greater chance AND greater

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					amount of weight gain associated with using olanzapine.
South West Yorkshire Partnership NHS Foundation Trust	Addendum	General	General	The recommendation to use in certain situations and in discussions with the client/family ignores the fact that this seldom seems to happen in practice. For example, I – a non-medic – still find myself being the one who has to raise the question/issue of adverse effects in relation to Olanzapine when it is being prescribed. Information on the extent of weight gain are seldom talked about, or I have noticed that recently these adverse effects get undermined or dismissed as "levelling off after a while". Until NICE is confident that the medics practising in this country are not simply operating from the medical model, and instead utilise a broader holistic framework where the effects on a person's overall wellbeing are included (weight; psychological state; self-esteem etc), caution should be taken in recommending drugs like Olanzapine.	Thank you for your comments and concerns being raised. We have discussed this with the committee who noted that practice may vary but emphasised a proper discussion should include discussion of the full range of potential pros and cons of weight gain and other adverse effects including the lower self-esteem and social isolation through the added stigma of obesity on top of a diagnosis of mental illness. This has now been added to the evidence to recommendations table.
South West Yorkshire Partnership NHS Foundation Trust	Addendum	General	General	Finally, the document recognises that prescriptions of so-called antipsychotics has increased markedly in children and young people. My concern is that the recommendations made do not curb that trend; moreover, they may make the situation worse by opening up prescribing practises.	Thank you for your comment. The recommendations formed were not intended to match the current trend in prescriptions but to reflect what the evidence is showing. In this case, the committee considered that there is clearly evidence of sudden and greater weight gain associated with olanzapine that clinicians and patients ought to be aware of when choosing which antipsychotic to use. The committee also added some caveat around the use of olanzapine which may reduce the

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					prescribing of this particular drug.
Northumberland Tyne and Wear NHS Foundation Trust	Addendum	8		The addendum states: When choosing between olanzapine and other 'second generation' antipsychotic medications, discuss with the young person and their parents or carers the possibility of greater weight gain with olanzapine. We are concerned by this as most recent evidence suggests that due to considerable risk of weight gain on olanzapine. Therefore, we suggest that wording of the addendum reflect this	Thank you for your comment. We have now amended the wording of this recommendation to emphasise both the greater chance AND greater amount of weight gain associated with using olanzapine. The recommendation therefore now reads: "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]".
Northumberland Tyne and Wear NHS Foundation Trust	Addendum	16	20-24	section 1.3.15 The evidence is that the weight gain with olanzapine is so significant (11.2kg in 24 weeks in young people compared with 4.8kg in adults (Kryzhanovskaya et al. (2012))) that we would avoid prescribing it to young people at all (unless no other medication was tolerated) so would suggest that the guidelines should perhaps be more strongly worded and advise avoiding olanzapine	Thank you for your comment. The Committee did not think the evidence regarding adverse effects was of high enough quality for olanzapine to not be offered in any circumstances and therefore avoided a 'do not use' recommendation. However, they highlighted that there is clearly some evidence of greater and sudden weight gain which clinicians and patients ought to be aware of when considering which

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					antipsychotic to use and have now amended the wording of this recommendation to emphasise both the greater chance AND greater amount of weight gain associated with using olanzapine. The recommendation therefore now reads: "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]".
National Association of Psychiatric Intensive Care and Low Secure Units	general	general	general	No comemnts	Thank you.
Royal College of Paediatrics and Child Health	general	general	General	Family history is very important, for individual and family fears and for risk to family members	Thank you for your comment however as indicated by the grey shading for recommendations where family history is referred to, this area of the guideline was not being consulted on at this point in

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					time. We therefore cannot accept comments on this section of the guideline at this stage.
Royal College of Paediatrics and Child Health	general	general	General	"of appropriate developmental level ….." is confusing and used repeatedly. All children should have age and developmentally appropriate explanations – even 5 year olds.	Thank you for your comment, however as indicated by the grey shading for recommendations where this phrase is used, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.
Royal College of Paediatrics and Child Health	general	general	General	Issues of consent to share information described in doc are confusing. Best to have an explanation in one place of how age 16, 17, children are **presumed** to be able to give consent (unless demonstrated unable to do so). Under 16 they may or may not be able to give their own consent, but his has to be assessed. If children are not able to consent parents can consent to treatment and information sharing on their behalf Consent is not all or nothing, and a child / young person may be able to consent, or refuse consent, to treatment and information sharing separately.	Thank you for your comment however as hyperlinked in the addendum and NICE version of this update, the area of consent is covered by the general medical council's Prescribing guidance: prescribing unlicensed medicines and 0-18 years: guidance for all doctors.
Royal College of Paediatrics and Child Health	general	general	general	The particular vulnerability – genetic and environmental of looked after children mean that psychosis arises more often in looked after children or may lead to a young person becoming looked after. Workers have to have sophisticated understanding of parental responsibility and how it is affected by various orders, situations.	Thank you for your comment, as noted in the linking evidence to recommendations section, the committee discussed that looked after children (whether psychosis is the reason behind their becoming looked after or not) may experience a delay in access to services because of

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					the complexity of the condition in terms of recognition and diagnosis and also the multiples of services involved in providing care for these children and young people.
Royal College of Paediatrics and Child Health	general	general	general	BMI should be mentioned all the way through, and given the severe obesity that can result z scores as well as BMI charts are useful.	Thank you for your comment. Where the evidence permits we have extracted details relating to BMI and these are reported in the evidence tables BMI is also referred to in the linking evidence to recommendations table as part of the supporting argument for the recommendation
Royal College of Paediatrics and Child Health	general	general	General	Given the increased risk of physical illness, and early death associated with mental illness, especially long term ,which is sadly often long term outcome, there should be an emphasis on physical health and a close working relationship with GP and trying to set up the sort of holistic care and understanding that may underpin future good physical care too Sexual health should be explicitly considered, along with keeping safe, contraception, risk of exploitation, unwanted [pregnancy, genetic risks and risks of drugs to foetus – as part of necessary information for young people and families.	Thank you for highlighting this however as indicated by the grey shading for recommendations 1.3.4 and 1.5.13, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.
Royal College of Paediatrics and Child Health	general	general	general	Somewhere, probably in 1.3…there should be mention of the safeguarding implications of neglect, refusal to follow advice by parents of a child, or dangerous or abusive alternative practices / treatments such as exorcism	Thank you for your comment. Issues regarding safeguarding are addressed in the following: 'Making decisions using NICE guidelines'. This is hyperlinked in the recommendations box of the NICE version..

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Royal College of Paediatrics and Child Health	general	general	general	Poor self-care is not necessarily a safeguarding issue	Thank you for your comment however safeguarding procedures is covered in section 1.1 of the guideline which was outside the scope of this particular update. This update was limited to pharmacological treatments, specifically adverse effects of olanzapine compared to other second generation antipsychotics.
Royal College of Paediatrics and Child Health	general	general	general	Enquiry about self-harm or harm to others should come in earlier. It is only mentioned in relapse.	Thank you for your comment, however as indicated by the grey shading of recommendations relating to self-harm, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept further comments on this section of the guideline at this stage.
NHS England	general	general	general	How will the guideline promote the capturing and action of children and young people's along with parent's experience of care across the health care system?	Thank you for your comment. Although experience of care of children, young people and parents are outside the scope of this update, the need to review/monitor care plans is covered by recommendations 1.3.6 and 1.3.30 of the original guideline for both pharmacological and non-pharmacological interventions.
Department of Health	general	general	general	No comments	Thank you.
RCN	General	General	General	The Royal College of Nursing welcomes proposals to update this clinical guideline. The RCN invited members who care	Thank you.

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				for children with mental illness to review and comment on the draft document. The comments below reflect their views.	
Royal College of Paediatrics and Child Health	general	1.1.24	general	Should include providing adequate information, support and advice when referring for physical health problems, eg obesity, diabetes.	Thank you for your comment, however as indicated by the grey shading for recommendation 1.1.24, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.
Royal College of Paediatrics and Child Health	general	1.2.2	general	Shouldn't this include a neurologist?	Thank you for your comment, however as indicated by the grey shading for recommendation 1.1.2, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.
Royal College of Paediatrics and Child Health	general	1.3.13	general	When a YP has both depression and psychosis it needs to be clear which diagnosis, if either "trumps" the other in terms of treatment	Thank you for your comment, however as indicated by the grey shading for recommendation 1.3.13, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.
Royal College of Paediatrics and Child Health	general	1.3.20	general	Shouldn't special mention be made of cannabis	Thank you for your comment, however as indicated by the grey shading for recommendation 1.3.20, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.

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Royal College of Paediatrics and Child Health	general	1.5.16	general	Should specify minimum monitoring intervals	Thank you for your comment, however as indicated by the grey shading for recommendation 1.5.16, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.
Royal College of Paediatrics and Child Health	general	1.1.7	general	There may be circumstances where it is NOT appropriate to copy all letters to parents / child	Thank you for your comment, however as indicated by the grey shading for recommendation 1.1.7, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.
Royal College of Paediatrics and Child Health	general	1.3.8	general	Plan should include key family contacts and who to contact in emergency	Thank you for your comment, however as indicated by the grey shading for recommendation 1.3.8, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.
Royal College of Paediatrics and Child Health	general	1.5.6	general	Shouldn't consideration be given to gender, and in some circumstances ethnicity	Thank you for your comment, however as indicated by the grey shading for recommendation 1.5.6, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.
Royal College of	general	Section 1.1.2	general	Should not be referred to as Gillick competence but as using Fraser guidelines	Thank you for your comment, however as indicated by the grey shading for

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Paediatrics and Child Health		and 1.1.12 and others			recommendations 1.1.2 and 1.1.12, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.
Royal College of Paediatrics and Child Health	general	1.1.3, and 1.3.4	general	Should include comments about any concern about safeguarding issues past or present, including domestic violence	Thank you for your comment, however as indicated by the grey shading for recommendations 1.1.3 and 1.3.4, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.
Royal College of Paediatrics and Child Health	general	1.8.11 and 13	general	Why is school only mentioned for statutory school age . it is important for many young people beyond that. YP should be helped to return to education e.g. repeat GCSEs A levels etc. if pos.	Thank you for your comment, however as indicated by the grey shading for recommendations 1.8.11 and 1.8.13, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.
College of Mental Health Pharmacy	short version	16	14	Currently reads "each drug" please use consistent language and continue to use the word "medication" as in the first line of the paragraph (10).	Thank you for your comment however please note there are several recommendations in this guideline that use 'antipsychotic medication' to refer to a group of drugs and then go onto say 'choose a drug….' (for example 1.3.18, 1.4.2, 1.8.6, etc). Retaining 'each drug' ensures that the new recommendations are consistent with the other recommendations in the guideline.
RCN	Short	16	20	The recommendation draws attention to the rapid and	Thank you for your comment, the

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	version			increased weight gain and places emphasis on shared decision making between the prescriber, parent and young person. In practice the decision making would include exploring the benefits and feasibility of starting a healthy lifestyle programme alongside an antipsychotic medication. There is therefore an opportunity to raise this within the recommendation.	committee noted the benefits of starting a healthy lifestyle programme including promoting good physical health, healthy eating, exercise and smoking cessation however acknowledged this is covered by a separate recommendation (1.5.13) in the original guideline which was outside the scope of this particular update. This update was limited to pharmacological treatments, specifically adverse effects of olanzapine compared to other second generation antipsychotics. The evidence to recommendation table, has however, been amended to summarise the committee discussions in this area.
College of Mental Health Pharmacy	short version	23	2-15	Given the structure of the document, and subsection titles I would have expected to read the section on further pharmacological options (eg clozapine here. Yet it doesn't appear unless you read to the end. I suggest either moving it here. Or at least adding a cross reference here to the third section on pharmacological treatment on page 32 (1.8.9 and 1.8.10	Thank you for your comment however as indicated by the grey shading on these recommendations, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.
College of Mental Health Pharmacy	short version	23	9-15	The whole paragraph number 1.4.3 which currently sits in this section about "subsequent acute episodes" is helpful advice but doesn't ONLY pertain to "subsequent episodes". Such guidance would be far better used if it was moved (exact wording retained) to the section on "Choice of antipsychotic medication" under "Treatment options for first episode psychosis" on page 16. Where currently there is no guidance	Thank you for your comment however as indicated by the grey shading on these recommendations, this area of the guideline was not being consulted on at this point in time. We therefore cannot accept comments on this section of the guideline at this stage.

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				at all for clinicians choosing between actual medicines. As it currently is, it simply reads as a warning against olanzapine in section 1.3.15 and lacks any active advice or steer. And the very first antipsychotic chosen is crucially important, prior to considering the second one later in treatment.	