

## Resources from “*Guidance on involving children and young people in specialised commissioning*”

### What are specialised services?

NHS commissioning structures are complicated! This is the simplest way we have found to explain specialised commissioning for children and young people.

Specialised services are the services that you might use if you have a more unusual illness, condition or health problem. They are the services that you would normally have to go to a hospital for. Sometimes if you have a rarer illness or are very poorly you might have to travel further to go to a hospital to see expert doctors who know a lot about the illness or condition.

Specialised commissioning processes is the way that the NHS decides what help, support and treatment is best for people with these health problems. They also need to decide which hospitals will be the best ones to offer this help and what medicines or treatment they will be able to give people. For each illness there is a group of expert doctors, researchers and up to three patients (two patients and one patient representative from an organisation) who meet to talk and advise the NHS about the best type of help and treatment people should have if they have this illness. This group is called a Clinical Reference Group (CRG).

At the moment children and young people do not normally attend these meetings but Clinical Reference Groups want to find ways to hear the experiences and views of young patients as well.

### *Res 1. What are specialised services*

### **Practical tip: From theory to practice**

Models can be useful tools to aid planning and review processes. Print out the model and take it to a meeting with colleagues. Discuss using the following prompts

- What type of participation with children and young people have colleagues seen or been involved with in the past?
- What were pros and cons of that activity?
- What do they feel would be a good model to aspire to within specialised commissioning?

In planning for Division Engagement plans in RCPCH, teams have been asked to consider the best part of their involvement to date, their aspirations for the future and the challenges or barriers they may face.

Once your participation activities are up and running it can be helpful for you and the children and young people you work with to review where they think the participation activity sits on a participation model. At times you will find that different people have very different perspectives on this!

*Res 2. Practical tip: From theory to practice*

### Basic checklist for inclusion of children and young people

- Connect with and publicise your activities (well in advance) to organisations that engage with children and young people who face health inequalities including:
  - work with children and young people with disabilities (special schools, social care, voluntary and community organisations)
  - Black, Asian, Ethnic Minority community groups
  - refugee and asylum seeking support organisations
  - Children and young people in care/care leavers
  - LGBTQIA child, youth and family groups to consider gender/orientation experiences
  - organisations working with children and young people living in poverty
  
- Ensure venues are accessible and child friendly.
  - Use the NHS Accessible Information standard to ensure that all communication needs are met and that information shared is accessible
  - ensure that it is explicit on publicity that the event / activity is accessible and that if people need support you will be happy to discuss their needs in advance. Children and young people have said that they often assume that activities will not be accessible unless the publicity explicitly states
  
- Discuss and /or plan the activities with the children, young people and their support workers in advance.

- Ensure that sessions are structured so that children and young people with disabilities, communication impairments or English as a second language can participate.
  - Make sure you understand how children communicate if they do not use verbal communication. Bring in BSL interpreters, establish a children and young people's communication guide or individual passport, and work with those who understand their communication methods well.
  - Allow enough time for children and young people to express themselves.
  - Work through organisations and people that have an existing relationship of trust with children and young people. This is especially important when there is cultural stigma surrounding the health issue (for example mental health) or where the children, young people or their families may have had negative experiences of institutions previously
- Schedule events and activities with an awareness of cultural or religious calendar, avoiding key dates/religious holidays. Provide quiet space for people who need to observe prayers during events

Cover travel expenses for children, young people and their accompanying support workers.

*Res 3. Basic Checklist for inclusion*

**Making a plan... A checklist for children and young people's involvement in strategic health decision making (adapted from NCB)**

Recommendation	Actions	Notes / comments / lead person / timeframe...
Ensure children and young people are a clear priority population when gathering the public's views	Update the Registered Stakeholder list to ensure child and youth advocacy and support groups, youth forums, parent voice networks and voluntary and community groups working with children and young people are included.	
	Make it explicit on publicity around consultation processes that you want to hear from children and young people as services users	
	Ensure that you have age and need appropriate information available and consultation approaches	
Identify a champion	Identify a champion (or two!) within the Clinical Reference Group who is the named individual responsible for promoting children and young people's right to be proactively and meaningfully involved within specialised commissioning processes for your area	
Create accessible information	Provide information and / or arrangements to promote and explain to children and young people what a specialised service is and how they can have a say in decisions made about these services	
	Ensure you have accessible versions of information for younger children and those with learning disabilities or additional support needs / varied communication preferences	

<p>Create a variety of options for children and young people to get involved</p>	<p>Allow children and young people to engage as individuals and within groups</p> <p>Support this engagement through a mixed methods approach - verbally, through the written word, and through artistic or creative ways (photography, art, drama, film)</p> <p>Provide options for remote engagement (via a local group, online or from their home) or in person (either on the ward or at specific events)</p> <p>Engage in ways that allow for quick fire involvement e.g. take 10 minutes as well as to provide opportunities to be involved on a longer term basis</p> <p>Communicate with children and young people directly where possible or through decisions makers / through a trusted person (parents, sibling, carer, nurse etc.)</p> <p>Children and young people using specialised services require engagement strategies that can adapt to the ups and downs of their health and wellbeing. Be sensitive to this and stay in touch during periods of ill health and less engagement.</p>	
<p>Wherever appropriate, children and young people should be given opportunities to make genuinely shared strategic decisions with adults.</p>	<p>Ensure that you have opportunities that go beyond consultation. These are opportunities where children and young people have the opportunity to:</p> <ul style="list-style-type: none"> <li>• share experiences</li> <li>• identify common themes and issues</li> <li>• look at possible solutions</li> <li>• debate the pros and cons</li> <li>• hear and discuss these options with professionals</li> <li>• be part of the final decision making process</li> <li>• support ongoing monitoring or review of the</li> </ul>	

	<p>impact of these decisions</p> <p>These steps can happen through a child or youth forum, ward or support group based workshops or with young Patient and Public Voice representatives on the Clinical Reference Groups.</p>	
<p>Make use of existing materials, resources and mechanisms for engaging children and young people.</p>	<p>What conversations can be had during clinic time (or while waiting to go into the clinic appointment)?</p> <p>What staff can help? (nurses, hospital volunteers, play specialists / activity coordinators)</p> <p>Do any forums, groups or participation projects exist that already bring together your target group of young service users?</p> <p>What charity, support or advocacy events are coming up that will be bringing together children and young people who use your service? Can Clinical Reference Group members pop along?</p> <p>Are there any reports that already document children and young people's views in your specialised service area?</p> <p>It is easier to embed your participation activities in existing events or places where children, young people and their families already go. It's more effective, efficient, cheaper and less wasteful of children, young people and their family's time!</p>	
<p>Monitor whether you are hearing the same voices repeatedly, striving to provide opportunities to those who might not normally be heard</p>	<p>Ensure that public consultations ask if the respondent is under 12, 18 or 25.</p> <p>Collect equal opportunities monitoring data from participation activities so you can see who you are reaching. Think about age, gender, ethnicity, religion, disability and other factors that may be relevant to your specialised area e.g. are they a young carer, care leaver, a young parent or is knowing their sexuality important to the end results?</p>	

	<p>Check that consultation and participation opportunities are shared with and accessible for children and young people from</p> <ul style="list-style-type: none"> <li>• different cultural backgrounds</li> <li>• on low incomes (travel costs for attending may act as a barrier?)</li> <li>• children and young people with disabilities</li> <li>• or other groups that may have socio-economic barriers preventing their involvement.</li> </ul>	
	<p>Ensure succession and progression support for young volunteers - what are the opportunities available to them locally to continue to be involved, engaged and be an active citizen?</p>	
<p>Promote and act as ambassadors for children and young people's participation in specialised health services</p>	<p>Commissioning processes support and promote the voice of the child and young person through service specifications for all providers</p>	
	<p>Share publicly how children and young people are being involved in decision making about specialised services.</p>	
	<p>Support children and young people involved to talk at conferences or events to share experiences and best practice of being involved</p>	
	<p>Let NHS England or the RCPCH know when you are doing something fantastic! They can help share your events and learning, celebrate your success and encourage others to understand your struggles and how you overcame them.</p>	
	<p>Provide opportunities for Clinical Reference Group members, commissioners and providers to access training and resources on children and young people's engagement through the RCPCH Engagement Collaborative  <a href="http://www.rcpch.ac.uk/and-us">www.rcpch.ac.uk/and-us</a> and the NHS Involvement Hub  <a href="https://www.england.nhs.uk/participation/">https://www.england.nhs.uk/participation/</a></p>	

**Res 4. Making a plan**



### Three things you can do now!

1. *Start the conversation!* Place participation of children and young people on the next Clinical Reference Group agenda and make it a standing item. Ask colleagues:
  - what is coming up that children and young people should be involved in? Which children and young people are most impacted by the discussion or potential decision?
  - which groups do Clinical Reference Group members know of that have either a children's or youth forum, project or programme?
  - which groups do Clinical Reference Group members know of that bring together children and young people for social or support events?
2. *Identify groups* that can help you reach and speak to children and young people and then ensure that the appropriate contact for these groups is detailed on the NHS Registered Stakeholders list
3. *Check* that any upcoming consultations are sent to these contacts and that responses received back from consultations can be and are analysed by the age of respondents

*Res 5. Three things you can do now*

## Supporting younger Patient and Public Voice representatives on Clinical Reference Groups

Joining Clinical Reference Group meetings (as they currently are structured) in person as the Patient and Public Voice representative works best as a follow on volunteering opportunity for children and young people who have already had some experience of talking about their experience as a patient. There are many children and young people who have gained experience and confidence through local or hospital based participation activities and who are ready and able to contribute to this structure of meeting with some basic support mechanisms in place. The rewards of having their perspectives present in first person is invaluable.

- Ensure the Chairperson specifically asks the young representatives for their opinions and provides space for them to express their ideas
- Identify other Clinical Reference Group members who can provide support for younger representatives. This could include touching base before, during and after to check if they have any questions about the agenda and that they feel they have had a chance to contribute, or simply to have a chat and provide a welcoming face at the beginning, breaks and end of meetings
- Ensure that you have a mix of face to face meetings as well as teleconferences to help people to get to know each other. *“Face-to-face is better. But if you can’t meet face-to-face then Skype. Skype is better than a teleconference” (young man, Alder Hey Youth Forum)*
- Send the Patient and Public Voice recruitment information to projects and services with active participation activities in place and encourage them to support younger representatives to apply
- Hold meetings at times and in places where young people can attend (not school / college hours), supporting children and young people’s right to the best health care (UNCRC Article 24) and the right to education (Article 28).

- Develop interactive approaches to Clinical Reference Group meetings where children and young people are members or present. Develop a workshop approach rather than a traditional board meeting and provide regular short thought breaks between agenda items to support children and young people to have time to move on to the next topic of discussion
- “It would be good if there was always name plates in front of the person so that you know who is speaking and what their role is, as it’s a lot to remember. Also to have a way to know who is on the phone - name plates or a photo flag so you remember they are there” (parent, RCPCH *&Us* Lay Representatives Review Group)
- “It would be good if you sent out who is who with a picture and information about them (Clinical Reference Group members) that way you know more before you meet them” (young woman, RCPCH Infant, Children and Young People’s Engagement Committee member)

*Res 6. Supporting younger Patient and Public Voice representatives on Clinical Reference Groups*

**Involvement...what methods can you use?**

Method	Why it is good	What's not so good about it
Peer consultation	<ul style="list-style-type: none"> <li>We heard from people we don't normally hear from. We got varied comments, coming from other patients</li> <li>It's good because it's not the adults asking them, it's other patients</li> <li>It's given us good socialisation skills especially for people of different ages</li> <li>We could go to young people who couldn't come to meetings</li> </ul>	<ul style="list-style-type: none"> <li>If they are really ill (they can't or don't want to talk) and we don't want to pressure patients into something</li> <li>Takes a lot of commitment from young people as peer interviewers</li> <li>It's not so comfortable to interview people your own age or older sometimes (good interviewing younger ones)</li> </ul>
Drawings / art projects	<ul style="list-style-type: none"> <li>Easier for young children and children with learning disabilities and language barriers</li> <li>Expressive</li> </ul>	<ul style="list-style-type: none"> <li>Hard to understand / interpret especially young children.</li> <li>Some children can't draw.</li> </ul>
Roadshow / workshops on wards	<ul style="list-style-type: none"> <li>Patients will be able to socialise, can share experiences, interactive</li> <li>Able to meet young people</li> <li>Young people get bored (on ward) even if they have their tablets and that, but speaking to someone else who is young it makes it easier for them to share their ideas.</li> <li>You would get really honest</li> </ul>	<ul style="list-style-type: none"> <li>Distracting</li> <li>some people might not be able to access it (may not be able to get out of bed)</li> <li>some may not feel well enough to join in.</li> </ul>

Method	Why it is good	What's not so good about it
	<p>responses because you would be with a group of people who would be having the same issues so it is less likely to be filtered.</p> <ul style="list-style-type: none"> <li>• It's almost like having that same face to face meeting but you are going to them.</li> <li>• <i>"You would be stupid not use it when you have a free group. Everyone is congregated in one place. You could invite other young people who have been discharged in"</i></li> </ul>	
Video (big brother style booth)	<ul style="list-style-type: none"> <li>• Feel more comfortable, free to express feelings.</li> <li>• Don't have to worry about things getting back to people</li> <li>• Good if there is someone actually interacting and interviewing you like in Big Brother</li> </ul>	<ul style="list-style-type: none"> <li>• Camera shy</li> <li>• Might not be accessible for wheelchair users</li> <li>• Might not feel that comfortable; feel awkward</li> <li>• You have no connection with other young people</li> </ul>
Drama	<ul style="list-style-type: none"> <li>• Good if you get it right can give ideas</li> <li>• It's really interesting</li> <li>• <i>"We created a piece of theatre that like showed all our experiences and ideas and then we sat in small groups and had a discussion about what we had seen and like we showed an experience of a bad consultation"</i></li> </ul>	<ul style="list-style-type: none"> <li>• How would you get their feedback</li> <li>• Some people might have issues interacting</li> </ul>

Method	Why it is good	What's not so good about it
Parent / carers as advocates	<ul style="list-style-type: none"> <li>• They are often the first person you talk to about experiences.</li> <li>• Younger children / children with communication difficulties might find it easier to talk to parents / carers in the first instance.</li> </ul>	<ul style="list-style-type: none"> <li>• Parents / carers might panic</li> <li>• Views can go through playground whispers / 'parent filter' and not be shared accurately.</li> <li>• Don't always share difficult stuff with parents / carers - want to protect them a bit.</li> </ul>
Online daily log - Young people do a daily update about their wellbeing and the service.	<ul style="list-style-type: none"> <li>• As long as it was confidential it could work</li> <li>• Anyone can access it</li> <li>• People might be used to doing this sort of thing at school / college</li> <li>• Large numbers of young people could give feedback</li> </ul>	<ul style="list-style-type: none"> <li>• No access to the internet</li> <li>• No form of dialogue or sense of being involved in decisions</li> <li>• Just sending through your experiences</li> </ul>
Youth Forum	<ul style="list-style-type: none"> <li>• Can be honest about opinions, more comfortable, relate to other young people</li> <li>• Get to discuss and debate ideas. Get to see if other young people have had the same experience as you</li> <li>• Face to face is better for building relationships and trust. Made good friends and got a lot of support.</li> </ul>	<ul style="list-style-type: none"> <li>• Some people don't like to share information.</li> <li>• It would be a bit harder for really sick patients.</li> <li>• Time consuming</li> <li>• You can't go if you are very unwell</li> </ul>

Method	Why it is good	What's not so good about it
Social media posting (Facebook / twitter / snapchat)	<ul style="list-style-type: none"> <li>• A place to vent. Anonymity can give you a chance to open up confidential Issues.</li> <li>• A closed Facebook group has wide outreach and is less intimidating.</li> <li>• Closed group is good if you want to share personal / intimate stories.</li> <li>• Could be promoted to young people on the ward</li> <li>• Easy way of connecting with people across country</li> </ul>	<ul style="list-style-type: none"> <li>• Putting up negative experiences on social media isn't always constructive. Might not be fair on staff - anyone can see it. People might get in trouble.</li> <li>• A closed Facebook group doesn't work for recruiting people</li> <li>• Not very co-ordinated</li> <li>• Shyness on social media - You might wonder where my words are going.</li> <li>• Online communication is great in theory but hard to build relationships, when we are in one place we are forced to talk</li> </ul>
Forms (smiley face, traffic lights)	<ul style="list-style-type: none"> <li>• Good for younger children, colourful</li> <li>• Might feel comfortable expressing yourself in writing</li> <li>• Less time consuming</li> </ul>	<ul style="list-style-type: none"> <li>• Can be boring for older children and hard for younger children</li> <li>• <i>"So long as it is not this huge long thing and you are sitting there forever writing on it."</i></li> <li>• <i>"What if you have more to say than just what is on the questionnaire?"</i></li> <li>• Form many not give an honest picture of how you</li> </ul>

Method	Why it is good	What's not so good about it
		are feeling
Email	<ul style="list-style-type: none"> <li>• Easy to put together thoughts in writing</li> <li>• Less time consuming</li> <li>• Would be better if you knew you were going to get a reply</li> <li>• If it was actually someone senior asking for your opinion who was going to read it</li> </ul>	<ul style="list-style-type: none"> <li>• Younger children often don't have email and older ones sometimes don't check it</li> <li>• Not a two way dialogue</li> </ul>
Talking to doctors / nurses (staff advocating for young people within Clinical Commissioning processes)	<ul style="list-style-type: none"> <li>• <i>“Good to tell staff on ward about little problems but about the whole service, I would prefer to tell someone else (more senior)”</i></li> <li>• Normally first point of contact so easier to share stories / experiences</li> </ul>	<ul style="list-style-type: none"> <li>• Don't want to seem critical or ungrateful</li> <li>• Difficult to tell them what you think</li> <li>• A lot of young people might not feel comfortable telling staff what might be directly affecting their treatment because they don't want to offend them</li> <li>• Brought up not to be rude to adults (criticising them can feel like being rude)</li> <li>• Some young people may feel shy and uncomfortable</li> </ul>



Method	Why it is good	What's not so good about it
		<p>about a certain condition they have. This is negative</p>
<p>Attending Clinical Reference Group meetings</p>	<ul style="list-style-type: none"> <li>• Speaking straight to people in charge</li> <li>• An opportunity to get feedback and have a discussion about your ideas.</li> <li>• Learn more. You know things haven't got lost in translation and they can ask us questions</li> <li>• Direct and professional opinions</li> <li>• Would need good facilitators</li> <li>• Face to face is important because it gives ability to bounce ideas with young people and really be able to get the conversation going</li> </ul>	<ul style="list-style-type: none"> <li>• Might be scary</li> <li>• Might be boring</li> <li>• Hard to get decision makers and young people together at a time that suits both</li> <li>• Will they be able to explain things without going into jargon?</li> <li>• They need to get more than one point of view from young people</li> </ul>
<p>Petitions</p>	<ul style="list-style-type: none"> <li>• If you get a certain numbers of signatures they have to discuss it in parliament</li> <li>• You could ask if people want to just fill out form or whether they</li> </ul>	<p>Can be confrontational rather than collaborative</p> <p>Wouldn't be able to share experiences</p>

Method	Why it is good	What's not so good about it
	<p>want to get involved further and or leave a personal story / testimony.</p> <ul style="list-style-type: none"> <li>• Can be youth led</li> </ul>	

Res 7. Involvement - what methods can you use?

### First participation project? Key things to consider;

**Safeguarding and Support.** Ensure all workers involved have the appropriate clearance to work with children and young people, have consent forms for engagement signed by parents and children and young people detailing contact details, medical and dietary requirements. Consider if involvement will require after care support, e.g. will there be sensitive topics discussed or could there be a sense of anxiety or concern on any of the issues raised? Make sure there is a first aider during your meetings and sessions. It is also important that adults involved (Clinical Reference Group members or support staff) are trained in safeguarding and data protection so they are clear when and how to escalate concerns that they may have with regards to disclosures made by children and young people. The Local Safeguarding Children's Board will be able to advise for your local area protocols.

**Confidentiality** and escalation of concerns. Think carefully about how you support children and young people to have access to appropriate information, papers, discussions whilst understanding what they can talk about outside of the meeting, what must remain confidential and who to talk to if you are not sure. This needs to be done in plain English and reiterated throughout their involvement.

**Finance and Resources.** All participation projects require adequate funding and resources in order to be successful. This includes money to cover travel expenses, providing refreshments that are proportionate to the travel and project time (e.g. lunch or dinner if staying for longer than 4 hours with travel, fruit and drinks if under 2 hours), you will need money or resources for printing, paper, post its and other project items.

**Plan your project** using the RCPCH model for balancing the focus of any engagement project – think fun, child/young person led and meeting the needs of your Clinical Reference Group programme of work.

**Promote your opportunity** in 5 different ways across a number of weeks leading up to your project. Use posters, letters, social media, personal face to face invites and text or email reminders. There are many different ways that people find out about an event or project – one approach does not work for everyone.

Deliver in a **child and young person focused** way. Would they respond better to it being in a room without a boardroom table set up or in an informal space like a lounge area? Vary the methods used so it is not all “round a flipchart” discussions.

Wherever possible, achieve something as a **finished product or output** every meeting so that there is always success – this could be as simple as blogging about the work of the project, developing a poster or top tips guide for workers, having a plan for who is doing what and when.

Consider **rewards and incentives** carefully. Providing travel, food and goody bags (stationary, trust or organisation branded items, freebies and giveaways) are normally appropriate rewards and incentives for involvement in participation projects. Termly pizza nights or end of project trips out to local facilities like bowling or a restaurant, personal thank you letters from the chair or clinical director are great ways to thank members for staying involved. Supporting skill development and how to articulate these skills on application forms, in CVs or for UCAS are also good ways to thank those involved, by helping them to take the learning and to apply it to the rest of their lives. Payment or vouchers for being involved can blur the motivation, create challenges around benefits or be taxable for the individual and may not be sustainable long term due to budget changes.

*Res 8. First participation project? Key things to consider*

## Who is in charge?

Start with an activity to explain who decides what in the NHS

- Ask the children and young people to write or draw on sticky notes some of the things that people might want to change or improve about their care or services in the hospital / NHS (for example, TV's not working on wards, hospital food, Doctors not explaining meds properly, long wait times or journeys to service)
- Have flip-chart paper with headings of different NHS decision makers on it for example:
  - Ward Matron
  - Hospital management
  - Local NHS trust
  - Clinical Reference Group and Specialised Service Commissioner
  - Central Government

Even better, if you can find photos, images or even draw your own stick people to represent these groups.

- Ask the children and young people to stick their sticky notes with their health care concerns onto the flip chart of the person they think is in charge for this area.
- Ask the group:
  - Why do you think this goes here?
  - Say if they have placed the sticky note under the right decision maker, and if not move to the correct place.
- Facilitate a discussion drawing out the following:
  - 1) How complicated the decision making process can be and sometimes why change can be slow!
  - 2) Different people are in charge and can change different things. It is important to know who is in charge of what
  - 3) Focus on what Clinical Reference Groups and Specialised Commissioners are in charge of discussing how to influence decisions, how best to share views and ideas.

*Res 9. Who is in charge?*



### Setting the agenda

Think about the specialised service area you work in. What knowledge and experiences do adults, children and young people have about the issue? Discuss in your groups and put your answers in the boxes below:

<b>What we know (children and young people) and they don't</b>	<b>What they know (adults) and we don't</b>
<b>What we both know</b>	<b>What neither of us knows (what we might need to find out)</b>

*Res 10. Setting the agenda*

## Troubleshooting...the children and young people way!

### Dilemma 1: “We have parent representatives involved. They are well placed to feed in children and young people’s views...”

- *“Feeding back through parents, I don't think that would best apply to me. When I was going through what I am going through initially I wanted to protect them (parents) a certain amount because I know it is probably harder for them than it is for me because I am going through it”*
- *“I think I would tell my mum but it would depend. Like there are some things that I wouldn't tell her, like if it were bad but if it were good I would tell my mum”.*
- *“Things get lost in translation (when parents speak for you)”*
- *“Parents can put their own filter on what you say - a panic filter”*

### Dilemma 2: “We don't have the time or skills to support children and young people to attend”

- *“If you care about young people then make time or ways for getting them involved”*
- *“have connections with charities or groups that already exist like the RCPCH who work with young people #showwayofsupportingyoungpeople*
- *“We can train and upskill you!”*
- *“young people will impact the next generation”*
- *“This is an important use of your time!”*
- *“Use your existing consultations to gain understanding. Give out surveys at clinics”*
- *“You don't need money?!? use local people, come to us”*
- *“Use current Patient and Public Voice representatives to reach out to other young people and get views”*
- *“Bring in young people as experts to do presentations to Clinical Reference Groups on what's important to them and then it can be questioned”*

### Dilemma 3: “The meetings are very technical. It would be difficult for children and young people to contribute in a meaningful way”

- *“Don't jump to conclusions about young people. First get them involved in the meeting then see how they cope”*
- *“Train young people before meetings so they understand more and are confident”*
- *“Mentorship by experienced young people for new people or offer shadowing”*
- *“Invite multiple young people to meetings and alumni / youth worker / experienced young people*

- *“You are making decisions about patients, to get it right surely patients should be consulted”*
- *“ We can attend (Clinical Reference Group meetings) for only what is appropriate”*
- *“You need to create an environment where young people can input and are asked for input as well as to asked for clarification”*
- *“Young people have strong opinions on many issues give them the chance to express these opinions”*
- *“Make the scientific language more simple and friendly and applicable to young people”*
- *“Pre-reading before the meeting? So people on the same level?”*
- *“Patients are the experts”*

**Dilemma 4: “The children and young people we help are spread out across the country, it’s hard to get people together”**

- *“Use more than one way of involving us”*
- *“Have a closed Facebook page that is promoted to young people when they are on the ward”*
- *“Workshops on the ward would be really useful and I think you would get really honest responses because you would be with a group of people who would be having the same issues so it is less likely to be filtered”*
- *“Talking to us while we are waiting for appointments or on the ward means we don't have to travel to give opinions - it adds value!”*
- *“Have a young person approach (contact) young people once a month asking how they feeling” (like a buddy system)*
- *“I love interaction with F1 and P2 doctors on wards and helping educate them through my stories and experiences”*
- *“Face to face is important BUT Skype can be a good alternative”*
- *“Online ways of communicating can be good but needs a good facilitator”*
- *“Other social media - Facebook, Skype, Twitter. keeps in contact with those across the country”*

**Res 11. Troubleshooting...the children and young people way!**



# Resources, toolkits and useful organisations

## Useful organisations

All of the following organisations either support you to connect to networks of child and youth projects, offer guidance or resources on their websites or can offer assistance to those looking to develop children and young people's participation.

- Ambition [www.ambition.org](http://www.ambition.org)
- Association of Young People's Health [www.youngpeopleshealth.org.uk/](http://www.youngpeopleshealth.org.uk/)
- British Youth Council [www.byc.org.uk](http://www.byc.org.uk)
- Council for Disabled children <https://councilfordisabledchildren.org.uk>
- Children's Rights Alliance for England [www.crae.org.uk](http://www.crae.org.uk)
- Generation R: Young people improving health through research  
<http://generationr.org.uk>
- National Children's Bureau [www.ncb.org.uk](http://www.ncb.org.uk)
- NHS Youth Forum <http://old.byc.org.uk/uk-work/nhs-england-youth-forum.aspx>
- Royal College of Paediatrics and Child Health [www.rcpch.ac.uk/and\\_us](http://www.rcpch.ac.uk/and_us)
- Save the Children England [www.savethechildren.org.uk](http://www.savethechildren.org.uk)
- UK Youth [www.ukyouth.org](http://www.ukyouth.org)
- Young Research Advisors: Involving children and young people in research (UCL and NCB) <https://www.ncb.org.uk/what-we-do/how-we-work/research/involving-children-young-people-research>
- Young Minds <http://www.youngminds.org.uk>
- You're Welcome' refresh <http://old.byc.org.uk/uk-work/you're-welcome.aspx>

## 'How to' guides and toolkits

- A toolkit for monitoring and evaluating children's participation (2014) Save the Children <http://www.savethechildren.org.uk/resources/online-library/toolkit-monitoring-and-evaluating-childrens-participation>
- Bitesize guide to setting up a youth forum in health services across England (2015) NHS England and the British Youth Council <https://www.england.nhs.uk/wp-content/uploads/2015/02/how-to-guid-yth-forum.pdf>
- Children's participation in Hospital: A short introduction to the theory and practice of involving children in improving the quality of care. (2012) Dedding, C. Schalkers, I. and Willekens, T. Dutch Child and Hospital Foundation, Zorgbelang the Netherlands
- CYP Me First Resources Hub for communicating with children and young people in health <http://www.mefirst.org.uk/resources/>
- How to involve children and young people in commissioning, (2012) Cutler, P / Participation works <http://www.participationworks.org.uk/resources/how-to-involve-children-and-young-people-in-commissioning/>
- How to involve children and young people with communication impairments in decision-making. (2008) Participation works [http://www.participationworks.org.uk/files/webfm/shop\\_files/howto\\_Communication/index.pdf](http://www.participationworks.org.uk/files/webfm/shop_files/howto_Communication/index.pdf)
- Kaizen Engagement Models - Engagement Strategy & Planning (2013) Kaizen <https://docs.google.com/file/d/0B5jfls5B703TWkJUN3ZZbXpTTWc/edit>
- Let's listen: Young children's voices, profiling and planning to enable their participation in children's services. (2011) Dr Cathy Hamer and Lucy Williams. Young Children's Voices Network (YCVN, NCB), <https://www.ncb.org.uk/listening-and-participation-resources>
- Listening as a way of life: Listening to young disabled children (2011) Dickins, M. NCB Young Children's Voices Network

- Listening to Young Children: The Mosaic Approach (2001) Clark, A and Moss, P. NCB.
- National Child and Maternal Health Intelligence Network hosts this page with signposting to useful resources about youth participation and commissioning  
<http://www.chimat.org.uk/camhs/participation/commission>
- National Coordinating Centre for Public Engagement. <https://www.publicengagement.ac.uk/plan-it/who-engage-with/resources-working-with-young-people>
- NHS Involvement Hub <https://www.england.nhs.uk/participation/>
- NHS Youth Forum's Top Tips to involve young people in healthcare planning (2015) <http://www.byc.org.uk/wp-content/uploads/2016/09/NHS-Youth-Forum-Tip-Brochure-FINAL.pdf>
- Not just a phase. A guide to the participation of children and young people in health services (2010)  
<http://www.rcpch.ac.uk/system/files/protected/page/RCPCH-not-just-a-phase-2010.pdf>
- Research *&Us* engaging children and young people in research  
<http://www.rcpch.ac.uk/cyp-research-charter>
- Royal College of Paediatrics and Child Health: how to guides and resources for participation <http://www.rcpch.ac.uk/and-us-resources>
- Participation Works [www.participationworks.org.uk](http://www.participationworks.org.uk)  
Participation Works provides policy updates, resources, information about innovative practice and links to key organisations and networks across the UK.



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NCB London

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Office of the Children's Commissioner and National Children's Bureau

[http://www.childrenscommissioner.gov.uk/sites/default/files/publications/FINAL\\_REPORT\\_We\\_would\\_like\\_to\\_make\\_a\\_change\\_Participation\\_in\\_health\\_decisions.pdf](http://www.childrenscommissioner.gov.uk/sites/default/files/publications/FINAL_REPORT_We_would_like_to_make_a_change_Participation_in_health_decisions.pdf)

UN (1989) United Nations Convention on the Rights of the Child

<https://www.unicef.org.uk/what-we-do/un-convention-child-rights/>