

Supplement 4a: Evidence from reference and focus groups

Black text – November 2019; Red text – February 2020; Green text – October 2020

No.	Questions	<7 years	7-11 years	11-14 years
1.1	How do children and young people, and the parents and carers of babies and young children, prefer to be involved and supported in planning their healthcare and making informed, shared decisions about their health?	<ul style="list-style-type: none"> • 	<ul style="list-style-type: none"> • Let you be honest • I like giving my opinion because: <ul style="list-style-type: none"> ○ 'I like giving my opinion for subjects that I like, it shows I love them if I give my opinion' ○ 'I like talking about opinions; it could help the person that you're speaking to so they can understand you' ○ 'It is better to tell them more about my opinion' ○ '[They] need to understand what is wrong with you' • I may not like giving opinion because: <ul style="list-style-type: none"> ○ 'I don't want to be picked on' ○ 'Some days I want to share more than other days' ○ 'I just don't like to [give my opinion] sometimes but sometimes I want to share more' ○ 'Don't know, might feel like you know what it is but you're not sure, might hurt in some places but don't know how you feel' ○ 'Mum and dad might help but they might not know as well as me' • I don't like giving my opinion because: <ul style="list-style-type: none"> ○ 'Opinions can be personal/ secretive, can be rude, thinking that I don't want to share, I could get into trouble' • I like being listened to because: <ul style="list-style-type: none"> ○ 'I like people listening to my ideas, I want to share how you are feeling' ○ 'Some people listen well and some don't' ○ 'Being listened to is better than anything – they can listen to you whether it's an emergency or not' • I don't like being listened to because: <ul style="list-style-type: none"> ○ 'People can say no' ○ 'Some things you want to share and others you don't' ○ 'If in a rush or you are a bad [very ill] patient or if in an emergency /bleeding out, being listened to is less important' • I am happy asking questions in hospital or of school nurse because: <ul style="list-style-type: none"> ○ 'Depends what it's about, something to do with health then they can help you' ○ 'They aren't expecting you to know anything' 	<ul style="list-style-type: none"> • I like giving my opinion because: <ul style="list-style-type: none"> ○ 'So I'm not left out' ○ 'I like people to know my opinion because otherwise... they won't know it. People might not take my thoughts into account, they might not do what I think is right to me' ○ 'Because I think my opinion matters' • I feel comfortable asking a nurse or a doctor a question if I don't understand because: <ul style="list-style-type: none"> ○ 'I have to go see a doctor every half a year and I do feel comfortable, I enjoy seeing the same doctor every time' ○ [One commented] 'I've never been in that situation' • I don't feel comfortable asking a nurse or a doctor a question if I don't understand because: <ul style="list-style-type: none"> ○ 'I just don't like asking questions – there's nothing they could do to make me feel more comfortable and I don't think this will change as I get older' ○ Curiosity kills the cat • I like to make decisions about my health and body because: <ul style="list-style-type: none"> ○ 'It's all about confidence and independence – I should have a say in what happens to me' ○ 'It's your body so you should choose what to do with it' ○ 'You need to be able to make decisions about what happens to you' ○ 'It's fine for people to talk through it with you, but if you don't want to do it then you should tell them' ○ 'You don't always have to agree with everything they are saying, but they can still be a part of it – because you will know what helps you even if they don't' ○ [one was unsure and said] 'I don't care what happens to my body' [then thought about it more and decided it was more important to them] • Only adults get to make decisions about their child's health care: <ul style="list-style-type: none"> ○ All disagreed with this statement ○ 'It's your decision, it is not up to adults to overpower you with what they say' ○ 'It's our bodies we should get a say in what happens'

			<ul style="list-style-type: none"> ○ 'Sometimes you don't even know if you're sick' ○ 'If you tell a doctor, they can help you better, in case you have a really bad infection or something' ○ 'People would have asked them questions before' ○ 'Would be scared if they did not tell you information' • I am unsure about asking questions in hospital or of school nurse because: <ul style="list-style-type: none"> ○ 'I might be scared if you ask a question' ○ 'They could hurt you' • I am NOT happy asking questions in hospital or of school nurse because: <ul style="list-style-type: none"> ○ 'Embarrassing, wouldn't ask anyone' ○ 'Nervous to say it out loud' ○ 'I don't really like talking to nurses or doctors... just how I feel' ○ You're used to your teacher as you see them every day, but you don't see the doctors every day, doctors you don't know them as well so you could get really nervous' ○ 'Something might be really, really important but you can feel embarrassed telling them' ○ You don't want to talk to everybody, some days just feel like that' ○ 'Sometimes you are tired, if you've had a seizure or something, so you might just want to listen or go to sleep... harder when you're not well' ○ 'Sometimes I feel nervous asking questions' ○ 'Ask your parents and then they ask for you' • I like to make decisions about my own body/health because: <ul style="list-style-type: none"> ○ 'If you don't want injections tell them to stop' ○ 'I like being healthy, but I prefer to look after myself' ○ 'If you had a tummy ache and mum and dad did not believe you it's not about your mum and dad deciding' • I am unsure about making decisions about my own body/health because: <ul style="list-style-type: none"> ○ 'I ask a lot of questions, understand what is happening' ○ 'When you're a ten year old kid like me, you might be quite unaware of things so you might need your parent or guardian or to help you in those times' ○ 'Parents may know better; I like a little help but mostly do it by myself' • I don't like making decisions about my own body/health because: 	<ul style="list-style-type: none"> • How comfortable asking questions and say how feeling if in hospital or from school nurse: <ul style="list-style-type: none"> ○ 'The setting makes a difference but also the person makes a difference' • What questions would you want to ask if having appendix out: <ul style="list-style-type: none"> ○ 'What's the appendix?' ○ 'How soon would it be taken out?' ○ 'What is the process/operation?' ○ 'How long the recovery?' ○ 'Where will it be done?' ○ 'Will I survive?' ○ 'Will I wake up?' ○ 'Will I have to be asleep for long?' ○ 'How long to fall asleep?' ○ 'Will it hurt?' ○ 'Am I allowed to eat/drink before the operation?' ○ 'When will I go back to school/college?' • What questions would you want to ask if having tooth taken out: <ul style="list-style-type: none"> ○ 'Will I still get braces? And what will I do if there is a gap?' ○ 'Will I be asleep/anaesthetic?' ○ 'Why do I need it out?' ○ 'How long until it will get sore?' ○ 'What if squeamish and scared of blood?' ○ 'What happens if you pull out the wrong tooth?' ○ 'Adult tooth vs children's tooth – different?' ○ 'Will I be able to talk?' ○ 'Accept it' ○ 'Question it/ask why –because didn't say you have to, only they want to' • What questions would you want to ask if taking a new prescription medicine: <ul style="list-style-type: none"> ○ 'Ingredients – allergies?' ○ 'How many times to take it?' ○ 'Why nurse not doctor? Doctor for all prescriptions?' ○ 'Side effects – will it make you put on weight?' ○ 'Will I have to wake up in night to take it?' ○ 'Dosage/strength – overdose?' ○ 'What happens if you miss a dose?' ○ 'Does it taste horrible? Nice or not?' ○ 'How can I take it - chewing, swallowing whole or liquid like calpol dissolvable?' ○ 'How to collect medicine?' ○ 'What happens if it makes me sick?' • What questions would you want to ask if having an X-ray [for a broken arm]: <ul style="list-style-type: none"> ○ 'When will I have the X-ray?' ○ 'How does x-ray machine work?' ○ 'Will I need a cast? And when will it come off?' ○ 'How long will it take?'
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			<p>comfortable asking as it isn't a personal thing'</p> <ul style="list-style-type: none"> ○ 'If your appendix burst what happens?' ○ 'I would want to ask and listen – What are you actually going to do? Will it ever be uninfected?' ○ 'What is going to sleep going to be like?' ○ 'Please don't kill me' ○ 'Will you be careful?' ○ Sub-question: Would you tell them if you were scared? 4 said they would feel comfortable saying this, 1 some of the time/depends, 2 wouldn't feel comfortable saying this <ul style="list-style-type: none"> ● What questions would you want to ask if seeing a GP/talking to a therapist once a week about fear of spiders: <ul style="list-style-type: none"> ○ 'Why once a week?' ○ 'Is it that important – some people just like spiders and some don't' ○ 'Am I allowed to bring a friend or family member?' ○ 'What time do you want us there?' ○ 'Why is it necessary?' ○ 'Is there something else more important?' ○ 'Why am I here?' ○ 'Different with physical and mental health' ● What questions would you want to ask if at the dentist/GP/hospital, having a tooth out: <ul style="list-style-type: none"> ○ 'It might hurt' ○ 'Would I be put to sleep?' ○ 'When you go to sleep, when you wake up are you still feeling tired?' ○ 'Will anaesthetic make you go weird and why?' ○ One boy explained that his mouth and lips went weird and droopy afterwards but he hadn't been told in advance this was going to happen – he didn't mind because he thought it was funny but thought if it had been something bad, more scary he would not have wanted to know in advance 'because then I'd say 'get off me!' and be running away' ○ 'Is it a big bit or a small bit?' ○ 'Is it a baby tooth or big tooth?' ○ 'Why do you have to take it out?' ○ 'Will I get it back as an adult tooth?' ○ 'Will I die? – worried' ○ 'I would say 'I feel fine' ○ 'Will one grow back?' ○ 'Will I get a fake tooth?' ○ 'Do you have to take the tooth out now?' ○ 'Could I have something different, like a filling?' ○ 'Will it help the pain?' <p>General feedback about asking questions:</p>	<ul style="list-style-type: none"> <ul style="list-style-type: none"> ▪ Step 5: do the medication, get the place ready, tell foster parent, get qualified person ▪ Step 6: having medication, getting diagnosed, visiting doctor every so often, visiting dentist every 6 months ● Shared healthcare decision-making scenario #3: Sarah is 13 and he lives with her mum, nana and an older sister who is 20 <ul style="list-style-type: none"> ○ 'Step 3 most important – sharing thoughts' ○ 'Book appointments on own' ○ 'She might want her sister there when booking but might want to be on her own in the appointment' ○ 'More support from her mum to help her understand what the doctor is saying' ○ 'Talk through with friends' ○ 'More/most things by herself (probably) because mature' ○ 'Individually and independence more support' ○ 'Moral support important' ○ 'More support 5-7 ' ○ 'Mum to come in and explain if she has a question' ○ 'Mum and nan to give more support with decision making ultimate decision is hers'
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			<ul style="list-style-type: none"> • Some more comfortable asking parents questions/talking to them • Some more comfortable asking doctors, nurse questions/talking to them • Writing question's down asking them is also a good option – some of the young people said this would make a big difference if they were too nervous to say it out loud, some disagreed: <ul style="list-style-type: none"> ○ 'I don't like writing' ○ 'I would rather ask them in person so it goes quicker so you don't have to wait for them to read it and write it down' ○ The worry will be over faster' [if you ask] 	
1.2	How should healthcare staff communicate with babies, children, young people and the parents or carers of babies and young children?	<ul style="list-style-type: none"> • I like it when doctors are friendly –all agreed (18/18) • I like it if the doctor/dentist/nurse listens to me when I talk to them: <ul style="list-style-type: none"> ○ Agree (27/31) <ul style="list-style-type: none"> ▪ 'I like it when they are nice' ▪ 'I like it when they listen to me' ▪ 'I like telling them about my holidays' ▪ 'I agree because they are very kind' ▪ 'I agree because they respect my zone and are kind to me and respect my zone' ▪ 'Because they are always nice to you by saying that it might not hurt' ▪ 'If it does hurt, you can tell them and they will listen' ○ Disagree (4/31) <ul style="list-style-type: none"> ▪ 'I don't like the doctors, I don't want the injection and I have to have it anyway' ▪ 'They don't listen' • Doctors care about what I think and say: <ul style="list-style-type: none"> ○ Agree (8/16) <ul style="list-style-type: none"> ▪ 'Because they always take care of us' ○ Disagree (5/16) <ul style="list-style-type: none"> ▪ 'Because they gave me [an injection] once and I said ow and they didn't listen' • I like it when doctors talk to me: <ul style="list-style-type: none"> ○ Agree (13/22) <ul style="list-style-type: none"> ▪ 'Because the doctor who I see is really nice and my mummy and little sister like her and know her' ▪ 'Because it might be important' ▪ 'Because they can see what is the matter' ▪ 'Because they tell me I'm big and strong' ▪ 'They are kind' ○ Disagree (7/22) 	<ul style="list-style-type: none"> • 'Say hello' • 'I like it when doctors are friendly and good at their job' • 'Doctors who have a big, friendly smile' • 'Doctors who make you feel relaxed' • 'Not be rude' • 'Doctors notice when you have been brave and haven't screamed' • 'Doctors and nurses not be too busy' • 'Listen to how you are feeling' • 'Doctors ask what you like and what you don't like' • 'Doctors treat us nicely, be a nice doctor' • 'Doctor's not being rude – swift 2 seconds and you need to get out now, she should take her time' • 'Smart – how they talk, but lots of long words can be confusing 'normal common words, please.' • 'Being friendly is the most important – if they're not friendly, they might ask you 'how have you been feeling today' [cross voice] and it won't help you answer but if they're friendly they might say 'how have you been feeling today' [kind voice] and you'll answer – so they link together' • 'When doctors say something... it's like, I don't know what this means. So if you ask a question you don't know what they mean' • 'If they use the complicated words I prefer if they [health professionals] talk to mum and dad but if they use words I understand I prefer them talking to me' • 'Doctors should ask: 'What do you want to ask?'' • 'Doctors should use clear words' • 'Doctors can use words you understand' 	<ul style="list-style-type: none"> • 'Listening' (MH services) x 2 • 'You can make jokes with the same people without being mixed up' (MH services) • 'Good people friendly' (MH services) • 'Doctors and nurses are friendly and welcoming' (MH services) • 'Go with the flow' (MH services) • 'Not short-tempered, grumpy' • 'Pay attention' • 'Make eye contact' • 'Friendly' x2 • 'Not time-limited' • 'Communication' • 'Don't just read from pages' • 'Welcoming' • 'Face to face support' • 'Tell us things' • 'Kind staff –explanations, so know what is happening'

		<ul style="list-style-type: none"> ▪ 'Because they are weird' ▪ 'Because they hurt' ▪ 'I don't like it when they don't give me a sticker' • How would the world's best doctor or the world's best nurse talk to you? <ul style="list-style-type: none"> ○ 'Be kind, be nice' ○ 'Helps me understand' • How would the world's worst doctor or the world's worst nurse talk to you? <ul style="list-style-type: none"> ○ 'Mean' x3 ○ 'Asks 'Why did you fall over?' x2 ○ 'Shouts at me' x2 ○ 'Bossy' x2 ○ Shouts 'You have to do this, and you have to do that.' ○ 'Cross – says 'You should have been more careful'' ○ 'Frustrated' ○ 'Rude' ○ 'Ignoring me' ○ 'Says 'Get out now!' when you might have fallen and broken your leg' • Doctors and nurses should use words I understand: <ul style="list-style-type: none"> ○ Agree (17/18) <ul style="list-style-type: none"> ▪ 'If they use words I don't understand, I don't know what is happening' ▪ 'I never know what it means' ▪ 'I don't know the words that a doctor is going to use' ▪ 'Don't know what the instrument is and when I don't know what it is and then they use it on me, it feels a bit strange and scary' ▪ 'It makes me feel scared when I don't understand' 		
1.3	How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?	<ul style="list-style-type: none"> • I would like the doctor to tell me what they were going to do before they did it (9/12) because: <ul style="list-style-type: none"> ○ 'I don't know so I want them to tell me what they'll do first' ○ 'I want to know what will happen' 	<ul style="list-style-type: none"> • What does consent mean? <ul style="list-style-type: none"> ○ 'Doctors shouldn't close the curtains and give treatment you don't know why' ○ Not being given medicine without permission' ○ 'I think it means something personal' ○ 'I know what a concern means' ○ 'Initials and signing something' ○ 'To make sure we are allowed' ○ 'Asking for permission' ○ 'Something personal' ○ 'Is it anything about your senses?' ○ 'Give them, a child if they think you feel good, they take you to the teachers' ○ 'Telling an adult you don't feel well and you keep it to yourself' ○ 'Maybe when you go to hospital' ○ 'Permission to get into the hospital' 	<ul style="list-style-type: none"> • What does confidentiality mean? <ul style="list-style-type: none"> ○ 'Private' (MH services) ○ 'Not exposed area' (MH services) ○ The group struggled to define this; they got it confused with confidence • What does consent mean? <ul style="list-style-type: none"> ○ 'Giving permission' ○ 'Permission you have given for someone to do something – asking my permission to share information with my school' • How would you like to be made aware about what your rights around consent are? <ul style="list-style-type: none"> ○ Face to face (4/6) <ul style="list-style-type: none"> ▪ 'Because you can sort it out in person', ▪ 'It is just best for them to do this in the moment, when you need it, whenever you start to access those services'

			<ul style="list-style-type: none"> ○ 'Asking the doctors or nurses if you can do something or not' • What does privacy mean? <ul style="list-style-type: none"> ○ 'It's if like I want to be alone' ○ 'I'm not sure' ○ 'Something private, like a bank' ○ 'When you go to the doctors and talk to them' ○ 'Toilets' ○ 'When you see a doctor you don't know' ○ 'It's if like I want to be alone' ○ 'Leaving people be' ○ 'Your own space' ○ 'In your tummy' ○ 'When going to the loo' ○ 'Parts of your body' ○ 'When you need some private space' ○ 'When you have private parts of your body as well' ○ 'Respecting when people want privacy you have to leave them be' ○ 'It's in my tummy' ○ 'When you want to be in private and you don't want people to see' ○ 'There are private bits of your body' • What does confidentiality mean? <ul style="list-style-type: none"> ○ 'Comfortable' ○ 'Give someone a piece of information' ○ 'When you feel confident and comfortable sharing your business with people, when you give someone a piece of information and they keep it private, but after 1 - 2 months they have to throw it away very careful, it would happen when you have a wedding' ○ 'Something you are confident with' ○ 'You are confident and a bit nervous at the same time' ○ 'It's when you're quite brave' ○ 'NHS' ○ 'Treatment' ○ 'Privacy' ○ 'Hospital' ○ 'Doctors' ○ 'Telling doctors what is happening' ○ 'Health care' ○ 'Does it mean having confidence?' ○ 'Doctors' ○ 'Hospitals' ○ 'Treatment' ○ 'When you tell the doctor how you are feeling' ○ 'Does it involve the NHS?' • When a doctor is talking about something private, I want to be by myself <ul style="list-style-type: none"> ○ 4 disagreed <ul style="list-style-type: none"> ▪ 'I want my parents or someone to be with me' 	<ul style="list-style-type: none"> ○ Over email ○ Reading a booklet (2/6) ○ Over the phone (2/6) <ul style="list-style-type: none"> ▪ 'You are talking which is better, I don't like typing or anything' ▪ 'Better to have a chat' ○ Over social media (0) ○ Texting (3/6) <ul style="list-style-type: none"> ▪ 'You can read it when you want' ○ One young person really didn't want it to be face-to-face because 'I just don't like leaving the house' • If you had a face to face or over the phone meeting, who would you want to talk to you about confidentiality and privacy? <ul style="list-style-type: none"> ○ Your own doctor (2/6) <ul style="list-style-type: none"> ▪ 'Better because they're going to give us more information and detail [than parents]' ▪ 'Definitely my own doctor would be best but this has changed over time. Would have picked my parent when I was younger' ○ Your parent/guardian (3/6) <ul style="list-style-type: none"> ▪ 'Because I know them more and it would just a feel bit more private because I tell everything to them... I feel like they would be a lot more supportive' ▪ 'More supportive and you're more comfortable with your parents' ▪ 'I'd pick my mum... she makes me comfortable, she could tell me anything and I could tell her anything' ○ No one 1/6) <ul style="list-style-type: none"> ▪ 'I would want to read about it online or in a booklet' ○ Other options offered were: a nurse, a different kind of healthcare worker, a school/college /university nurse or a teacher but none of the young people selected any of these options. • Who would you want in the room with you when a healthcare professional talks to you about private things? <ul style="list-style-type: none"> ○ Parent/guardian (5/6) <ul style="list-style-type: none"> ▪ 'I would want my mum and the doctor' ▪ '[My parents] are very supportive and can help you understand what is going on' ▪ 'They [parents] could probably help you understand better' ▪ 'To help you understand and relax a bit so it's a bit more comfortable with your parent in the room'
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			<ul style="list-style-type: none"> ▪ 'I pick no because I want my parents to be with me' ▪ 'I think the same because I need someone to be with me, I want my parents to be with me' ▪ 'I am standing by no because my mum is really special to me and I really love her and I wouldn't want anyone else. I would want to bring my mum with me' ▪ 'I just want my dad to know to help me and if my dad is not there he cannot hear my private conversation' ○ 5 agreed <ul style="list-style-type: none"> ▪ 'My mum gets too worried and is annoying, I don't like it when mum worries' ▪ 'I get really funny sometimes if I am with other people and I need to talk about something private and if someone hears I can get angry and hurt someone. With everybody else there' ▪ 'I really like doctors' ▪ 'If it was private, I would not want anybody to know because it is a secret' ○ 2 unsure <ul style="list-style-type: none"> ▪ 'I think I would need my mum with me but at the same time, when the doctor says something like you're coming down with something my mum will be like 'Oh my god you need to do this you need to do that' ▪ 'I like when my mum worries about me sometimes but at the same time I feel like she does it a bit too much.' ▪ 'Sometimes yes, it depends what it was about' • I would prefer it if the doctors spoke to my parents about privacy and consent than myself <ul style="list-style-type: none"> ○ 1 disagreed <ul style="list-style-type: none"> ▪ 'Sometimes when they make me leave I don't think the doctors will keep everything confidential. I feel like sometimes they kind of like, they'll say can you leave the room and I don't like that because my mum is making decisions on my behalf and then some things they don't keep everything private and confidential, sometimes things can leak' (they = the doctors) ○ 2 agreed 	<ul style="list-style-type: none"> ▪ 'So you don't have to go out [of the room] and then repeat what the doctor has said' ▪ 'Mum to help you understand and relax a bit' ○ Just myself (1/6) <ul style="list-style-type: none"> ▪ 'Definitely I would rather be by myself but I'm not sure if I could as there is a requirement not to be on your own if you are under 16 I think' ○ Other options offered were: a sibling, carer or support worker but none of the young people selected any of these options. • Do you think a healthcare professional should communicate to children and young people directly about consent and privacy, or should they speak to your parent/guardian? <ul style="list-style-type: none"> ○ Talk to both of us (6/6) <ul style="list-style-type: none"> ▪ 'To make sure there is general awareness' • Do you feel able and confident to choose who you would like to share your private health information with? <ul style="list-style-type: none"> ○ Yes (5/6) <ul style="list-style-type: none"> ▪ 'I can make up my own mind' ▪ 'I feel confident in what I want' ○ No (1/6) <ul style="list-style-type: none"> ▪ 'I would want a bit of support from my parents with this'
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			<p>virus, it makes me worried because I can die and get worried if the doctor will tell my parents they will tell everyone and get worried.'</p> <ul style="list-style-type: none"> ▪ 'This worries me a lot' ▪ 'If they did tell someone I would never go to the doctors again' ▪ 'I like doctors and I don't want people to find out that I have something bad with me' <ul style="list-style-type: none"> ○ 5 unsure <ul style="list-style-type: none"> ▪ 'if they don't tell them, they might not be sure' ▪ 'It depends what they would tell them' ▪ 'I don't know' ▪ 'If it was bad, I would be worried they would tell my parents. If it is good then I don't mind' <ul style="list-style-type: none"> • Who would you want to help you make decisions about your consent? <ul style="list-style-type: none"> ▪ 'Mummy or daddy or the doctor' x2 ▪ 'People who know about your healthcare' ▪ 'Mum is good at helping me' ▪ 'Dad because he is a doctor' ▪ 'Mum and dad because they know me' ▪ 'I would ask other nurses because other nurses help other people so they can help me' 	
2.1	How do children and young people, and the parents or carers of babies and young children prefer to access healthcare information?	•	•	<ul style="list-style-type: none"> • 'Have helplines' (MH services) • 'Don't make it overwhelming' • What sources of information would you use if you didn't understand or didn't feel able to ask a question: <ul style="list-style-type: none"> ○ 'Tiktok – video of young person explaining' ○ 'Video of adult explaining' ○ 'Books' ○ 'My favourite way to get answers would be from my mum' ○ 'Alexa?' (The young people agreed that they were not very comfortable asking Alexa question about health - much more comfortable asking Google) ○ 'Google' ○ 'Leaflet from hospital/school etc'.
2.2	What are the best ways to help children and young people and the parents and carers of babies and young children	•	<p>Would you want to know all the risks in advance [having a tooth out] or not be told?</p> <ul style="list-style-type: none"> • Some would want to know: <ul style="list-style-type: none"> ○ 'So it isn't a bad big, surprise' ○ 'If I know the risks it would make me feel better' 	<ul style="list-style-type: none"> • How should risks and benefits of having a filling be explained? <ul style="list-style-type: none"> ○ 'Talk to us about the things you are concerned about' ○ 'Eat healthy' ○ 'It will reduce pain'

	understand the risks and benefits of healthcare decisions?		<ul style="list-style-type: none"> ○ 'I'd like to be told at least 1 week before to prepare for it' • Some were unsure: <ul style="list-style-type: none"> ○ 'I want to know the risks but don't want to get scared, so could say what the risks are but then say all the things they were doing to stop the risks' • Some would not want to know <ul style="list-style-type: none"> ○ 'Could be really bad, if it's a surprise you might be more worried' ○ 'If they told you, you would be in pain you would be really worried and wouldn't want your teeth pulled out so might try to fix it yourself and not go in' ○ 'If I hear that, I'd get really scared and say to my dad I didn't want to do this anymore' ○ If it was serious, I'd be scared so prefer not to know 	<ul style="list-style-type: none"> ○ 'Don't worry it is quick' ○ 'Rating' ○ 'Don't worry, talk to us if you are concerned. These are risks but they are very rare' ○ 'It prevents infections to tooth' • How should risks and benefits of having a vaccine be explained? <ul style="list-style-type: none"> ○ 'A side effect is that you may feel sick after' ○ 'When you're done you get stickers' ○ 'There may be temporary side effects but I'm much more protected now' ○ '3 in 1 booster vaccine for teenagers' ○ 'The jab protects you from illnesses' ○ 'Is it safe? Sure?' ○ 'It helps your immune systems' ○ 'That vaccine means that I can't get them' ○ 'You can have an allergic reaction but 1 in 100 people get that' ○ 'Sometimes, some people may have side-effects. But don't worry, it's rare'
3.1	How do children and young people want their parents or carers to be involved in their care and decisions about their care?	<ul style="list-style-type: none"> • 'When I have my head cut open, my mum was there with me. It was nice because my mummy loves me' • Would you want to talk to a doctor or nurse on your own? <ul style="list-style-type: none"> ○ 'Yes because I think they are going to be very kind. If she was worried they would not be kind, she would want to be with someone else, but trust they will be kind.' ○ 'Yes, because your mum might interrupt' ○ 'Yes, because the doctor wouldn't hurt me' ○ Yes, because if it might hurt, our mums can always cuddle us' ○ 'It's scary on your own' ○ 'No because I would feel scared and a bit lonely. I would want mummy and daddy with [me].' ○ 'I would like to go with someone because if I went on my own I would feel scared – would want my mummy, daddy and my brother' ○ 'Want my mum with me because what if a stranger came in and the doctor was in a different room? Wouldn't want to be left on my own if the doctor went out the room' • I like it when doctors talk to my parents more than me: <ul style="list-style-type: none"> ○ Agree (7/18) <ul style="list-style-type: none"> ▪ 'Because our parents might tell [the doctor] something important' ▪ 'Because you don't want to be there all by yourself' 	<ul style="list-style-type: none"> • 'Let your parents come into appointments/injections with you' • 'Parents being allowed into appointments with you' • Parents and carers should help you make decisions: <ul style="list-style-type: none"> ○ Agree: <ul style="list-style-type: none"> ▪ 'Good for them to choose for you' ▪ 'Mum says I'm going to be fine' ▪ 'You should get help to make your health decisions because you could be wrong' ▪ 'I don't know what I'm doing, if I think something is right, I ask my parents 'is it right or wrong?' and sometimes they tell me I'm wrong' ▪ 'I want to make own choices but also need help. Need to make joint decisions' ○ Unsure: <ul style="list-style-type: none"> ▪ 'Don't know, sometimes I would and sometimes I wouldn't' ▪ 'Parents have more experience – things can go wrong if forced' ▪ 'I'm in the middle because you want to make your own choices but your parents do too, so you want to listen to them but you think you're right at the same time – and I don't know if they know the answer or not. Has to be a bit of me and a bit of them' ○ Disagree: 	<ul style="list-style-type: none"> ○ Parents/carers should help you make decisions: <ul style="list-style-type: none"> ○ Agree: <ul style="list-style-type: none"> ▪ 'Parents can help talk it through with you, they can help you make good decisions – point out the good things about your decisions and the bad things' ▪ 'They can help explain it to us' ▪ 'Easier to ask parents than doctors because you just trust your parents' ▪ 'Parents made you, they should have a say in what happens – but this is just a say, not forcing you to have decisions' ○ Disagree <ul style="list-style-type: none"> ▪ 'Sometimes having them involved makes it more difficult. You have to make your own mistakes. And they start nattering on about everything, so you don't get to make the choice in the end' • Parents/carers should make decisions for you: <ul style="list-style-type: none"> ○ Agree <ul style="list-style-type: none"> ▪ 'In case you do something wrong' ▪ 'I make loads of mistakes, so my mum picks me up and helps me going' ○ Unsure <ul style="list-style-type: none"> ▪ 'We should make our own decisions but they should have an input on what happens'

		<ul style="list-style-type: none"> <ul style="list-style-type: none"> <ul style="list-style-type: none"> ▪ 'The doctor might be telling them something important and they will know' ○ Disagree (11/18) • When I see the doctor I want my mum or dad to be with me: <ul style="list-style-type: none"> ○ Agree (11/15) <ul style="list-style-type: none"> ▪ 'I feel comfortable because my mum is with me and I can sit on her lap' ▪ 'I don't like it there when the doctors check my mouth so if I get scared, I need my mummy to help me with the scared... and my daddy can help drop me off there' ▪ 'Makes me feel safe' ○ Disagree (3/15) <ul style="list-style-type: none"> ▪ 'I want my friends to come and take care of me instead' 	<ul style="list-style-type: none"> <ul style="list-style-type: none"> ▪ 'Will change when I get older, I have to learn to progress' • Parents/carers should make decisions for you: <ul style="list-style-type: none"> ○ Agree: <ul style="list-style-type: none"> ▪ 'Rather not do it myself, parents know what I need' ▪ 'I don't know what to do about my health, so my parents tell me what to do, what to eat etc.' ▪ 'This might change as I get older when I will feel more happy but now I want parents to help me, I might want them to make decisions for me when I get older too' ▪ Sometimes might feel like you're in a cage... I don't want them to take control, but sometimes you might feel insecure so you will need your parents to take control then' ▪ 'If you didn't like it or unsure, helpful for them to choose for you' ○ Unsure: <ul style="list-style-type: none"> ▪ 'Sometimes it gets annoying so they make you do what you don't want to do' ▪ 'They might not choose the best thing' ○ Disagree: <ul style="list-style-type: none"> ▪ 'I know what's right and what's wrong, they make decisions, not what I want' ▪ 'When I want to play and my dad says no so I take care of myself when I'm outside' ▪ 'I like having independence, I want to do it on my own.' • Who should the healthcare professionals explain things to? <ul style="list-style-type: none"> ○ 'Explain to my parents' (x5) ○ 'Explain to me and my parents' (x5) ○ 'Explain things to me' (x2) • Who could help you make decisions about your health? <ul style="list-style-type: none"> ○ 'Mummy' ○ 'Daddy' ○ 'Someone in my class' ○ 'Friends' ○ 'Doctor' ○ 'Grandpa' ○ 'Dogs' ○ 'Nanna' • When I go and see the dentist, I like it when someone comes in with me <ul style="list-style-type: none"> ○ 3 agreed 	<ul style="list-style-type: none"> <ul style="list-style-type: none"> ▪ 'Parents and the actual person it is happening to should have an equal say' ▪ 'It is your choice, but if something is too complicated or if it will scare you but it will help you a lot, if it has to happen, but if it is just up to you, you might choose not to do it but it could be vital' ○ Disagree: <ul style="list-style-type: none"> ▪ 'Because you should be able to make your own decisions' ▪ 'If I was two years younger, I would be more in agree [parents should make decisions for you] as two years ago I was only 9 and couldn't speak up for myself. In 2 years I have gained more confidence' ▪ 'You develop a sense of individuality' ▪ 'For some people it would have been important to make their own decisions at any age' ▪ 'In difficult circumstances e.g. parent dying, it can be much harder to make decisions – or when decisions feel too big to make' • Who could help you make decisions about your health? <ul style="list-style-type: none"> ○ 'Parents' ○ 'Adult siblings' ○ 'Family friends you trust' ○ 'Teacher' ○ 'Grandparent' ○ 'Psychologist' ○ 'Priest' ○ 'Carers/guardians' ○ 'Health care worker' ○ 'Group leaders' ○ 'School nurse' ○ 'First aiders' ○ 'Uncle and aunts' ○ 'NHS'
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			<ul style="list-style-type: none"> ▪ 'I want my mum with me and she did it last time' ▪ 'I don't like being alone and last time my mum came with me when I had a tooth out' ▪ 'I don't like the dentist' <ul style="list-style-type: none"> • I like it when the doctors speak to my parents before they speak to me <ul style="list-style-type: none"> ○ 5 agreed <ul style="list-style-type: none"> ▪ 'Because I want to know what the doctor is like first' ○ 5 disagreed <ul style="list-style-type: none"> ▪ 'I would like to know what is happening' 	
3.2	How do children and young people want healthcare staff to support them?	<ul style="list-style-type: none"> • I think doctors are nice because (6/13): <ul style="list-style-type: none"> ○ 'Because they help you a lot' ○ 'They give us medicine' ○ 'I do because I take my teddy' ○ 'They like you' • I don't think doctors are nice because (7/13): <ul style="list-style-type: none"> ○ 'They give me injections' ○ 'I don't like them' ○ 'I just don't like them' ○ 'It is scary' • I like getting stickers at the doctors because (13/13): <ul style="list-style-type: none"> ○ 'Because I like stickers' ○ 'I like the pictures on them' ○ 'Because they have dinosaurs on them' ○ 'I like them because they have green on them' • I like fun stickers (12/12): <ul style="list-style-type: none"> ○ 'I want unicorns on my stickers' ○ 'Planets on stickers' ○ 'An elephant on stickers' ○ 'Picacho' ○ 'Transformers' ○ 'A vet on my sticker' ○ 'Rabbits on stickers' • I like going to the doctor because (7/16): <ul style="list-style-type: none"> ○ 'Because my mum is there, she is a nurse' x2 ○ 'I like going to the belly doctor' ○ 'I like injections' ○ 'I am happy going to the doctor because they are nice to me' ○ 'They talk to me' • I don't like going to the doctor because (8/16): <ul style="list-style-type: none"> ○ 'I don't like having injection in my arm' ○ 'I am not happy to go to the doctor because I feel a bit nervous and scared' • I'm unsure about going to the doctors because: <ul style="list-style-type: none"> ○ 'Sometimes I get nervous and don't like what they have to do. Don't like it if they are giving an injection, but... I would be happy if they didn't have to give an injection and just give medicine' 	<ul style="list-style-type: none"> • 'Have a therapist who helps you make decisions but does not tell you what to do' • What should the doctor do to make you feel more comfortable [having appendix out/having an x-ray]? <ul style="list-style-type: none"> ○ 'Bring animals or toys' ○ 'Should reassure you – tell you 'you're not going to die'' ○ 'Telling you it's not going to hurt' x2 ○ 'Say 'you'll be asleep the whole time'' • What can healthcare professionals do to make you feel more comfortable [having a tooth out]? <ul style="list-style-type: none"> ○ 'Sofa, kitchen etc. if the room felt like home' ○ 'If it is fun – e.g. like a bedroom, put your feet up' ○ 'Need to be really friendly – so you feel you have known them for a long time so you can trust them more' ○ 'Especially if they talked about what things they liked so you get to know them better, so you can know who they are' ○ 'Get to know them better' ○ 'Fun games – bouncy castle, Wii, X-box' ○ 'Would be nice to have animals in doctors' surgeries, hospitals be more comfortable' ○ 'Animals just make you feel better' ○ 'I actually don't like animals, only cats, would need to choose... actually I don't think we should have pets. One word to explain it: allergies... hair balls could transmit diseases' ○ 'When you stroke them it calms down your blood' ○ 'Before I had surgery, I was scared as hell as I thought I was going to lose... my mum was crying, I would like to have had an animal to calm me down, would have helped me feel calm' ○ 'Getting to bring a cuddly toy in, that would help' ○ 'A huge teddy to squeeze' x2 	<ul style="list-style-type: none"> • 'Care about our feelings' • 'Someone to explain what happens next – looks at lots of options, in advance' • 'Someone to help me make decisions' • What might influence if you feel able to ask a healthcare professional a question: <ul style="list-style-type: none"> ○ 'Privacy' ○ '1 on 1' ○ 'Smaller room' ○ 'Quiet' ○ 'Not overheard' ○ 'Proper training - trusting the person knows what is going to happen' ○ 'Paper to write questions down so don't have to ask verbally' ○ 'Question box for nurse if you don't want to see them' ○ 'Gender' ○ 'Adults better than people your age – preferable parent' ○ 4 said easier if parents/carers in room; 3 said harder if parents/carers in room

		<ul style="list-style-type: none"> • What makes someone the world's best doctor or nurse? <ul style="list-style-type: none"> ○ 'The biggest smile' ○ 'A big smile' ○ 'He is smiling' ○ Looks friendly' • What would make someone a bad doctor or nurse/ the world's worst doctor or nurse? <ul style="list-style-type: none"> ○ 'They are scary, cruel or mean' x4 ○ 'They will hurt you' x2 ○ 'They give you injections or hurt you with something sharp' x5 ○ 'If they trapped you' ○ 'They might say something to our parents about what we have done which isn't true' ○ 'They won't give you breakfast, lunch or dinner' ○ 'They wouldn't help you' ○ 'They wouldn't let you play with your phone or iphone' ○ 'They might ask your mum and dad to leave and then say mean things to you when your mum or dad aren't there, like 'why are you so stupid'' ○ 'They wouldn't save you if you needed saving, they would go home' ○ 'They won't work well with others' ○ 'They won't give stickers at the end' x2 ○ 'They wouldn't show you respect' ○ 'They wouldn't help you when you ask them to' ○ 'The doctor does not care how you are feeling when you tell them' ○ 'They might shout at you and tell you that you did something wrong' x2 ○ 'They might do something bad to you' • If you could change one thing to make you feel less scared or give you a better experience what would it be? <ul style="list-style-type: none"> ○ 'Mum and dad with me always' ○ 'Same doctor every time' ○ 'Come to my house' ○ 'Getting a lollypop or sticker every time and have toys to play with so I am less scared of an injection' ○ 'Give you stickers afterwards' (x4) ○ 'Being friendly and kind' ○ 'Not giving injections when you are afraid' ○ 'Do not give injections' ○ 'Let you be asleep if something bad is going to happen' ○ 'Get a toy if you have been good' ○ 'Playing games' ○ 'Seeing the same people' ○ 'Giving you medicine you need' ○ 'TV so can watch the tv when bad stuff is happening' 	<ul style="list-style-type: none"> ○ 'Needs to be a friendly animal, not one in the jungle who would attack' • What would help [seeing a therapist or GP]? <ul style="list-style-type: none"> ○ 'What is the person I am going to see's names? It would make me feel better and less nervous if I knew things about them and didn't need to ask their name' ○ 'Picking a [different] counsellor if you didn't like the other one, someone you like who is friendly – I could ask to go and see someone else if I found out which doctor I was going to and knew I didn't like them' ○ 'Would want to mention 'I like this but don't like this'' ○ 'Bringing a friend or family member – you'll feel comfortable because there is someone there you are really familiar with, you have known them for a really long time' x2 <ul style="list-style-type: none"> ▪ Sub-question: Would you feel more comfortable having someone familiar with you? 5 said more comfortable, 2 said they would feel the same, 0 said they would feel worse • I like it when the doctor explains things to me about my treatment <ul style="list-style-type: none"> ○ 13 agreed <ul style="list-style-type: none"> ▪ 'If its urgent you could get surgery really really quickly, 'but isn't that going to make your mum nervous?' (asked by another child) 'in case it's really bad I would want to know about it' ▪ 'I'd like to know so it's not a big surprise and then they don't scare me by myself' ▪ 'They told me first and I tried it and then my dad helps me' ▪ 'It might be scary not knowing' ▪ 'Sometimes I don't like to hear it and sometimes I don't want to hear it' ▪ 'I don't want anything to happen if they lied or did not explain it, I want them to tell me the truth' ▪ '[I] want to know what's going to happen before it happens' ▪ 'Makes me feel less worried' ▪ 'I once had something on my elbow and they told me everything and I can't imagine what it would be like if they didn't tell me' ○ 4 disagreed 	
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		<ul style="list-style-type: none"> ○ 'If you can get better' ○ 'If you can take your favourite toy or teddy' ○ 'If mummy and daddy can stay' ○ 'Bringing my tablet' ○ 'Reassuring me/encouraging me not to be scared' ○ 'Watch my favourite TV show' ○ 'Having squeaky toys to play with' ○ 'Breakfast in bed!' ○ 'Cuddly toys (Eric!) ○ 'Colouring' ○ 'Having a drink and some food (would like a choice)' ○ 'Sweets and chocolate' 	<ul style="list-style-type: none"> ▪ 'They make it sound urgent and I don't like urgency. Dr makes me nervous – they need to be calm, looks scary. Doctors are supposed to make you calm but they make more nervous. I would prefer it if they told me in a calm way' ▪ 'I don't want to think about it' ▪ 'Sometimes you don't really want to know what is going to happen to you' ▪ 'Sometimes it makes you freak out when you know what they are going to do but sometimes if you don't know they'll put you to sleep' ▪ 'I might get scared when it's happened' ○ 2 unsure <ul style="list-style-type: none"> ▪ 'If it's something bad, I don't want to know but I also do want to know because it will make me better.' ▪ If it wasn't urgent, it depends what it is' • If I was going to have an operation, I would want the doctor to tell me the risks and why they were doing it. <ul style="list-style-type: none"> ○ 3 agreed <ul style="list-style-type: none"> ▪ 'I want to know what not to do so if I can't eat something, I'd rather know what not to eat or what to eat' ▪ 'I'd rather know what it means' ○ 1 unsure (no quotes) 	
3.3	How can children and young people be empowered to advocate for themselves?	<ul style="list-style-type: none"> • 'I help myself sometimes and I use my brain' • 'I like to talk to the doctor because it is my body.' 	<ul style="list-style-type: none"> • I feel comfortable speaking to the dentist or doctor by myself <ul style="list-style-type: none"> ○ 4 disagreed <ul style="list-style-type: none"> ▪ 'I like it when my parents are with me' (all agreed with this statement) • What can the doctor do to make you want to speak to them by yourself? <ul style="list-style-type: none"> ○ 'I don't know, they look scary' 	<ul style="list-style-type: none"> • What would help you be involved in decisions about your own health and speak up for yourself? <ul style="list-style-type: none"> ○ Willingness of young person to talk and the doctor to let you talk (mentioned by multiple young people) ○ Doctor being willing for a young person to have a say – saying it at the beginning of the session. <ul style="list-style-type: none"> ▪ 'Giving us permission'. X2 ▪ 'When starting to make your own decisions you need lots of support, Doctors need to explain and provide lots of information to help you do this' ○ Pre-meetings with healthcare staff. Video or phone telephone call before the main session or drop in session at school. Chance to talk in a more informal way to build trust e.g. doctor could find out what you enjoy doing etc. x 2 ○ 'I don't know, I'm not a confident speaker'

				<ul style="list-style-type: none"> ○ Communicate in other ways e.g. write it down, text it, draw it ○ 'Confidence' ○ 'Communication skills' ○ 'Giving it a go and if it doesn't work out it doesn't matter' ○ 'I don't know, I'm not a confident speaker' (several young people felt they just weren't confident and there wasn't much that would change that) ○ 'Socialise with more people that you don't know, get used to it' ○ 'Keep trying' ○ 'Bank of resources e.g. pamphlets and videos to help young people understand the situation and feel able to speak up' ● How could confidence be developed? <ul style="list-style-type: none"> ○ Only one young person had specific ideas for how confidence could be developed (the others thought you were either confident or not) ● What could a doctor do or say to make you feel more confident advocating for yourself? <ul style="list-style-type: none"> ○ 'Give me permission to speak – tell me' ○ 'Having someone there' ○ 'Said things in a way you could understand it' ○ 'Just ask you' ○ 'Ask me 'are you ok' or 'what do you think'' ○ 'Explaining what's going on' ○ 'Tell you what's happening' ○ 'At the beginning, explain you can have a choice and ask questions' ○ Meet you and get to know what you like first' ● What qualities do you need so you could advocate for yourself? <ul style="list-style-type: none"> ○ 'I try to put myself in other people's shoes' ○ 'Patience' ○ 'Strong in what they say and mean what they say' ○ 'Trustworthy – still keep secrets from my friends even if they're not my friends anymore' ○ 'Wanting to help' ○ 'Good listener' ● What qualities would you like to learn so you could advocate for yourself? <ul style="list-style-type: none"> ○ 'Practice' ○ 'Go on a course' ○ 'Doing drama' ○ 'Just going through it' ○ 'Joining groups like this one' ○ 'Trying it'
3.4	How can the views of babies, children and	●	●	<ul style="list-style-type: none"> ● What is an advocate? <ul style="list-style-type: none"> ○ 'My mum is one... for vulnerable people'

	<p>young people be best represented by independent advocates?</p>			<ul style="list-style-type: none"> ○ 'Makes sure their voice gets heard' ○ 'Helps them have their voices heard' ● What skills/qualities should an advocate have? <ul style="list-style-type: none"> ○ 'Confidence' x 2 ○ 'Keeping it confidential' x2 ○ 'Always there to help, not just when they want' ○ 'Not shy' ○ 'Can explain things clearly' ○ 'Public speaking' ○ 'Understanding if they have learning difficulties' ○ 'They have to care' ○ 'Not sugar coating anything' ○ 'Never over reacting' ○ 'Understanding – 'they understand what the child is thinking and why they are feeling that way' ○ 'Empathetic/sympathetic' ○ 'Wants to help' ○ 'Nice' ○ 'Trustworthy' ○ 'Patient' ○ 'Caring' ○ 'Not over reacting and acting calm' ○ 'Understanding they have learning disabilities – speaking slowly, putting yourself in their shoes, understanding what they might need to help' ○ 'Good listener' ○ 'Always there to help, not just when they want' ○ 'Act professionally' ○ 'Professionally and well dressed' because this will help you to trust them, wouldn't trust them if they are just in jeans' ○ 'Be protective of the young person' ○ 'Addressing a child how they want to be addressed – by their first name or by a nickname or something like that' ○ 'Use terminology that isn't confusing' ○ 'Get down to the level of the young person' ○ 'Speak to them and comfort them' ○ 'Prepared for any scenario' ○ 'Training to support others'
<p>4.1a (qual)</p>	<p>What factors are important to babies, children and young people to improve their experience of healthcare services?</p>	<ul style="list-style-type: none"> ● 'I don't like going to the doctors' ● 'I love games' ● 'I like it feeling comfy' ● 'I don't like the doctors because they have to do injections and vets have to do injections for your pets' ● 'You're not allowed to have food at your doctors and this means you get hungry' ● 'I went to the doctors before going to school and had a jab and it really hurt but my mummy was 	<ul style="list-style-type: none"> ● 'Food and water' ● 'Change the hospital food, it's dry' ● 'Nice hospital food' x 2 ● 'Food to suit my needs' (pescatarian) ● 'Good chef (to cook the meals I like)' ● 'Doctors who do their job properly' ● 'Having someone who has done the job before, not someone who is new and inexperienced' ● 'Experienced staff doing things right' ● 'Doctors doing the procedures correctly' 	<ul style="list-style-type: none"> ● 'Having a service available' (MH services) ● 'Good food' x 2 ● 'Not being forced to eat food you don't like' ● 'Giving people the help they need' (MH services) ● 'Whenever you need someone, they're always there' (MH services) ● 'Staff who are able to respond/help straight away – good service' ● 'Giving support at home' (MH services)

		<p>there. It was good because she holded my hand while I did it'</p> <ul style="list-style-type: none"> 'I had to have a few injections and there were toys and they gave me a plaster' 'I've been to a dentist to sort out my mouth. They opened my mouth wide in case I've been good and have clean teeth' 'I don't like going to the doctors because of injections' 'They might make me feel a little bit better' 'Everybody wants to feel better' <p>Appearance of healthcare professionals:</p> <ul style="list-style-type: none"> The children were shown pictures of a variety of healthcare professionals (in uniform, not in uniform, smiling, looking serious, male, female) and asked to pick the one that looked like the world's best and world's worst, and then to explain their decision. Overall, the children always preferred people who were smiling, looked friendly and who looked smart and professional. They didn't like pictures of people who were looking cross. 'He looks like a doctor from what he is wearing' 'The thing around his neck makes him look like a doctor' x 2 (picture was a doctor in a white coat with a stethoscope around his neck) 'Better for them to wear a white coat than every day clothes' 'Blue gown - looks like a doctor' 'Wearing white coat so looks like a doctor' 'Nice shirt – looks like he would help people in danger' 'I really want to see a girl doctor' (4 girls agreed with this, 3 boys wanted to see a man doctor, most didn't mind) 'I like her smile and her hair' 'Nice outfit' (picture was of a nurse in traditional uniform tunic) 'She looks nice because she is smiling' x3 	<ul style="list-style-type: none"> 'Lots of caring and helpful doctors' 'Getting the right diagnosis' 'Helpful – solve the problem' 'Getting better' 'Only getting treatment you need' 'Treatment not hurting' x 2 'Examination not hurting' 'No needles' 'Getting right prescription' 'Not catching something contagious from another patient' 'Give you stickers' x3 'Helping people if there's a fire' 'Important to be comfortable, needs to feel like home' x3 'Games – if something is sad but I am playing a game it makes it better because games make me happy' 'Seeing the same person – happy, if you've broken your arm, if you can't get in/in a rush, means you have to be there at the same time' 'Needs to be as quick as possible but I really want comfy chairs' 'I love the hospital – free food' 'More important than it being close to home is if it feels like home because [if not] you might feel a bit sick, but if it feels like home it will be much better. If it feels like home then you'll know it feels safe so you'll feel less sick' x 2 'I want it to be fast I guess, but not too fast or they might make mistakes' 'My top one is 'explain it with games' – and chocolate! Because if they are explaining something really sad, I won't get sad because I will be playing with games which makes me happy' 	<ul style="list-style-type: none"> 'Home/online visits in the comfort of the patient's home' (MH services) 'Whenever you need someone, they're always there 'Not adults only there' 'Tailored specifically to them (MH services) x2 'Cost-free' x2 'Really fast' 'Qualified staff' 'Know what they are talking about' 'Trustworthy' Knowledgeable' 'Avoid sensory overload' 'Not bland' 'Not reserved' Having the right medicines' x2 'Parent-like person who just comforts (rather than treats)' 'Don't leave us on our own – no attention when on a ward' 'Not being expected to do something you physically can't do'
4.1b (quant	What factors are important to babies, children and young people to improve their experience of healthcare services?	<ul style="list-style-type: none"> <SEE SEPARATE RANKING SUMMARY> 	<ul style="list-style-type: none"> <SEE SEPARATE RANKING SUMMARY> 	<ul style="list-style-type: none"> <SEE SEPARATE RANKING SUMMARY>
5.1	How can and how should the perspective of children and young people, and of the parents or carers of babies inform the design of healthcare services?	<ul style="list-style-type: none"> 	<ul style="list-style-type: none"> 	<ul style="list-style-type: none">

5.2 (quant)	How can the experience of babies, children and young people be measured so as to improve their experience of healthcare?	•	•	<ul style="list-style-type: none"> • What methods could be used to obtain feedback?: <ul style="list-style-type: none"> ○ 'Verbal' ○ 'Face-to-face' ○ 'Computers are good – children and young people like tech and feel comfortable with it' ○ 'Token box voting could be misused – would need to hand out the tokens' ○ 'Token boxes – adopted into a wall-vote system' ○ 'Some text is too talky/intimidating' ○ 'Have surveys on iPads – cuts down on writing – some people can't write/press buttons – need audio/speech options' ○ 'Surveys delivered by people same age - easier to communicate – cuts out jargon. Better communication' ○ 'Tech/button surveys are easily manipulated' ○ 'Tick box questionnaires can be inaccurate – need explanation of why you've ticked that box' ○ 'Ask/give survey whilst patient is still in services' care – if you leave it until later it may not be done' • What questions should be included? <ul style="list-style-type: none"> ○ 'Do you think you are getting enough care?' ○ 'Rate you care/treatment 1-10' ○ 'Keep it simple – people don't want to spend a lot of time on it' ○ 'Make it easy/smooth' ○ 'Make it positive – not upsetting' ○ 'Use symbols – easy for people who have another language, not English' ○ 'Have option for someone to talk through + fill it in with you – they have to be honest and record what you actually said' ○ 'Did you like your treatment?' – What could we do differently?' ○ 'What is your perfect hospital experience?'
6.1	What features of environment in which healthcare is provided are important to babies, children and young people to improve their experience of care?	•	<ul style="list-style-type: none"> • 'Room to watch movies' • 'Replace curtains – I don't like hearing noises' • 'More than 1 play area' • 'Have a bell for people who can't walk' • 'Have a calm waiting room' • 'Spilt the waiting room in half or have different waiting rooms for play and calm' • 'No bad smells' • 'Clean rooms/chairs' • 'Colourful – rainbows, multicolour' • 'Climbing frame (to keep me busy whilst waiting)' • 'Characters to paint on the walls' <ul style="list-style-type: none"> ○ Suggested characters included: 	<ul style="list-style-type: none"> • 'Nightlight' • 'Soft beds' x2 • 'Tool (panic button) to use when you want procedure/treatment to stop' • 'Big rooms, not cramped' x2 • 'Furnished' • 'Comfy' • 'Clean/hygienic' x 4 • 'Countryside' (MH services) • 'Automated reception area – to do on phone/tablets' • 'Fish + music etc in waiting room, toys, tv with kids shows, box of books'

			<ul style="list-style-type: none"> ▪ Mr Bean ▪ Horrid Henry ▪ Superman ▪ Gumball and Aryn ▪ Spiderman ▪ Ironman ▪ Corrie [Coronation Street] ▪ I'm a celeb [Ant and Dec] <ul style="list-style-type: none"> • 'Sensory room, including slime' • 'Builder to build new rooms for different activities' • 'A window so you can talk to your friends – window clean so you can see out' • 'I really want the comfy chairs... the electric chairs that recline' 	<ul style="list-style-type: none"> • 'Not cheap seats – comfortable' • 'Not too busy' • 'Not too claustrophobic'
7.1	How can health services support babies, children and young people to participate in usual activities (for example family relationships, schooling, peer friendships, social activities)?	•	<ul style="list-style-type: none"> • 'Ask us 'What do you like to do?'' • 'Tablets to play with' • 'Toys that you like' • 'Toy maker like Santa' • 'Drawing' • 'Make up video games' • 'Entertainment for inpatients' • 'Have a TV and tech you can use' x2 ('and engineer to fix TV when they're broken') • 'Internet / Computers / Computer games' x3 • 'iPhones' • 'Play games' • 'Have wi-fi available' • 'Play arts and crafts' • 'Play football – have balls in hospital you can use' • 'Flying glowing insect battle [glow flies]' • 'Toys (top trumps, nerf guns)' • 'Have someone to help in the shower – mum, doctors' • 'Have your friend or mum helping you' • 'Have an alarm so we can call for help, have special alarms/reminders to remember to brush our teeth and hair etc.' • 'Do homework in hospital' • 'Ask if someone can go to hospital to help you learn – like your teacher. Get your teacher to email work to your parents' • 'Be home schooled' • 'Have someone to help you with spelling – ask your teacher to speak to your doctor for extra homework' • 'Company – have parents to stay' • 'Have friends and family to see us' • 'Understand our food likes/dislikes' • 'Eat ice cream and chocolate' • 'Have sweets and some treats' • 'Read books, need to have/share books in hospital' • 'Play with dogs' • 'Have cats – animal therapy in hospital' • 'Animals' ○ Suggested animals included: 	<ul style="list-style-type: none"> • 'Don't wake us up' • 'Free wi-fi' x2 • 'Dogs/animals' • 'Cards and games' • 'Toys in consultation room' • 'Interactive/games' • 'Having someone to be there' (MH services) • 'Using tech to play games (to take our mind off)' • 'Teddies for comfort' • 'Help to be clean (shower/bath)' <p><i>NB: List below from group when questions phrased as 'What services keep us healthy to enable us to do our usual activities?'</i></p> <ul style="list-style-type: none"> • 'Meditating helps us to relax' • 'Going to the shops or shopping – shop mobility' • 'Travelling – organised weekly trips' • 'School/friends can help with mental health' • 'Feeling happy helps us to have a bright mind' • 'Clean helps us to not feel sweaty' • 'Dentists/GPs help us know what healthy to eat' • 'Reading help us to get comfortable' • 'Communicating help us to understand other people' • 'Having water helps us to not be dehydrated' • 'Seeing eye specialist' • 'Sleeping helps us to recharge ourselves for the next day' • 'Dentists help us have healthy mouths' • 'School help us to be educated' • 'Reading – opticians – glasses' • 'Eating- dentists – make sure mouth OK' • 'Having a good relationship with your family helps us to feel comforted' • 'Hearing ear specialists' • 'Having friends helps us to not be lonely' • 'Dentists = help to look after our teeth – look at our teeth to make sure they are healthy – give fillings if we need them – stop pain' • 'Stress relievers help us to be 100% focused'

			<ul style="list-style-type: none"> ▪ Dogs ▪ Cats ▪ Ferret ▪ Labrador (good with kids) ▪ Rabbits ▪ Salamander ▪ Lizards. <ul style="list-style-type: none"> ○ 'Although some people might be going to the doctors because of an animal so there should be a separate room' <ul style="list-style-type: none"> • 'If you cannot sleep – have food, have a lullaby, someone read a bedtime story, take a sleeping tablet' • 'Calm and sleepy lights, 3D projector' • 'Doctors be funny, make me feel happy' • 'Swimming with a broken arm – have something to protect the cast; keep the cast out of the water, sit on special equipment' 	<ul style="list-style-type: none"> • 'Being well locked after help us to be encouraged to do things. Being relaxed helps us to figure things out'. • 'Horse riding – scans for hips and back – to help stay balanced – to know if you need surgery' • 'Shower or bath – making sure you don't drown in bathtub'
8.1	What are the facilitators of, and barriers to, accessing healthcare services for babies, children and young people?	<ul style="list-style-type: none"> • Who is someone you go to if you are not feeling very well? <ul style="list-style-type: none"> ○ 'A doctor/surgeon' x15 ○ 'A nurse' x6 ○ 'School nurse' ○ 'Policeman' x3 ○ 'Mummy' x8 ○ 'Daddy' x7 ○ 'Brothers/sisters' x2 ○ 'Nanny and grandad' x2 ○ 'A friend' ○ 'Dentist' x10 ○ 'Ambulance' ○ 'A fire engine/firemen' x2 ○ 'Teachers' x4 ○ 'Optician' x3 ○ 'Audiologist' ○ 'Person that does X-rays' ○ 'Mountain rescue' ○ 'Lifeguard' ○ 'Bus driver/taxi driver' ○ 'Waiter' ○ 'Pets' ○ 'Teddies' ○ 'Mainworker/keyworker/careworker' x3 ○ 'Charity' • Where might you go if you are not feeling very well? <ul style="list-style-type: none"> ○ 'Hospital' x8 ○ 'Dentist for your teeth' x4 ○ 'Chemist/pharmacy/Boots' x3 ○ 'Eye doctor/optician' x5 ○ 'Doctor' x4 ○ 'Sometimes have medicines at home' x2 ○ 'Ear doctor' ○ 'A tummy nurse or a tummy doctor' ○ 'For an X-ray' ○ 'An ambulance' x4 ○ 'The surgery/GP' x2 	<ul style="list-style-type: none"> • 'Hospital nearby/near my house' • 'Short waiting times' • 'Doctor is there when you visit; not a waste of time' • 'Not missing a lot of school to see the doctor' • 'Swift in and out' • 'More doctors so you don't have to wait long' • 'Close to home – emergency, it's important to be close to home, if you're in a rush, ambulance can get there quickly' x 2 • 'If not in an emergency, still important it is close to home so you can easily go there and back' • 'If you are close to home, then the hospital will keep having to move to wherever you are and is that really a good idea? If the hospital moves closer to you then other people won't be able to get there quicker' • What is a barrier? <ul style="list-style-type: none"> ○ 'It can protect you' ○ 'A prison cell' ○ 'It can keep you safe' ○ 'As you get older, you keep things private – that is a barrier to healthcare. You notice that your parents are a bit more like 'have you registered for your SATs' you don't want them to worry about your healthcare as well.' ○ 'Something that separates something from something' ○ 'It is something that can be invisible or visible' ○ 'When you are not allowed to go somewhere, it's because there is a barrier there' ○ 'You cannot get across' ○ 'You can break or jump over them' • What are barriers to accessing healthcare and how could they be overcome? <SEE SEPARATE TABLE BELOW> 	<ul style="list-style-type: none"> • 'In a convenient location' • 'Not too much travelling' • 'Same gender' • What are barriers to accessing healthcare? <ul style="list-style-type: none"> ○ 'Hospital is too far away from home' x2 ○ 'Scared of doctors' ○ 'Death!!!' ○ 'Might be afraid of hospitals' ○ 'Might not want to be stuck inside a hospital' ○ 'Being squeamish' ○ 'Being scared of needles' x2 ○ 'When family don't know where you are' <ul style="list-style-type: none"> ▪ 'When I feel ill I just want my mum but she might be stuck in traffic' ○ 'Scared of loud noises, and so scared of the ambulances' ○ 'Anxiety' ○ 'Covid worries' ○ 'Not having family around' ○ 'Don't know what side-effects of the treatment are' ○ 'Not enough time/too busy/already have plans – if you have a busy schedule you might not have enough time' x3 ○ 'Embarrassed' ○ 'Overwhelmed' ○ 'Might want to go to a friend's house or an after school club/already have plans/ interrupting social life' ○ 'The days and times [for appointments] might be difficult' ○ 'Waiting times' ○ 'Missing out on education' <ul style="list-style-type: none"> ▪ I quite enjoy science, there's no experiments if you have to go to hospital' ○ 'Being a burden'

		<ul style="list-style-type: none"> ○ 'Mountain rescue place' x2 ○ 'Royal college of nursing (mummy works there)' ○ 'NHS' x3 ○ 'A place to get flu vaccine' ● Are health services scary? <ul style="list-style-type: none"> ○ Agree (12/18) <ul style="list-style-type: none"> ▪ 'Because I don't know what is happening or what is going to happen' ▪ 'I went to the dentist and I was scared because I thought something bad might happen to my teeth' ▪ 'It might hurt' ○ Disagree or not sure (6/18) 	<ul style="list-style-type: none"> ● What are the most significant barriers to accessing healthcare? <ul style="list-style-type: none"> ○ 'Feeling embarrassed' ○ 'Not telling anyone you feel unwell' ○ 'Gender of doctor' ○ 'Not being able to explain what is wrong' ○ 'Not being taken seriously by healthcare staff' (x2) ○ 'Not knowing how to ask for help' <ul style="list-style-type: none"> ▪ 'If the staff is not taking my health seriously and I could die and I would get really worried' ▪ 'If it was something private I would feel embarrassed' ▪ 'what would make me less embarrassed is choosing what I get to talk about' ▪ 'Not being taken seriously by health staff would be really dangerous and worrying' ▪ 'Too far to travel there – 'I don't like travelling without company. I'd rather they came to me' ▪ 'I don't know how to ask for help' ▪ 'At home no body actually listens to me. It makes me feel sad when people don't listen to me' ○ 'Coronavirus' ○ 'Scared of the doctor' ● How could you overcome these barriers? <ul style="list-style-type: none"> ○ 'I'm a bit scared.' ○ 'If one of my family died, I would go to their house and stay until the doctor comes there. I'm scared in case I had to get plastic surgery. I am going to be brave.' ○ 'Because I've been before and it wasn't bad, nothing would stop me going before.' ○ 'If I go alone, then I might feel scared and terrified a lot.' ○ 'If the doctor asked where are your family, where do you live, he might be an imposter and try to rob me' ○ 'Something that might stop me is if I have to go to the doctor and have an operation I might die. But something that stops me more is if my mum goes to the doctor and I went with her and she died and then I had no one to take care of me.' ○ 'The big long injections would stop me' ○ 'If my family are not there I would not have anybody to hold my hand getting a big injection' ● Would it matter to you if the doctor was a boy or a girl? <ul style="list-style-type: none"> ○ Yes – 2 (both girls) 	<ul style="list-style-type: none"> ▪ 'Worrying about being a burden... there could be someone with a lot worse than you and you would take up too much time when they should' ○ 'Not knowing the doctors' <ul style="list-style-type: none"> ▪ 'Don't know who they [the doctor] are' ▪ 'If they are new you don't know if you can trust them or not' ● How could these barriers be overcome? <SEE SEPARATE TABLE BELOW> ● Case study 1: Alex is 10, has a learning disability and has a hearing impairment. He lives in a single parent family and has 3 siblings who are all between 7 – 14 years old. ● He gets nervous when he is around people he does not know very well and does not like going to the doctors. He does not talk to his parents about why he does not like going to the doctors. ● What barriers do you think Alex might have if he needed to access healthcare? <ul style="list-style-type: none"> ○ 'Scared' ○ 'Parent is always busy with other children' ○ 'Sounds overwhelm him' ○ 'He doesn't want to worry parent' ○ 'Maybe he has other learning difficulties' ○ 'His hearing impairment might make him nervous around loud noises' ○ 'His parents have other things on their plate' ○ 'He might be worried about what people are saying about him because he can't properly hear' ○ 'He doesn't know how to explain that he doesn't like the doctor' ○ 'Scared' ○ 'Doesn't want to admit that he is scared to his parents' ○ 'His learning disability might make it harder for him' ○ 'Physical barriers' ○ 'Not being able to hear' ○ 'Fear – not wanting to be around doctors' ○ 'Parent may not be supporting him because of time and finances with 4 children and one parent' ● What solutions might help Alex access healthcare? <ul style="list-style-type: none"> ○ 'Bursary for young people to access' services e.g. to get public transport or a taxi ○ 'He needs to speak out to his parents so he can get extra support' ○ 'I would tell him there is nothing to be scared about [about telling his parents]'
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			<ul style="list-style-type: none"> ▪ Tell an adult ▪ Mum or dad 'can you help me' ▪ 'He could tell a doctor' ▪ 'He could walk to the doctors' ▪ 'If he can't find a doctor anywhere he should tell an adult and ask for help' ▪ 'His parents' ▪ 'He could be brave and go on his own' ○ Barrier 2: Remi is worried about how to travel to the dentist as it is too far away <ul style="list-style-type: none"> ▪ 'He could ask for a lift' (x2) ▪ 'Ask a friend' ▪ 'If he has money he could get the bus' ▪ 'I think he would want someone to go with him' ▪ 'Use the computer' ▪ Over the road ▪ Boat/ferry/train/drive ▪ 'I would want someone to help me on the train' ▪ 'I would ask people on the bus to help me' ▪ 'I'd ask the bus driver to help me' ▪ 'I would just have to go over the road and it is easy' ▪ 'My mum would know' ▪ 'There is an app called NHS COVID19' ○ Sub-question: Would you rather talk to the dentist on the phone or app or see him in person? <ul style="list-style-type: none"> ▪ 'Facetime or phone. I'd rather just Facetime' ▪ 'I'd rather see them in person because if they had enough time they could get it done in the same day. So it's over and done with so I don't have to go over these stepping stones again' ○ Barrier 3: Remi is worried the dentist will do something painful to his teeth <ul style="list-style-type: none"> ▪ 'Ask them if they can give him a toy/teddy' ▪ 'Think happy thoughts' ▪ 'Ask for something to watch/play as a distraction' ▪ 'Get the dentist to explain what they are doing to do' ▪ 'Drink water' ▪ 'Going with a friend' ▪ 'Marshmallows to look at instead' ▪ 'Tell him it won't hurt' ▪ 'I would not be worried' ▪ 'I would take him to the doctors' ▪ 'Going with a friend would help me' 	<ul style="list-style-type: none"> ○ 'Services closer to home' • What solutions might help Sam access healthcare? <ul style="list-style-type: none"> ○ 'Could ask a teacher for assistance' ○ 'Having a helper in school to go with her could help' ○ 'Physical access e.g. ramp, bigger school office' ○ 'Making all services accessible' • Case study 3: Ali is 15 and has autism. His mum and dad both work 2 jobs and work until very late in the evening, getting home sometimes around 11pm. • He does not go to see his doctor that much but when he does go, he gets really anxious about seeing his doctor. • What do you think could be a barrier for Ali to see his doctor? <ul style="list-style-type: none"> ○ 'Worried about what the doctor will say' ○ 'Anxiety' ○ 'Worries about getting an anxiety attack' ○ 'Travel and not going often makes him going to the doctor into an unknown' ○ 'If he's 15 he might be expected to do things by himself, but he needs support' ○ 'He might need a special helper [if his parents aren't around]' ○ 'He might want to have someone beside him' ○ He can't really talk to his parents or go with them if they work long hours' ○ 'Parents don't have time to talk and he doesn't have a person to go with' ○ 'Not having a good understanding of what to do' ○ 'Not knowing what is wrong with him – thinking it is maybe nothing' • What solutions might help Ali access healthcare? <ul style="list-style-type: none"> ○ 'Quiet room could help' ○ 'Stress toys' ○ 'Home doctor' ○ 'Could get a guardian or friend to go with him, or a TA if a friend wasn't allowed out of class' ○ 'Have a childminder go with him'
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8.2	What factors promote, or present barriers to, continuity and coordination of care for babies, children and young people?	<ul style="list-style-type: none"> • Do you want to see the same person every time or would you mind if you had to see different doctors every time? <ul style="list-style-type: none"> ○ Yes <ul style="list-style-type: none"> ▪ 'I want to see the same doctor every time because if there was a new doctor they might be not nice. Makes you less nervous and scared' ▪ 'Because they might not hurt me if they know me' ▪ 'Because I like my doctor' ▪ 'I went to see a doctor and they were very kind and the next time [a different doctor] was a bit mean so I want to be with the first one' ▪ 'They will be friendly and might not hurt you' ○ Not sure <ul style="list-style-type: none"> ▪ 'Need to know they are going to help you every time – what if they don't respect me?' ▪ 'I don't mind because I just care they are kind to me' ○ No <ul style="list-style-type: none"> ▪ 'If I did see a doctor and they were rude to me I wouldn't want to see them again. If I saw a different doctor every time but they were kind to me, I would be fine to see a different one every time' ▪ 'Because I'm just used to different doctors' 	<ul style="list-style-type: none"> • 'Kind doctor who helps you so you want to go back' • 'Good to see the same person, means you can trust them' x2 • 'If you see the same person every time – it makes me feel happy... if you can't see the same person, because you're in a rush or something or go in the morning, you might not be able to' • Is it important to see the same doctor every time you go? <ul style="list-style-type: none"> ○ 2 agreed <ul style="list-style-type: none"> ▪ 'The doctor knows me, and they know my past so won't have to explain again' 	<ul style="list-style-type: none"> • 'Same people every time' • 'Don't lose details for an appointment – avoid repetition' • 'Don't do things twice – taking blood'

Barriers to accessing healthcare	Solution
7-11 reference group	
'You don't want parents to worry'	
'You're scared and frightened of the doctor' (x4)	<ul style="list-style-type: none"> • 'Explains things better and in an easier way so it doesn't sound scary' • 'Translate' • 'Have toys in waiting room' • 'Show you what is going to happen to you on a YouTube video' • 'Ask us if we want a sticker' • 'Be friendly' • 'Holding hand' • 'Dad/Mum coming with me and holding my hand' • 'Being brave' • 'Make them happy again' • 'Make you laugh' • 'Make a funny joke' • 'Do something fun for me' • 'Distract them' • 'Make them focus on something else' • 'Make sure you know how to get help' • 'Share why we feel scared – ask parents to help' • 'Bring a cuddly toy' • 'Have a dog or a pet to hug' • 'Tell the doctor why you feel scared' • 'Tell your parents then they can tell the doctor' • 'If you have to stay overnight, the doctors could show you what to press if you need help and they can come' • 'If you have a dog, or just any pet, you could maybe give it a hug' • 'Think of things you like to do and try and forget'
'Doctors use big words that I don't understand and my mum has to translate it for me'	<ul style="list-style-type: none"> • 'Make it more informal' • 'Break it down for us' • 'Explain in a way we speak to our friends' • 'If you don't speak English – have a translator'
'You're embarrassed' (x4); 'worried that my parents might be embarrassed too'	<ul style="list-style-type: none"> • 'Choosing what to talk about, not talking about private parts' • 'Not going to the doctors – talking to mum' • 'Make people laugh' • 'Have a funny doctor' • 'Have separate areas for children' • 'Say why you are embarrassed' • 'Maybe telling them why are you feeling embarrassed, they could help you'
'Don't have internet to make an appointment'	
'Don't know what will happen – if you go to the dentist you don't know if they will drill your teeth out'	
'Don't want to miss your school club that you really like'	
'Don't have time'	

'GP closes too early and you can't make any medical appointments'	
'Might think people will make fun of you – if you tell someone you have a health condition and they tell everyone, they all make fun of you; people might laugh at me'	<ul style="list-style-type: none"> • 'Make the doctor's more private'
'Live too far from the one they want to get to because maybe their friends goes there a lot and they rate it really good'	<ul style="list-style-type: none"> • 'Find another one near you' • 'Ask one you like for a recommendation for a different doctor'
'Can't see the same doctor every time (makes a big difference)'	<ul style="list-style-type: none"> • 'Ask for recommendations' • 'If they knew all doctors were friendly, they would go every time'
'Sometimes when you go to new doctors it's a bit weird'	<ul style="list-style-type: none"> • 'Ask for the same doctor'
'Worried you'll get told off'	
'Appointment is too late'	<ul style="list-style-type: none"> • 'Make 12pm [appointments] for children and young people so you can leave school – go and come back to school' • 'Dr asks what time is best' • 'Adults are more flexible than children'
'If you have a friend who has had the same treatment that you're getting and they tell you all about it and it sounds scary to you, you might not go because it seems scary'	
'Too far to travel'	<ul style="list-style-type: none"> • '[Doctor/service should] come to me' • 'If I was in a lot of pain, it would be really bad going to a different doctor that was too far away' • 'If it's something that is not serious, I would be fine going further' • 'If it was serious I would go to a different doctor or to accident and emergency'
'Not being taken seriously by health staff' (x4)	<ul style="list-style-type: none"> • 'Doctors and nurses not acting silly, acting serious and really focusing' • 'Make sure I am put in the right place to make me better and to tell me the truth' • 'Right place – make sure I get the right treatment and they aren't doing something on the wrong part of the body'
'Gender of the doctor/rather see a girl doctor'	
'If it was a scary different hospital'	
'Not being able to explain what is wrong'	<ul style="list-style-type: none"> • 'Doctor not just saying 'ok' but actually listening and telling you what will actually help'
'Not knowing how to ask for help'	<ul style="list-style-type: none"> • 'Ask Mum'
'Not knowing'	
'Alone'	
'Scared about doctor being an imposter – fake doctor'	<ul style="list-style-type: none"> • 'Seeing the same doctor' • 'Knowing they will take care of you'
'Nobody to hold your hand'	
'If it was something that might hurt me, I won't like it'	<ul style="list-style-type: none"> • 'Put me under anaesthetic' • 'Explain what was going to happen, would help because it might be serious, so I want to know what's going on'
'Not sure what will happen with the information' 'Sometimes you don't know where your information is going to. If you didn't want anyone else to know you didn't know where that information is going. Don't want it to go somewhere not appropriate for you like going on the internet'	<ul style="list-style-type: none"> • 'Ask doctors not to tell before we share'

<p>'Catching germs in hospital'</p> <p>'Might be worried you went there and the germs spread from someone who is poorly'</p>	<ul style="list-style-type: none"> • 'Make doctors and nurses aware and ask them how to stay safe; say to the person who is looking after you, how do I not catch the germs?'
<p>'Friendships'</p>	<ul style="list-style-type: none"> • 'Make new friends – finding things in common' • 'If someone is being mean you could go and find someone else' • 'You could find someone you don't know at all and ask them to play with you. You could make friends with someone who is unwell like you and you had the same illness'
<p>'Our emotions – feeling sad or nervous'</p> <p>'If you feel really sad and if you feel really nervous'</p>	<ul style="list-style-type: none"> • 'Tell doctor how we feel, and friends and parents'
<p>Worried if it is your 1st time – not sure what will happen</p> <p>'Worried it's your first what they will do and think'</p>	<ul style="list-style-type: none"> • 'Let everyone know it is your first time and they can reassure you' • 'Tell the doctor it is your first time and you are worried then they can tell you all about hospitals and it will be ok'
<p>'Wanting to be a turtle'</p> <p>'When you need space, it shows you have a barrier around you and people can't enter and it's a place you feel safe'</p>	<ul style="list-style-type: none"> • 'Ask questions to healthcare workers to feel less upset' • 'Instead of going into turtle, you could ask questions about why this is happening'
<p>'Being worried – not sure what is happening'</p> <p>'Worried if you don't know what's happening'</p>	<ul style="list-style-type: none"> • 'Doctor meeting at the door – introduce themselves 'say a bit about yourself'' • 'Sharing what will happen'
<p>'Nervous about things going wrong'</p>	<ul style="list-style-type: none"> • 'Ask for an explanation of what will happen' • 'You could ask the person what is going to happen and what will happen if something went wrong so they could answer you' • 'The doctor now knows you are worried about if something went wrong'
<p>'Worried we wouldn't see our friends for a while'</p>	<ul style="list-style-type: none"> • 'Play team with games' • 'Have games to play with other children' • 'Go with friends' • 'When you met the doctor they said the play team could come in with games and if you did not have a virus you could walk around' • 'If you had a virus they could bring games to you and if you didn't you could go and find games to play with other children and make friends there' • 'Maybe you could go on Zoom with your friends'
<p>11-14 years reference group</p>	
<p>'Just want to be at home and in bed'</p>	<ul style="list-style-type: none"> • 'If hospitals were more comfortable it would help' • 'If there was a bookshelf – being able to read books to escape' • 'Access to phone and wifi' • 'Around people you actually like 'rather than being left alone in the children's ward'' • 'Not having it look as professional, having it look more normal'
<p>'Long waiting times'</p>	<ul style="list-style-type: none"> • 'More services'
<p>'CAMHS threshold, depends on severity so you might not be able to get help'</p>	<ul style="list-style-type: none"> • 'More funding for MH services' • 'Not basing on it severity, more funding, more services'
<p>'Lack of support from teachers, parents and the general environment around you'</p>	<ul style="list-style-type: none"> • 'Services need to reach parents/teachers/schools to give them info about how to support children to access services'

'Ability to physically get to services'	<ul style="list-style-type: none"> • 'Travel bursary' • 'Services should be in each area'
'Not having enough information and knowledge'	<ul style="list-style-type: none"> • 'Services should communicate more, go to secondary schools, give workshops etc. and deliver support in schools'
'Fear and being scared'	<ul style="list-style-type: none"> • 'Having a teddy to hold onto' • 'Knowing the risks, knowing it's not going to kill you' • 'Worried about fertility with treatment – having information about the risks' • 'Having parents there/right there beside me'