

Consultation on draft guideline – deadline for comments 5pm on Friday, 16 April 2021 email: infant&younghealth@nice.org.uk

Please read the checklist for submitting comments at the end of this form. We cannot accept forms that are not filled in correctly.

We would like to hear your views on the draft recommendations presented in the guideline, and any comments you may have on the rationale and impact sections in the guideline and the evidence presented in the evidence reviews documents. We would also welcome views on the Equality Impact Assessment.

In addition to your comments below on our guideline documents, we would like to hear your views on these questions:

1. Which areas will have the biggest impact on practice and be challenging to implement? Please say for whom and why.
2. Would implementation of any of the draft recommendations have significant cost implications?
3. What would help users overcome any challenges? (For example, existing practical resources or national initiatives, or examples of good practice.)
4. The recommendations in this guideline were largely developed before the coronavirus pandemic. Please tell us if there are any particular issues relating to COVID-19 that we should take into account when finalising the guideline for publication.

See [Developing NICE guidance: how to get involved](#) for suggestions of general points to think about when commenting.

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Organisation name – Stakeholder or respondent (if you are responding as an individual rather than a registered stakeholder please leave blank):		Association for Young People’s Health (AYPH)			
Disclosure Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.		N/A			
Name of commentator person completing form:		Rachael McKeown			
Type		[office use only]			
Comment number	Document [guideline, evidence review A, B, C etc., methods or other	Page number Or 'general' for comments	Line number Or 'general' for comments on whole document	Comments	
				<p>Insert each comment in a new row.</p> <p>Do not paste other tables into this table, because your comments could get lost – type directly into this table.</p>	

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	(please specify which)]	on whole document		
1	Guideline	General	General	It is noted that this guideline applies to the 0-17 age range and we welcome focus on ensuring that children and young people receive the best quality care from health services. However, the age banding excludes the experiences of all young people in these settings (a young person is defined as aged 10-25). We believe that all young people across all ages should be treated equally and with high-quality care as outlined in this guideline.
2	Guideline	General	General	The draft guideline does not reference that young people can attend consultations alongside their friends – suggest this is included.
3	Guideline	010	015-027	Suggest including guidance on how to include and involve parents/carers, peers or another trusted adult in scenarios where communication with the child or young person is hard. Parents/carers and peers can provide support for a child or young person who is scared or not engaging with the healthcare professional, though this should not detract from the intention to provide youth-centric care. Children and young people may be more likely to feel safe if their parents/carers or peers feel safe in the healthcare environment too.
4	Guideline	011	023	Suggest adding 'and who else will be involved in the delivery of their care'.
5	Guideline	012	006	Not all children and young people can access digital tools and apps. Other means should also be available. Engagement with young people has found that not all young people have access to devices, phone credit or privacy / safe spaces to access care digitally. During Covid-19, there have been barriers to young people accessing primary care through digital routes (for example, e-consult originally did not let young people request a GP consultation without parental consent, though this has since been reviewed). The UN Convention on the Rights of Child clearly articulate young people's right to accessing health services independently. There is a risk that if young people are unable to access services digitally, then there will likely be delays to care, their health needs may deteriorate and they may be less likely to access services in the future. Furthermore, digital exclusion may exacerbate existing health inequalities.
6	Guideline	012	006	Any digital tools and apps should be age / developmentally appropriate and designed from the outset with children and young people in mind.
7	Guideline	013	024	Suggest including information on who young people can discuss their concerns with if they are unsure about information and ways to help them to be more confident in accessing and understanding credible information.
8	Guideline	017	016	Suggest changing 'parents and carers' to 'parents or carers'.
9	Guideline	017	018	Children and young people should be fully supported to be involved in making decisions about their care, including their consent to treatment, when this is age and developmentally appropriate. Suggest that the best practice should link to use of Gillick / Fraser competence, as there is currently a lack of consistency within practice about how to assess and apply these guidelines.
10	Guideline	018	001	The glossary section explains that consent can be verbal or written. Suggest including this within the main body of the text here for clarity.
11	Guideline	018	013	More information on managing disagreement / conflict between professionals and parents / carers can be found at: https://adc.bmj.com/content/104/5/413

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12	Guideline	021	006	Typo – additional comma at the end of the sentence.
13	Guideline	026	015	Guidance on healthcare clothing and the use of masks is likely to have been updated under Covid-19 procedures.
14	Guideline	027	003	Children and young people from “under represented groups” are identified as “for example, black, Asian and minority ethnic groups, people with learning disabilities, people from a disadvantaged background, LGBT+ people, people who have not been able to, or have chosen not to, use the service before” Suggest consider also including: homeless young people, Looked After Children / children in care, care leavers, children in institutional care / the justice system, migrant / asylum seeking / refugee young people, young parents, young people affected by sexual violence. Suggest also that there is a recommendation / guidance for health professionals to be alert to health inequalities in all aspects of their care.
15	Guideline	028	006	The healthcare environment should also support the child or young person’s education needs if they need to continue studying.
16	Guideline	029	004	The healthcare environment should be “appropriate for their age and developmental stage”. Suggest explicitly referring to the importance of youth friendly services. This should link to the Department of Health and Social Care’s ‘You’re Welcome’ standards provide quality criteria for young people friendly health services. AYPH were recently commissioned by PHE to refresh these standards, which are currently awaiting sign off from PHE / NHSE / DHSC. More information available at: https://www.gov.uk/government/publications/quality-criteria-for-young-people-friendly-health-services More information on the evidence-base as to the value of providing youth friendly services is available at: https://adc.bmj.com/content/106/1/9
17	Guideline	032	027	Children and young requiring “additional support” are identified as “for example, looked after children, children in institutional care, care leavers” Suggest consider also including: homeless young people, care leavers, migrant / asylum seeking / refugee young people, young parents, black Asian and minority ethnic groups, people with learning disabilities, people with complex physical / mental health conditions, people from a disadvantaged backgrounds, young people affected by sexual violence, LGBT+ young people, people who have not been able to, or have chosen not to, use the service before. Suggest also that there is a recommendation / guidance for health professionals to be alert to health inequalities in all aspects of their care.
18	Guideline	033	012	Consultation with young people during Covid-19 has uncovered that not all young people prefer the use of digital / virtual consultations. There are four key issues specific to young people’s needs that need to be addressed before ‘digital’ becomes ‘default’: equality of access to services, protection of confidentiality, the quality of the consultation and ensuring adequate safeguarding. This is a particularly pertinent issue for certain groups of young

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				people, our work on the We're All Right project highlighted specific concerns for young people affected by sexual violence. More information is available here: https://www.youngpeopleshealth.org.uk/digital-by-default-or-digital-divide-virtual-healthcare-consultations-with-young-people-10-25-years
19	Guideline	034	008	Children and young people requiring “additional support” during the continuation of care are identified as “for example, care leavers, homeless young people, children or young people with complex needs or disabilities” Suggest consider also including: people with learning disabilities, Looked After Children / children in care. Suggest also that there is a recommendation / guidance for health professionals to be alert to health inequalities in all aspects of their care.
20	Guideline	034	015	Digital health records – AYPH has previously conducted research for NHS England on the implementation of their digital strategy. Engagement with young people found that young people believe there is a lack of clarity and awareness about where healthcare information is stored and what is shared between healthcare professionals. 87% believed having access to their own medical record would be a good thing, but only 50% thought that their parents having the same level of access would be positive. Young people expressed concerns around information sharing that should be addressed prior to the sharing of information via digital health records. Notably: what information is shared with what professionals, whether the information is written in youth-friendly language, inappropriate sharing of information / leaking. There are specific concerns relating to privacy for specific groups of young people – for example, young people with HIV do not want all health professionals to be aware of their status if they are seeking medical opinion on an unrelated issue. Concerns around confidentiality are highest for health conditions or issues that may be stigmatised – for example, mental health, sexual health and gender identity. More information is available here: http://www.youngpeopleshealth.org.uk/wp-content/uploads/2016/05/NHS-digital-consultation-April-16-final.pdf
21	Guideline	034	019	Suggest including a hyperlink to the Act.
22	Guideline	036	007	Suggest that the recommendations for research encourages data on health outcomes to record age bands using the quinary age bands where possible, to align with ONS/WHO recommendations, and to capture developmental variation.
23	Guideline	048	021	Typo – full stop missing from the end of the sentence.

Insert extra rows as needed

Checklist for submitting comments

- Use this comment form and submit it as a **Word document (not a PDF)**.
- Complete the disclosure about links with, or funding from, the tobacco industry.

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- Include **page and line number (not section number)** of the text each comment is about.
- Combine all comments from your organisation into 1 response. **We cannot accept more than 1 response from each organisation.**
- Do not paste other tables into this table – type directly into the table.
- Ensure each comment stands alone; do not cross-refer within one comment to another comment.
- **Clearly mark any confidential information or other material that you do not wish to be made public. Also, ensure you state in your email to NICE that your submission includes confidential comments.**
- **Do not name or identify any person or include medical information about yourself or another person** from which you or the person could be identified as all such data will be deleted or redacted.
- Spell out any abbreviations you use
- For copyright reasons, **do not include attachments** such as research articles, letters or leaflets. We return comments forms that have attachments without reading them. The stakeholder may resubmit the form without attachments, but it must be received by the deadline.
- **We do not accept comments submitted after the deadline stated for close of consultation.**

You can see any guidance that we have produced on topics related to this guideline by checking [NICE Pathways](#).

Note: We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the comments are too long, or publication would be unlawful or otherwise inappropriate.

Comments received during our consultations are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

Data protection

The information you submit on this form will be retained and used by NICE and its advisers for the purpose of developing its guidance and may be passed to other approved third parties. Please do not name or identify any individual patient or refer to their medical condition in your comments as all such data will be deleted or redacted. The information may appear on the NICE website in due course in which case all personal data will be removed in accordance with NICE policies.

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By submitting your data via this form you are confirming that you have read and understood this statement.

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