

# NCB Reference Groups - Consultation Comments

Section	Guideline wording	Children and young people's feedback	Developer's response
1.2.1	"Ensure that children and young people (and their parents or carers, as appropriate) have a positive experience by: being friendly"	<p>YP in the 11-14 group agreed that healthcare professionals being friendly was really important but thought the wording of 'have a positive experience by being friendly' was not clear enough, and thought examples of what 'friendly' meant (i.e. eye contact, smiling) would be useful.</p> <ul style="list-style-type: none"> <li>- <i>"Your friendly might be different than their friendly. This doesn't really sum it up, put in some examples"</i></li> <li>- <i>"What do you mean by friendly? Tell us what that means, say 'reassure them, be smiley, be welcoming'"</i></li> <li>- <i>"could say 'being friendly and welcoming, creating an environment the young person feels comfortable within'"</i></li> </ul> <p>[The young people rated this 5.4/10]</p> <p>Likewise, in a 7-11 group when we asked about this, the children suggested additional information about what being friendly meant: "having a big friendly smile," "talk to me about my worries" "they would try to make you in a happier mood"</p>	We have included examples of what being friendly means in the recommendations on communication (smiling, saying hello, using eye contact).
1.2.2	"Communicate with children and young people and their parents or carers with:... cultural sensitivity"	Most children and young people in the 11-14 group and both the 7-11 groups we asked about this were unsure of what 'cultural sensitivity' meant. However, when it was explained, a majority agreed this was important	We have defined cultural sensitivity in the 'terms used' section and in the glossary.
1.2.2	"Communicate with children and young people and their parents or carers with: ... a non-judgemental attitude"	A non-judgemental attitude was important to some of the young people in the 11-14 group, but others were confused about the difference between not being judgemental and being decisive/making 'judgements.' One	We have defined non-judgemental in the 'terms used' section and in the glossary.

		<p>young person explained <i>"Surely they should be a bit judgemental so they can decide what to do if you are ill or something, so they can... make the right decisions."</i></p> <p>Most children in both the 7-11 groups we covered this section with were unsure about what being non-judgemental meant. However, when it was explained to them, they agreed this was important.</p>	
1.2.4	<p>"Take time to listen to and address the concerns and fears of children and young people, and of the parents or carers of babies and young children. Treat their concerns and feelings (such as fears and embarrassment) with empathy and understanding."</p>	<p>Young people in the 11-14 group mostly liked this section but thought it should mention the importance of reassurance when discussing fears. One described it as <i>"good but reassurance is missing"</i>, while another young person said <i>"Listening and addressing [fears] is important but so is reassuring us that everything is going to be okay. The whole emotion bit at the end is important too."</i> [The young people gave it an average of 7/10]</p>	<p>We have added offering reassurance into this recommendation.</p>
1.2.7	<p>"Use developmentally appropriate creative and interactive tools to help effective communications with babies, children and young people (for example, play dough, puppets, games)"</p>	<p>Young people in the 11-14 group did not particularly like this section of the Guideline and identified it as the least important part of the 'Communication' section. Comments mostly focused on the given examples of "play dough, puppets and games" which children in both age groups did not like.</p> <p>Comments from 11-14 group:</p> <ul style="list-style-type: none"> <li>- <i>"It depends what sort of age group, but play dough and games might not be needed as much if they are older"</i> and another stated <i>"this isn't really appropriate for our age."</i></li> <li>- One young person suggested that this section should include <i>"interactive tools that are better for older kids like drawing and writing"</i></li> </ul>	<p>We have removed the use of puppets, and added pictures, diagrams or writing as examples instead.</p>

		<ul style="list-style-type: none"> <li>- <i>"this is better for younger children, - puppets and stuff are not really helpful or appropriate for us"</i></li> <li>- <i>"Using pictures and photos would be better and easier for the doctor and us"</i></li> <li>- Another young person thought that a "Question box should be an option, this might be better for teens and young adults too"</li> </ul> <p>[The young people gave it an average of 5.7/10]</p> <p>Likewise, in one 7-11 group the children suggested "can't they take a picture?" and "they could show a diagram"</p> <p>In another 7-11 group, the children we asked specifically about this wording. 8/10 of the children said they did not think this would help them understand they did not think these tools would help them communicate. Instead, they suggested healthcare professionals could "maybe [use] some pictures" or demonstrate on "another human being"</p>	
1.2.16 & 1.2.17	<p>"When giving information to the child or young person, or the parents or carers of babies and young children:</p> <ul style="list-style-type: none"> <li>•use their preferred method where possible. This may be in person face-to-face or using other methods (for example email, phone call, text message or video call)" &amp;</li> </ul> <p>"Ensure information for children and young</p>	<p>All 8/8 children in a 7-11 group we spoke to thought that healthcare staff phoning or texting them directly with information about their healthcare would be very important. This emerged as their top priority for how healthcare staff should provide information.</p>	<p>We have retained these recommendations.</p>

	<p>people is provided privately when appropriate, for example: ... by telephoning or texting them directly”</p>		
<p>1.2.19</p>	<p>“Provide information for children and young people that is... presented in accessible formats and language that can be understood by them (for example through an interpreter, translated into another language, or as an easy-read version using pictures and symbols)”</p>	<p>YP were not sure about this section as they thought this point was crucial but that the wording didn’t reflect this strongly enough.</p> <ul style="list-style-type: none"> <li>- One young person rated it a 5/10 and explained <i>“it needs to say more about this because it is so important and it’s not really clear what this means.”</i> Others agreed it wasn’t as strong as it could be but weren’t sure how to improve it.</li> <li>- Young people talked about the importance of healthcare staff <i>“Making language they use accessible and understandable by any young person”/ “should say for them to use clear words”</i></li> <li>- One young person explained <i>“This is important because while you might say you have understood, you might not really have understood what something means or what is going to happen. Making the language simple means you know people will have really understood it.”</i></li> </ul> <p>[The young people ranked this a 6.2/10]</p> <p>One 7-11 group we spoke to also thought this issue of accessible, clear language was “really, really important.” One made the additional point that <i>“your parents might not speak English and they won’t understand it, so if they can’t understand it then you will really need to understand it.”</i></p> <p>All 6 out of 6 children in another 7-11 group we spoke to all agreed that</p>	<p>We have defined accessible in the ‘terms used’ section and in the glossary. We have used simpler language in the recommendation and used the term ‘simple and clear language’.</p>

		using simple language was really important.	
1.3.7	<p>1.3.7 Discuss with children and young people how much information they would like about risks and benefits and take this into consideration.</p> <p>Recognise that some children and young people:</p> <ul style="list-style-type: none"> <li>•might not want to know about risks, or not on a particular occasion</li> <li>•might need additional opportunities to discuss risks and benefits</li> <li>•might benefit from alternative methods of communicating risks and benefits</li> <li>•might need to take a break when discussing risk, and to come back to the topic later</li> <li>•might want to discuss the risks and benefits without their parents or carers present.</li> </ul>	<p>The children in a 7-11 group mostly agreed with all of these bullet points. Notably, all 8/8 thought that being given additional opportunities to discuss risks and benefits was really important.</p> <p>However, 7 out of 8 did not think it was important that healthcare staff gave them the option to discuss risks and benefits without their parents and carers present.</p>	<p>We have retained these recommendations, including the last bullet. Although the children did not think the last bullet was important, the committee agreed that it was important to emphasise in this section of the guideline, as well as others, that children and young people should be offered the opportunity to see a healthcare professional on their own.</p>
1.5.5	<p>Ensure that children or young people who do not have a parent or carer to support them, or whose parents or carers are not able to support them, are offered other sources of support (for example, an advocate, social worker, youth worker, nurse or play specialist).</p>	<p>Children in one 7-11 group were asked whether they would want to be supported by an advocate, a social worker, a youth worker, a nurse or a play specialist if they did not have their parents with them, and 5/11 said they would whereas 6/11 said they would not like to be supported by any of these people. Instead, they suggested <i>"maybe someone in your family who is not your parent, like your sister or your aunt or someone"</i></p>	<p>We have added the option to be supported by another family member or friend to this recommendation.</p>
1.5.13	<p>Facilitate self-advocacy in children</p>	<p>The young people thought most of these points were very important. However, they were all less keen on</p>	<p>We have retained this recommendation, including the bullet</p>

	<p>and young people. This may include:</p> <ul style="list-style-type: none"> <li>•allowing enough time in consultations and appointments</li> <li>•providing confidential and private spaces</li> <li>•providing information on their rights to advocate for themselves</li> <li>•establishing the child or young person’s preferred method of communication, paying particular attention to those who do not communicate verbally</li> </ul>	<p>the third bullet point: “providing information on their rights to advocate for themselves.” 5 out of 7 young people in the 11-14 group felt this was not important at all.</p>	<p>point on providing information on rights to self-advocate. Although the young people thought this was not important, the committee were aware that the young people in the 11-14 group were probably very aware of their rights to advocate for themselves, but that not all children and young people would be aware of these rights.</p>
1.5.14	<p>Assume that all children and young people have views and opinions about their own healthcare, and actively encourage them to express what matters to them.”</p>	<p>The young people really liked this section of the Guideline and rated it 9.9/10</p>	<p>We have retained this recommendation.</p>
1.5.15	<p>“Empower children and young people to advocate for themselves by... considering the use of age- and developmentally-appropriate healthcare-management applications, such as smartphone apps.”</p>	<p>The young people thought most of the bullet points in this section of the Guideline were fairly important. However, they were less keen about the wording around using Apps. 2 young people thought this was of middling importance and 5 thought it was not important at all.</p>	<p>We have retained this recommendation. Although the young people in the reference group thought this less or not important, the young people on the committee (who were slightly older) were very positive about the use of healthcare-management apps.</p>
1.5.16	<p>“Support children and young people to develop skills in advocating for themselves by offering opportunities to be involved in feedback, service design or improvement or other</p>	<p>The young people liked this section of the Guideline and rated it an average of 8.5 out of 10, although one mentioned that they may be biased as young people who were involved in a project to give their experiences of health! One young person suggested <i>“local hospitals should have youth forums</i></p>	<p>We have already suggested a variety of ways to give feedback in the recommendations so we have not added the examples of youth forums at local hospitals or feedback</p>

	engagement activities”	<i>where they invite local young people to speak to experts in their local areas and local GP services should have feedback forms specifically for young people that they can fill out and put into a feedback box at the main reception area.”</i>	forms at GPs to the recommendation.
1.6.1	<p>“Ensure babies, children and young people who are inpatients have access to food that meets their needs. This should include:</p> <ul style="list-style-type: none"> <li>•a balanced diet that will help with their recovery – The young people thought this was very important</li> <li>•a choice of food options that are culturally and dietetically appropriate at every meal (e.g. things like food that is Halal or vegetarian) – The young people thought this was the most important of the three</li> <li>•food choices and menus that have been developed in conjunction with children and young people – This was the least important to the young people, and they pointed out that different young people like different things</li> </ul>	<p>The young people thought the points in the Guideline were important, particularly “a choice of food options that are culturally and dietetically appropriate,” although they found the wording of this hard to understand and it had to be explained to them.</p> <p>However, they felt a lot was missing and that it didn’t reflect their previous comments about food.</p> <ul style="list-style-type: none"> <li>- The young people in the 11-14 group thought it was important children and young people were given food that they liked, as well as food that met their dietary and other needs.</li> <li>- Several young people also mentioned the importance of having a choice of food “<i>Could they ask what we want?</i>” / “<i>Important that we have a few options we can pick from</i>”</li> <li>- “<i>Although [being] balanced health-wise [is important] there needs to be a wide range of options to meet needs and wants.</i>” All the 11-14s liked the wording of “<u>needs and wants,</u>” with one explaining “<i>it would make you feel worse if there is only food you really hate and at the moment the suggestions are only about need</i>”</li> <li>- Young people also thought having fresh food was</li> </ul>	We have added more detail about choice of food options, healthy food, flexibility and the availability of snacks to this recommendation.

		<p>important - <i>“There should be fresh food, rather than frozen food or stuff that comes out the microwave, because this is much nicer and will help you feel better”</i></p> <ul style="list-style-type: none"> <li>- One young person wrote it is <i>“good if there are snacks if you are hungry”, another suggested “[they could] make healthy but nice foods such as granola bars and fruit easily available like in vending machines or in the room”</i></li> <li>- The young people thought the point about CYP involvement in developing food menus was less important as different young people had different tastes. <i>“I think it is more important that there is a variety of food young people can choose from than a few young people having a say in the menu”</i></li> </ul> <p>[The young people gave this section an average rating of 4/10]</p>	
1.6.2	<p>“Pain-related anxiety Minimise the fear and anxiety about pain which may be experienced by babies, children and young people during healthcare interventions by:</p> <ul style="list-style-type: none"> <li>• preparing them with information about interventions or procedures</li> <li>• being honest about possible pain and what will be done to</li> </ul>	<ul style="list-style-type: none"> <li>- Overall, the young people really liked this section of the Guideline, and felt it covered a lot of different areas and reflected their key concerns.</li> <li>- However, a few young people mentioned the title of this section “pain-related anxiety” which they didn’t like. <i>“Maybe just call it ‘Pain’ or ‘managing pain,’ I am not sure why it mentions anxiety at all?”/ “why does it say anxiety, if this is about real pain?”</i></li> </ul>	<p>We have not changed the title of this section as it was not within the remit of the guideline to discuss pain management. We have changed ‘minimise’ to ‘reduce’ as suggested. We have included injections as an example as this was mentioned frequently in all the groups.</p>



	<p>alleviate pain (reduce the pain)</p> <ul style="list-style-type: none"> <li>• use play and distraction techniques before, during and after procedures or interventions which are likely to be painful</li> <li>• show children and young people their experiences of pain, are believed</li> <li>• avoid language that minimises the child or young person's experience of pain (for example, saying a procedure they found painful "didn't really hurt")."</li> </ul>	<ul style="list-style-type: none"> <li>- One young person also thought the first sentence to "minimise the fear and anxiety about pain" could be confusing with a later point about not minimising experiences of pain, and suggested it could say "<i>reducing the fear and anxiety about pain</i>"</li> <li>- [The young people gave this an average of 8.5 out of 10]</li> </ul>	
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