

RCPCH Guidance

Involving children and
young people in specialised
commissioning

June 2017

RCPCH Guidance:

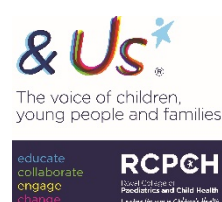
Involving children and young people

in specialised commissioning

2017

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Contents

Executive Summary: Involving children and young people in specialised commissioning	5
Key ingredients	6
Section 1: Introduction	9
Section 2: Understanding children and young people's participation	11
Section 3: Including the least heard	16
Section 4: Key ingredients for successful participation	21
Section 5: Getting Started	27
Section 6: Consult: Making current consultation and Patient and Public Voice mechanisms more accessible	35
Section 7: Developing participation and co-production	42
Section 8: Trouble shooting: Your dilemmas solved and myths dispelled by young people!	59
Section 9: Resources, toolkits and useful organisations	62

Resources

Res 1. What are specialised services	10
Res 2. Practical tip: From theory to practice	15
Res 3. Basic Checklist for inclusion	19
Res 4. Making a plan	30
Res 5. Three things you can do now	31
Res 6. Supporting younger Patient and Public Voice representatives on Clinical Reference Groups	40

Res 7. Involvement – what methods can you use?	52
Res 8. First participation project? Key things to consider	54
Res 9. Who is in charge?	57
Res 10. Setting the agenda	58
Res 11. Troubleshooting...the children and young people way!	61

Case Studies

Case Study 1. Involving young children in developing national policy	20
Case study 2. RCPCH &Us Roadshows and Clinic Chats	25
Case study 3. Young Patient and Public Voice representatives on Clinical Reference Groups	41
Case study 4. Peer led consultation: Alder Hey Youth Forum, developing this guidance	45
Case study 5. HIV Clinical Review group	56

Figures

Fig 1. Degrees of Participation	14
Fig 2. Voice at RCPCH	34
Fig 3. Motivators for engagement	43

Executive Summary: Involving children and young people in specialised commissioning

"I feel like I have got knowledge in this area and I have been treated in places like here where you get excellent treatment and places where not so much, so you can see why stuff works well" (Young man, Teenage Cancer Trust Unit UCLH)

Children and young people make up a significant proportion of the users of NHS Specialised Services. About 30% of emergency and urgent care activity relates to children and young people and 15% of children and young people have a long standing illness¹ yet they rarely have a voice within decision making about these services at a national strategic level.

Children and young people have told us how important they think it is that they have a voice about services at the commissioning stage. They want a direct line of communication with Commissioners and Clinical Reference Groups; however they also want it to be inclusive, creative and flexible. A move to greater use of working groups within Clinical Reference Groups provides an opportunity for more creative and focused engagement of children and young people in Specialised Commissioning, yet challenges around resources and support still remain. These challenges will require Commissioners and Clinical Reference Groups to work in partnership with parents, existing support groups and voluntary organisations and with the wider hospital based community of clinicians, play specialists, activity workers and hospital volunteers to maximize opportunities to engage children and young people in this work.

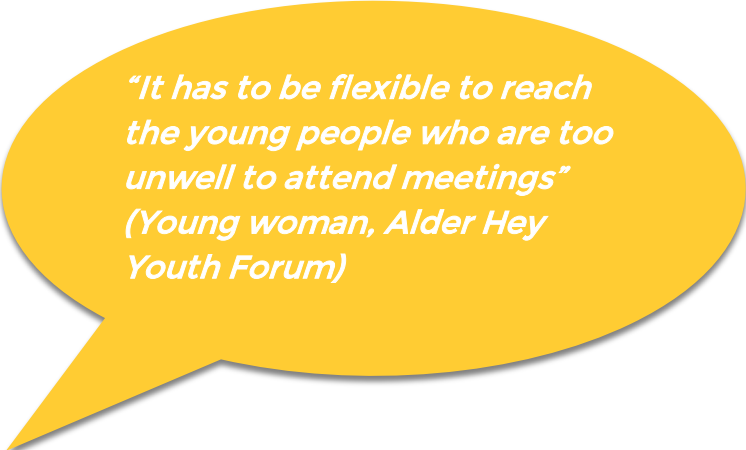
This guidance offers advice and tips, much of which comes directly from children and young people that use the services, about how they would like to be involved in Specialised Commissioning procedures. It highlights how children and young people can be engaged directly with Clinical Reference Groups but also looks at many other methods that children and young people have identified for them to have a voice at a strategic level.

¹ Report of the children and Young People's Health Outcomes Forum 2014/15)

Key ingredients

We want more choice and flexibility

Children and young people wanted to see a range of different approaches for different ages, abilities and interests (including more creative and interactive approaches). It was important that mechanisms to have a say include younger children, those that do not communicate verbally, those subject to the Mental Health Act 1983 (amendments 2007), and to accommodate periods of significant ill health. During times when their health is a factor, it may reduce or change the way children and young people engage, for example rather than attending events in person, they could contribute online (surveys, youth proofing, virtual conference calls).



"It has to be flexible to reach the young people who are too unwell to attend meetings"
(Young woman, Alder Hey Youth Forum)

We want to meet, talk and share experiences with other children and young people

Children and young people who had used specialised services often talked of feeling quite isolated when they were unwell or there being stigma amongst their peers about their illness. Methods of engaging where children and young people got to meet others of a similar age with the same condition repeatedly came up as popular. Events, forums and groups provided an opportunity for peer support and a chance to make a difference - a winning combination!

We want to feel like we are making a difference and be involved, not just consulted

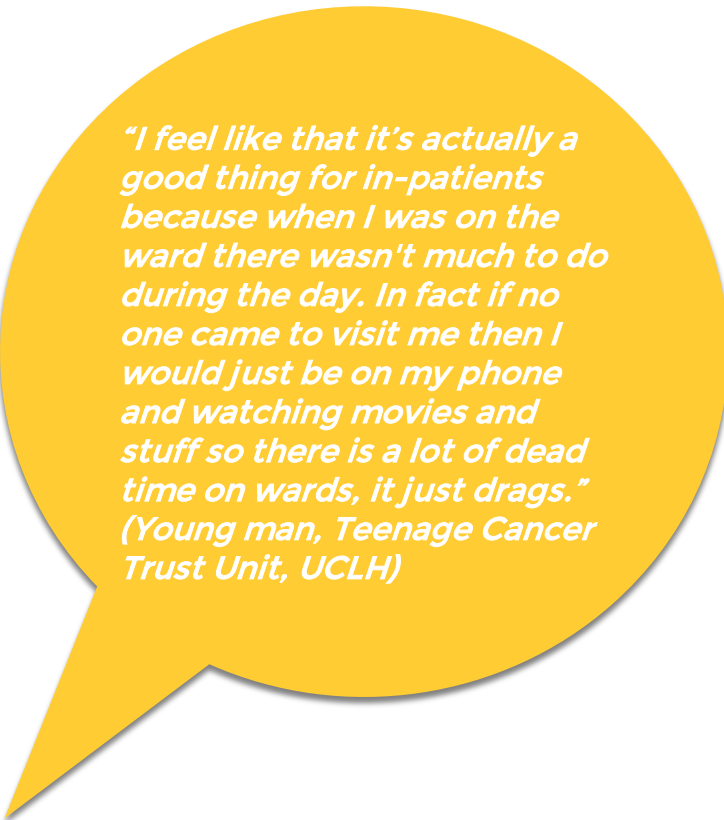
Children and young people wanted to get involved in activities where they could make a difference and help other children and young people who might be going through what they had experienced. Whilst questionnaires and surveys are commonly used, children and young people did not find them interesting or engaging and felt

that they rarely knew how their answers were used. They wanted to engage in a process of dialogue and to see the impact of their involvement.

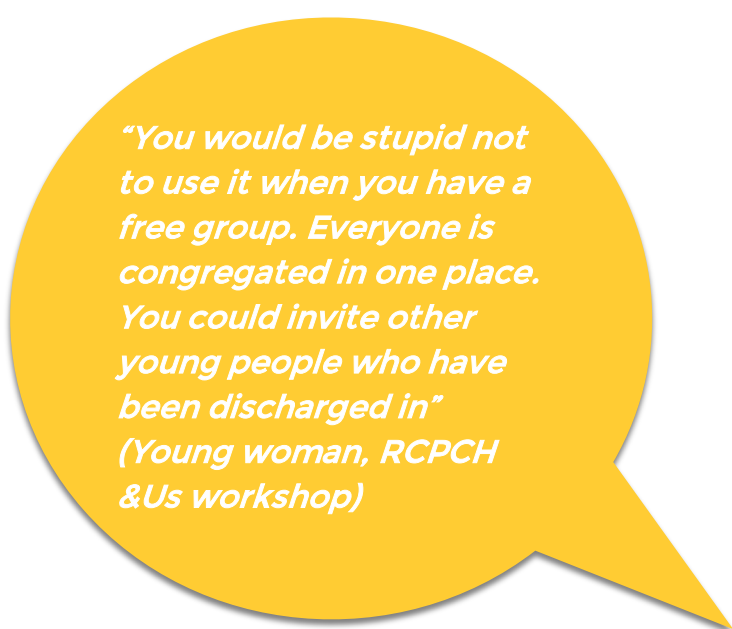
Come and talk to us on wards, in waiting rooms and at support groups we already attend

Children and young people who used specialised services often spent a lot of time in hospitals. As one young person put it *"I have grown up here, it's like a home"* (young woman, Alder Hey Youth Forum). The young people could see a lot of opportunities to engage whilst they were waiting for appointments or when they were in-patients and bored on the wards. They felt this was a good use of time as they had to be there anyway. This approach worked best when children and young people were approached first by someone they knew already to check if they were interested and feeling well enough to engage.

Younger children and those older children who found groups, meeting new people or different environments difficult were also more likely to open up and share experiences when in familiar surroundings. Partnerships with existing support groups are a great way to reach these children and young people.



"I feel like that it's actually a good thing for in-patients because when I was on the ward there wasn't much to do during the day. In fact if no one came to visit me then I would just be on my phone and watching movies and stuff so there is a lot of dead time on wards, it just drags."
(Young man, Teenage Cancer Trust Unit, UCLH)



"You would be stupid not to 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"
(Young woman, RCPCH &Us workshop)

Listen to parents and carers but don't only listen to parents and carers

Many young people, especially the older members, talked about how they did not always share fully their thoughts and feelings with parents and carers as they didn't want to worry them. Parents and carers also at times were feeding back young people's experiences with the 'parent filter' on – highlighting the elements that they felt were important. Working with parents and carers to listen to children and young people is crucial, however it is not the same as hearing from children and young people themselves!

Just take 3

Try these three steps to begin involving children and young people in your work:

1. Find out through the Clinical Reference Group members, particularly your Patient and Public Voice representatives, which organisations, local or national, are bringing young service users together. Contact them and add these groups to your Registered Stakeholder lists
2. Make sure information about consultations goes out with 'child friendly' versions and actively invites responses from children and young people. Make sure consultation results can be analysed so you can see if a respondent is a child or young person service user
3. Begin the discussion about opportunities for more creative engagement with your child or young person service users at Clinical Reference Groups and with possible partners.

For more information, practical tips and activities see the full Guidance on Involving Children and Young People in Specialised Commissioning at www.rcpch.ac.uk/andus-participation

Section 1: Introduction

“NHS England is committed to involving patients and the public at each stage of the commissioning cycle for specialised services.” (NHS England, 2016).

There are well established systems in place for NHS Patient and Public Involvement in Specialised Commissioning. However these are often quite intimidating and inaccessible to children and young people. The children and young people who helped shaped this guidance clearly told us that they would like to be involved in decision making about Specialised Services. They want to make sure that decision makers understand their experiences and that services are shaped to meet the particular and changing needs of younger patients. They also want to use their experiences of being unwell and the knowledge they have of specialised services to help benefit other children and young people.

As part of this project, young people from Alder Hey Youth Forum led peer consultation and asked other children and young people on the wards about their experiences of giving feedback. Overwhelmingly the children and young people said they felt like the nurses and doctors listened to them. However, very few had been asked for their feedback on the service outside of completing a short survey or in relation to top level commissioning decisions.

There has been a strong movement for increased children and young people's participation in public sector decision making over the last 20 years. At a strategic level younger voices within health are still noticeably absent from decision making. In 2013 the Office of the Children's Commissioner for England conducted research into the level of children and young people's voice in strategic health. They found *“No coherent national programme of activity to encourage local bodies to include children and young people in strategic health service commissioning or other vital decision making about NHS provision”* (OCC, 2013). The focus of the OCC research was on local strategic health policy, but the same observations can be made of children and young people's views, voice and presence within specialised strategic commissioning processes.

This guidance is for those involved in Specialised Services Commissioning. The aim is to encourage and support you to take the lead and begin the journey of children and young people's participation or further develop and refine your programme. It will also

be of interest to anyone, including children, young people, their parents and carers, the voluntary sector, and providers of health and social care services; who wants to find out more about how to involve children and young people in the commissioning of specialised services.

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

Section 2: Understanding children and young people's participation

"You are making decisions about patients, to get it right surely patients must be consulted?" (young person, RCPCH &Us workshop)

Children and young people make up 25% of the population. About 30% of emergency and urgent care activity relates to children and young people and 15% of children and young people have a long standing illness (Report of the Children and Young People's Health Outcomes Forum 2014/15). They are a significant population of service users of specialised NHS services, yet they are a group that is consistently underrepresented in Patient and Public Voice activities (NHS Equality and Health Inequalities Analysis, 2016).

Many of the children and young people who use specialised services in the NHS have used them over a long period in their lives or had very intense experiences of ill health. They have great insights both about the services but also about how children and young people manage to juggle complex health conditions with the pressures of growing up. More importantly they have a right to have a say in their care and the services that are provided to them.

"I feel like I have got knowledge in this area and I have been treated in places like here where you get excellent treatment and places where not so much, hmm so you can see why stuff works well" (young man, Teenage Cancer Trust Unit UCLH)

"Young people have strong opinions on many issues - give them the chance to express these opinions" (young woman, RCPCH &Us workshop)

- Involving children and young people can lead to improved services. Children and young people can bring a different perspective to stubborn challenges that service delivery faces. They can help to highlight areas where services are working well and help professionals identify any professional blind spots
- Being involved in participation or co-production (not just responding to consultations) can be a really empowering process for children and young people at a difficult phase in their life. Young people we spoke to also talked about how their involvement had helped them reduce their anxiety about time in hospital, gain peer

support from meeting other young people who were living with similar conditions and develop a greater sense of acceptance and control over their health.

The rights based perspective to children and young people's participation is backed up by the following legislation:

- The Health and Social Care Act 2012 indicates in section 13Q and section 14Z2 that the NHS has a duty to involve service users and the public in service changes, this includes children and young people
- The Equality Act 2010 and public sector equality duty (PSED) aim to ensure there is no age discrimination.
- The UN Convention on the Rights of the Child 1989 (UNCRC) Article 12, was ratified by the British Government in 1991 and enshrines that:

'State parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child'. The UN Convention of the Rights of the Child (UNCRC) Article 12.

In September 2016, NHS England launched its "Framework for Patient and Public Participation in Specialised Commissioning". This guidance forms part of the support materials to go alongside this framework.

Definitions

Within this guidance the term "children and young people" refers to those under the age of 18 or up to 25 if they have a disability. However we recognise that some specialised services, for example teenage cancer wards, are already responding to feedback from young people and are designing services to support transition of young people into adult services by having a broader age range of up to 25 years. In this instance we would also suggest that the principles and methods discussed in this guidance could usefully support these young people to have a greater voice.

Models of participation

There is a lot of research and theory surrounding participation of children and young people. Here we touch on a couple of the models for participation which may be useful in your work. Commonly you will see models of participation represented as a ladder (Arnstein, 1969, Hart 1987). In the original models the bottom three rungs of the ladder; manipulation; decoration and tokenism, were not considered participation. Hart provides a useful explanation of these rungs of 'non participation' and what to avoid in your practice.

"An example of manipulation is a situation where children are consulted but given no feedback at all. The most common method is for children to make drawings of something, such as their ideal playground. Adults collect the drawings and in some hidden manner synthesize the ideas to come up with 'the children's design' for a playground. The process of analysis is not shared with the children and is usually not even made transparent to other adults. The children have no idea how their ideas were used. Decoration, the second rung on the ladder, refers, for example, to those frequent occasions when children are given T-shirts related to some cause, and may sing or dance at an event in such dress, but have little idea of what it is all about and no say in the organizing of the occasion. The young people are there because of the refreshments, or some interesting performance, rather than the cause. Tokenism is used here to describe those instances in which children are apparently given a voice, but in fact have little or no choice about the subject or the style of communicating it, and little or no opportunity to formulate their own opinions. (Hart, p9, 1992)

The NHS Framework for Patient and Public Participation in Specialised Commissioning, presents a ladder of participation in which the bottom two rungs are informing and consulting and then stepping up to the involving, collaborating, devolving and co-production (at the top). All of the rungs represented in the NHS Framework are valid and valuable at different times.

The following model is an Office of the Children's Commissioner (OCC) presentation of the Save the Children's Degrees of Participation (Phil Treseder, 1997). The different degrees of participation are not represented hierarchically (to avoid the suggestion that there should be a race to the top of the ladder) as all are equally valuable at different times. The OCC has summarised the model as Inform, Consult, Involve. It is these three broad categories that we will work with in this guidance.

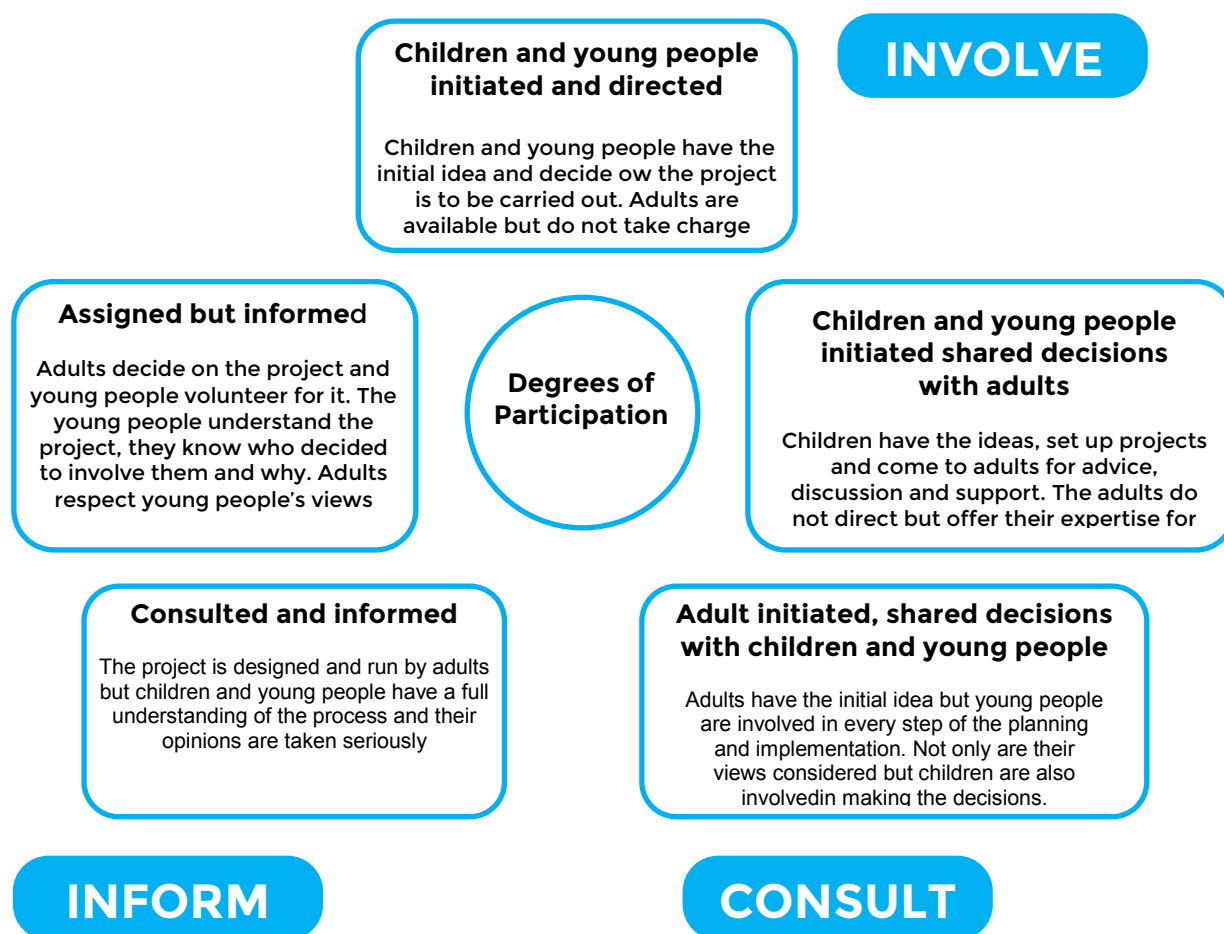


Fig 1. Degrees of Participation

RCPCH has developed an additional level of “represent” to highlight the aspiration to have children and young people themselves representing the needs, wishes and views of their peers at strategic forums.

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

Section 3: Including the least heard

“Never accept that horrible label “hard to reach” because it blames people not taking up the service” Parent Patient and Public Voice representative, Clinical Reference Group

“Young people tell us all the time what they think, through words, actions and behaviour. If we really do want to design services which are based on what children say, then we need to listen, pay attention and reflect on what they are telling us in their daily lives.” (McLaughlin, 2015)

NHS England has made a commitment to ensure people who experience health inequalities are included in participation activities. Children and young people are identified as one of the groups who are frequently underrepresented in Patient and Public Voice activities. Children and young people who face health inequalities are doubly excluded. Adult perspectives on what children and young people are capable of suffer from a lack of resources; poor publicity; short notice for activities or use of consultation approaches that are inaccessible. All these serve to reinforce exclusion.

For example, NCB guidance into listening to young children with disabilities (Dickins, 2011) highlights that children and young people with disabilities are:

- subject to a much higher degree of adult intervention and their scope for making day-to-day choices and decisions is often severely limited
- have many things done to, and for, them and they are significantly more vulnerable to abuse than non-disabled children (NSPCC, 2003)
- are more likely to be subject to a number of medical interventions and treatments
- are more likely to be subject to various kinds of assessment procedures and less likely to be involved in the process
- are more likely to be excluded from consultation processes because these are often based on written and spoken language
- are supported by parents and staff who are more likely to see their roles as advocates rather than listeners
- are more likely than other children to have contact with multiple carers who lack the skills to understand their communication system.

More often than not it is considered 'too difficult' to engage younger children/children and young people with more complex disabilities in strategic decision making. However by designing and anchoring participatory approaches within children and young people's day to day lived experience, working in partnership with local projects, hospitals, parents and carers, these children and young people can also play an active and rewarding role. Through their engagement, services will become better at listening and less likely to miss abuse or the needs of the most vulnerable service users.

Again ensuring that the information reaches the organisations engaging with these children and young people with sufficient time for them to engage is the crucial first step. The next most important thing is to be flexible with the methods used to engage. For example the most appropriate approaches to active involvement of children and young people with disabilities will depend on the nature of their needs. Often children and young people who have learning disabilities or difficulties with varied communication preferences, will be able to express their views effectively using sign, symbols, body language, photographs and videos, gesture, drawing and playing. Methods which avoid extensive group discussion, writing or reading will also work better for younger children.

Children and young people with complex mental health problems may need more time to get to know the person with whom they are speaking. They may also need to be visited where they are –either in hospital or at home - rather than expected to attend another venue. In these situations it is better to allow the children and young people time and space to reflect on and communicate their experiences of health services through creative methods or three-way conversations with those who know them well.

When you are planning your event or activity, discuss in advance with the children, young people and / or their support workers what approaches would work best for them and what access needs they have. NHS guidance and standards around accessible communication for disabled patients can be found here <https://www.england.nhs.uk/ourwork/accessibleinfo> including useful tips for commissioners, decision makers and individual practitioners.

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

Including younger children (under 5s)

Often inclusion of children and young people in decision making is restricted only to those most able to participate in adult structures. This often requires a high level of verbal communication and ability to digest a lot of written information. In reality this excludes younger children, those who do not communicate verbally, and those who have lower literacy levels or who would find a formal meeting too daunting (or boring!). However when our goal is to hear, understand and have these perspectives help shape policy and service provision, it becomes obvious that we have to adapt our methods.

There has been much work carried out concerning creating a listening culture amongst early years and with children with varied communication needs and disabilities (Hamer & Williams, 2011).

Three key elements have emerged as particularly important for work with the youngest children:

- The use of observation of the child's behaviour, likes, dislikes, experiencing a setting from their view point
- To provide the children with opportunities for making choices
- To engage children in designing spaces. Allow them to identify what they like and dislike about current space.

The Mosaic Approach (NCB 2001) highlights best practice in involving young children in sharing voice and views in individual decision making or shaping services through their feedback.

Case study: involving young children in developing national policy

The National Children's Bureau's (NCB) Early Years Unit was asked by the Department for Education to work with 3 and 4 year olds to input into the 2009 Draft Code of Practice of the Free Entitlement for 3 & 4 year olds. The Early Years Unit partnered with a number of local early years settings to work with the children there. Key findings emerged:

- pick up and collections caused anxiety, especially when the children were uncertain of routine or who was picking them up
- play was important to help manage transitions in and out of sessions and could reduce anxiety at these times
- friends could help relieve anxiety at arrival and end of sessions
- food and drink routines were significantly important to the children
- outside play and creativity were most popular activities for the children.

Advice was then incorporated into the guidance to support early years providers to manage these transitions more effectively for the children based on the key findings.

Case Study 1. Involving young children in developing national policy

Section 4: Key ingredients for successful participation

Throughout the consultation about this guidance, young service users shared their top tips to supporting their engagement. They have been grouped here to provide you with their top tips for making children and young people's participation a success.

We want more choice and flexibility

Children and young people repeatedly said it was important to “*recognise we are all different*”. One approach or activity was not enough. They felt it was really important to use different approaches for different ages, abilities and interests. They also felt it was important to be flexible and to recognise that their health fluctuates and this changes how much and the way that they could get involved at different times.

“It has to be flexible to reach the young people who are too unwell to attend meetings” (young woman, Alder Hey Youth Forum)

“I was asked to do an interview, I didn't mind the idea of speaking to someone but then I didn't do it cos I was too unwell. I like the idea of peer consultation. It would be good to speak to someone who actually knew what you had been through” (young man, Teenage Cancer Trust Unit, UCLH)

Online forums and feedback - things that people could do in their own time when they were feeling well enough (but maybe bored because they were not well enough to go out/leave their bed) were good starters. Even better was to have the option and to know that they could get more involved during periods of good health when they might want to attend events and meet people face to face - it was about not feeling forgotten when they couldn't physically be there.

“I feel like until you actually go through it you can't really understand what's best for you and also everyone is different and everyone experiences different side effects” (young man, Teenage Cancer Trust Unit, UCLH)

“Drawing might work better for the younger ones or those who can't talk” (young woman, Alder Hey Youth Forum)

We want to meet, talk and share experiences with other children and young people

Peer support and social activities were seen as a really important element of participation activities. Many of the young people talked about feelings of isolation when you have a diagnosis of a long term condition. Methods of engaging where young people got to meet other young people with the same condition repeatedly came up as the most popular with young people saying:

- They wanted to be able to explore their experiences in a safe environment (with people they could relate to who had gone through the same thing) before they shared it with decision makers
- Having the chance to develop their confidence was important, as well as understanding the experiences of others which would also mean that they were not just talking from their own point of view
- Meeting other young people also meant that they felt less alone and more supported. Some young people talked about having made friends through participation activities who they were able to share things that they felt they could not share elsewhere
- Young people said that even where wards were designed to be more social it could be hard to make friends and connections and that these type of activities could help bring young people together for a purpose
- One recommendation that came up a few times was that a youth forum should meet and then either send representatives to Clinical Reference Groups (or working groups) or attend as a group to present their views and experiences
- The idea of closed online forums also came up as a good way for young people to connect and share experiences as well as recommendations for services. There were concerns however, about how you would be able to trust those in the forum. One idea that emerged was that the online forum was promoted to children and young people when they are inpatients. This was seen as a way of staff ensuring that the forum was targeted to those who had the condition and it was a safe forum.

“Run fun workshops during the holidays for other children with the same chronic illness to relate to each other” (young woman, King’s College Hospital)

“Provide more opportunities for young people to feedback to each other” (young man, Teenage Cancer Trust Unit, UCLH)

We want to feel like we are making a difference and be involved, not just consulted

Children and young people were very keen to get involved in activities where they felt they could help other children and young people who might be going through what they had experienced / were experiencing.

Young people said that they wanted:

- evidence that their recommendations had been put into practice or an explanation as to why they could not be actioned from professionals and young people
- a thank you for their time and views
- a visit to a unit and to see the change or meet the decision makers.

The children and young people also said that they wanted a two way dialogue about their ideas, not just feedback on what happened. Young people stated they wanted to move beyond consultation to models of co-production and more active collaboration. This desire for direct discussion with decision makers also meant that they felt having child and youth representation on Clinical Reference Groups was important.

Children and young people could see that consultation activities (surveys, forms, online feedback) were useful for collecting information and views, and they enabled large numbers of children and young people to take part. However they were also described as boring and not very satisfying. Children and young people mentioned that they rarely knew what happened with the information they provided, and that they didn't feel involved or like they had made a difference with these methods. They also reflected that they had none of the social or support benefits of more interactive participative approaches.

"Filling out a form again - that's another thing that I don't really feel is very personal. You just never know where that goes" (young man, Teenage Cancer Trust Unit, UCLH)

"If ideas are raised by young people then they should be told if it is possible / or not and if not why - explicit dialogue" (young woman, RCPCH &Us workshop)

"If I was able to put forward ideas and share my experiences then people (in Clinical Reference Groups) could give me their ideas. I could say whether that would work or not. Or if I came up with a solution, (they could) brainstorm my opinion and I could

hear back whether that is possible or affordable” (young man, Teenage Cancer Trust, UCLH)

Come and talk to us on wards, in waiting rooms and at support groups we already attend

Children and young people who used specialised services often spent a lot of time in hospitals. As one young person put it *“I have grown up here, it’s like a home” (young woman, Alder Hey Youth Forum)*. The young people from the Youth Forum could see a lot of opportunities to engage with children and young people whilst they were waiting for appointments or when they were in-patients and bored on the wards, or unable to leave to attend events. During the production of this guidance we found that young people and their families were very keen to use time in waiting rooms and on wards to feedback.

“I feel like that it’s actually a good thing for in-patients because when I was on the ward there wasn’t much to do during the day. In fact if no one came to visit me then I would just be on my phone and watching movies and stuff so there’s a lot of boring time on wards, it just drags.” (young man, Teenage Cancer Trust Unit, UCLH)

“You would be stupid not to 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” (young woman, RCPCH &Us workshop)

The young peer consultants from Alder Hey enjoyed carrying out the peer to peer consultation on the wards. They talked about how they had got to hear the views of young people who wouldn’t normally get involved in the hospital youth forum but they also said they had to be considerate of the person they were talking to:

“You have to be sensitive about who you approach, and how when on wards so not to invade their privacy or disturb them if they were feeling very poorly. It’s best if nursing staff let them know in advance so they had a chance to think about whether to take part or not” (young woman, Alder Hey Youth Forum).

There are also play specialists and activity workers, participation officers, public and patient involvement leads and often volunteers in hospitals, all of whom can help support participation activities with children and young people.

Case study: RCPCH &Us Roadshows and Clinic Chats

In 2016, the children and young people's engagement team at RCPCH embarked on a series of consultation activities going out to children and young people through RCPCH &Us Roadshows and Clinic Chats.

The team developed creative activities to capture voice on strategic policy consultations using the Recipes for Engagement tools (www.rcpch.ac.uk/and-us-resources) and delivered these through 60 minute workshops. By visiting universal settings (schools/youth clubs), targeted settings (special schools/hospital youth forums) and specialist settings (in-patient units/condition specific forums) a range of voices were supported to contribute their voices and views.

For those where it was not possible to see a group of children or young people together, Clinic Chats were trialled, which involved visiting waiting rooms (with clinician permission) to speak with families while waiting for their appointments to answer three questions about the service or setting

1. what is your best example of care
2. what is your wish for care
3. what three words would you use to explain this service

Staff spoke to those involved in clinic chats at the start of every discussion to be aware of the open waiting room context and of publically disclosing sensitive information. The questions were designed to remain service focused rather than individual case based.

Case study 2. RCPCH &Us Roadshows and Clinic Chats**Working with parents and carers**

"It's vital at the end of the day (that young people have a say in commissioning), it's for them. By the time it (their views) goes up and down and the young people have said 'this doesn't work for us', there is no money, time or resources to change it" (parent, Alder Hey Hospital)

“Even if you haven't got them around the table for all of it (Clinical Reference Groups meeting), bring in four or five of them to come in for part of it” (parent, Alder Hey Hospital)

Almost all children and young people talked about parents and carers being an important first port of call to express thoughts and feelings about the service they used. Many, especially younger children, were keen initially to have parents and carers involved in helping them to communicate their experiences of a service. However for many older young people this did not feel right. They preferred to speak on their own behalf.

Children and young people talked about protecting their parents from some of the more difficult experiences that they went through with their healthcare, not wanting to complain or worry their parents. This meant there was feedback about services that they were not happy with, that they would not always share with their parents / carers.

Finally, children and young people were concerned that when parents and carers spoke on their behalf that it was with the *parents filter* on. Views were slightly altered or adjusted or it became like a game of playground whispers where children and young people's views were “*lost in translation*”.

Section 5: Getting Started

Making a plan... A checklist for children and young people's involvement in strategic health decision making

In 2014, the National Children's Bureau conducted research into children and young people's participation in strategic decision making on behalf of the Office of the Children's Commissioner (England). They made a series of recommendations for local health and wellbeing boards about how children and young people could be involved in strategic decision making. The following checklist is adapted from these recommendations and provides a basic checklist for developing participation in your area of work.

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	
Create a variety of options for children and young people to get involved	<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>	
Wherever appropriate, children and young people should be given opportunities to make genuinely shared strategic decisions with adults.	<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"> • share experiences • identify common themes and issues • look at possible solutions • debate the pros and cons • hear and discuss these options with professionals • be part of the final decision making process • support ongoing monitoring or review of the impact of these decisions 	

	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.	
Make use of existing materials, resources and mechanisms for engaging children and young people.	<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>	
Monitor whether you are hearing the same voices repeatedly, striving to provide opportunities to those who might not normally be heard	Ensure that public consultations ask if the respondent is under 12, 18 or 25.	
	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>Check that consultation and participation opportunities are shared with and accessible for children and young people from</p> <ul style="list-style-type: none"> • different cultural backgrounds • on low incomes (travel costs for attending may act as a barrier?) • children and young people with disabilities • or other groups that may have socio- 	

	economic barriers preventing their involvement.	
	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?	
Promote and act as ambassadors for children and young people's participation in specialised health services	Commissioning processes support and promote the voice of the child and young person through service specifications for all providers	
	Share publicly how children and young people are being involved in decision making about specialised services.	
	Support children and young people involved to talk at conferences or events to share experiences and best practice of being involved	
	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.	
	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 www.rcpch.ac.uk/and-us and the NHS Involvement Hub https://www.england.nhs.uk/participation/	

Res 4. Making a plan

Where to start? - Three things you can do straight away without extra resources or time

It can feel a little daunting developing the participation of children and young people from scratch, especially if you already have a full workload and no clear budget set aside to take it forward. Fear not! Start with these three easy steps which aim to help you uncover and utilise some of the existing resources there may be amongst your specialised commissioning colleagues.

Public and Patient Voice representatives are often well connected to service user support, advocacy groups or charities. Colleagues may know of other active local groups or hospital youth forums that could be engaged. An essential place to start is to find out which organisations are already bringing together children and young people that you want to engage. Find out who they are and make sure that they know about you.

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

How to reach children and young people

"Where is it that the child or young person feels comfortable? Use that project or person to reach the young people" (Parent Public and Patient Voice representative)

For many children and young people it is better to engage with them in an environment that they are used to being in, with people that they feel comfortable being around. This can be especially important for younger children and those with disabilities or health conditions where a new environment can feel overwhelming and / or distracting. It can also allow you to undertake activities which are grounded in their day to day lived experience and therefore more likely to be authentic.

For example, young children can take you on a walking tour of a ward or outpatients unit and tell you about their experience of coming to a service. They can use smiley face stickers or take photos around the ward to illustrate how they felt about different elements of the service.

Hopefully the discussions amongst Clinical Reference Group members, Public and Patient Voice representatives, and your wider networks, will have identified some organisations who are already bringing children and young people together that you wish to speak to. If you are lucky then you may find that there is already a children or youth forum in existence that is keen to engage with you. However, sometimes there will not be a pre-made group to connect with and you may have to look wider at other ways to engage with children and young people. One significant advantage that many members of the Clinical Reference Group will have is their existing clinical work which provides opportunities for clinic chats, creative participatory approaches (for examples see the Recipes for Engagement booklet at www.rcpch.ac.uk/and-us-resources) and chance to identify children and young people for challenge days or forum meetings.

Key to knowing where to start is to consider what you want to know about and which children and young people will have this experience. It may be that you really need to speak to children and young people who have used your service but for other issues this may be less of a priority.

The RCPCH have a model which identifies three different voice groups in relation to health decision making. This has been adapted to the Clinical Reference Group context;

Specialist Voice: children and young people who you know have experience of your specialised service. They could be accessed by;

- Your clinics via personal invitations. Many children and young people who have been very involved began after a worker or individual explained how important their views were to them. The personal approach from a professional who they trust and has knowledge of their experience is key
- Outreach in waiting rooms through clinic chats
- Visiting inpatients on wards working with people that they trust e.g. play specialist, activity worker or through peer consultation (see section 7)

Targeted Voice: children and young people who have expressed an interest in having a voice about health care issues, or children and young people who are from targeted voice backgrounds e.g. sibling carers for conditions covered by your specialised service, condition specific child and youth advisory groups led by charities or other at risk groups. They could be accessed by;

- hospital forums, hospital participation projects or hospital based play specialists, activity workers
- Patient support groups / charities or advocacy groups for topics associated with your specialised area (look for groups that organise events to bring young people together)
- Your local Healthwatch – many now have young inspectors or a Youthwatch model
- Voluntary sector and specialist children and young people's charities
- Special schools
- Parent voice mechanisms e.g. Parent Carer Forums, local disability parent networks

Universal Voice: children and young people who are actively engaged in community or speaking up on young people's issues, those who do not have experience of the specialised service but can share experiences from a child or youth perspective. They can be accessed by;

- Local child and youth councils, children in care councils, youth action projects
- Schools
- Children's centres, play-schemes, youth services
- Uniformed groups locally, local charity or community child and youth projects (e.g. Beavers, Guides, sports clubs, church youth clubs)

“Invest time in developing partnerships with organisations who are working with children and young people. It's better and easier to tap into existing networks like the Challenging Behaviour Foundation. My local Autism Network for example has 590 children” (Parent Patient and Public Voice representative)

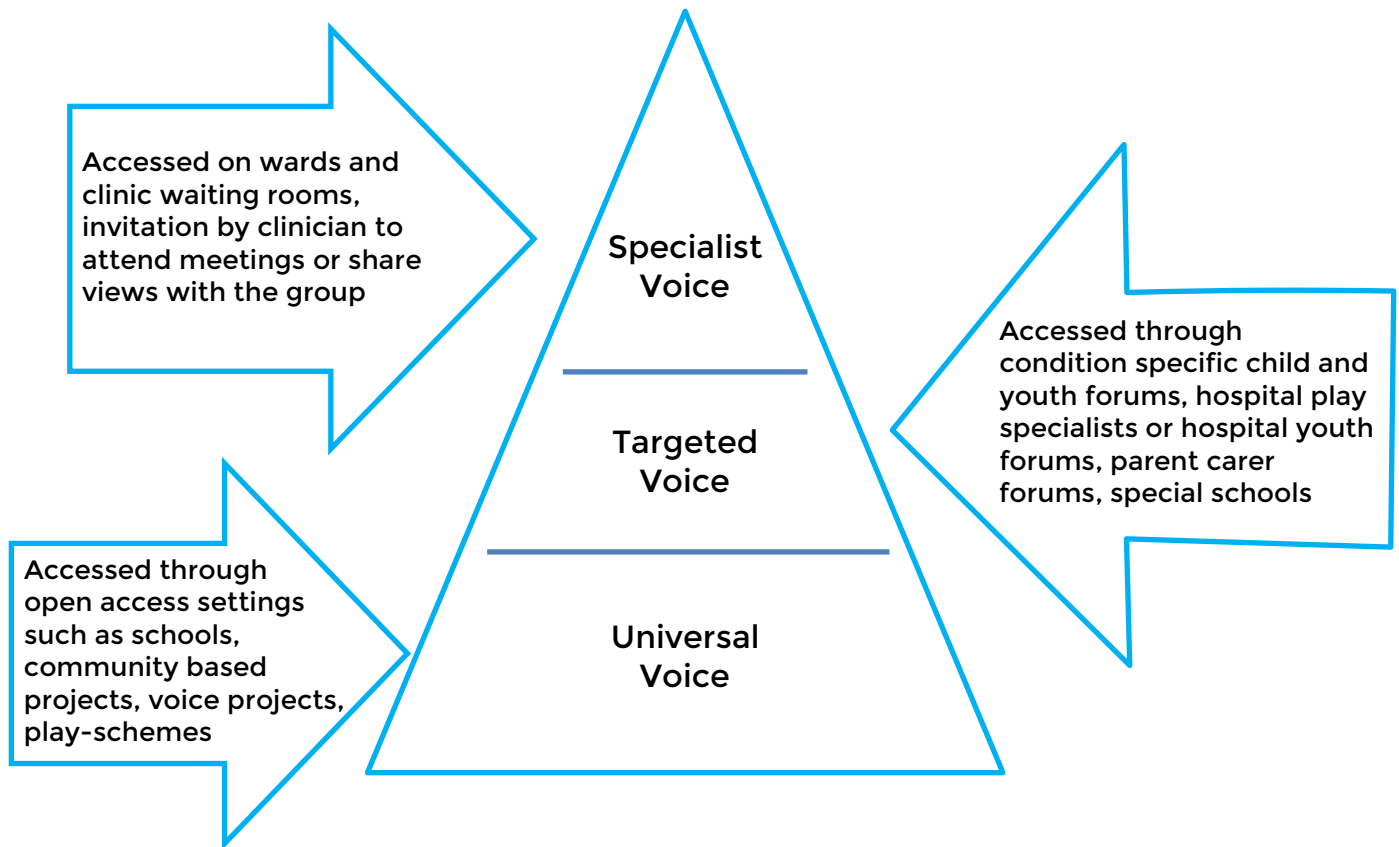


Fig 2. Voice at RCPCH

Section 6: Consult: Making current consultation and Patient and Public Voice mechanisms more accessible

"I have done a couple of surveys online, but I didn't get any feedback personally so I don't know what's going with the surveys or nothing. It felt ok to do it for her but in terms of my personal views I just felt like it was just impersonal and not really what I would advise for getting young people to express their views" (young man, Teenage Cancer Trust Unit UCLH)

"I would like forms because I am more comfortable expressing my feelings in writing" (young woman, Chest Clinic, King's College Hospital)

Making consultation more exciting

Most children and young people told us that surveys and forms are boring! They do not give children and young people a chance to meet and share experiences, discuss or see their ideas recognised or gain feedback on what impact they have had. These are all things that the children and young people valued highly. However quantifiable responses that can be easily collated and analysed are sometimes essential. Children and young people also said there should be more than one method of engagement. The young people involved in our peer consultation project suggested that forms can be useful when:

- you are too unwell to attend events or meetings
- you are too far away to take part in other activities
- you are not yet confident to share your views or experiences face-to-face
- you prefer to express yourself through writing.

Here is the feedback from children and young people about how to make surveys and questionnaires more engaging:

- Involve children and young people in designing and piloting the survey or form *"I would like feedback forms for older children with interesting designs (I am willing to help design! :-)" (young woman, Chest Clinic, King's College Hospital)*

- Make sure that you use pictures to help those who are younger or find reading or writing difficult *“Use smiley faces for the younger ones” (young woman, Alder Hey Youth Forum)*
- *“Put the forms next to the bed so young people don't have to ask staff for them” (young woman, Youth Forum member, Alder Hey)* Young people worried that staff may think they are complaining about them if they asked for a feedback form or to complete your specialised service survey
- *“Use the personal touch and ask young people directly to fill it out” (young woman, Alder Hey Youth Forum)*
- Use the time when children and young people are waiting for appointments or bored on wards *“I have been asked for feedback through an online survey. I was given the link while in hospital and logged on through my phone. It was quick and easy” (young man, Teenage Cancer Trust Unit UCLH)*
- Get creative *“create a worry box where you could put in what you were worried about and your doctor could read it” (young girl, Bristol University Hospital)*, *“leave space for drawings and art work” (young person, Alder Hey Youth Forum)*
- *“If there was an email at the bottom they could be updated on what's happening over it” (young person, Alder Hey Youth Forum)*

Young people in one hospital talked about the popularity of an activity where children could draw a fish and then they would see it projected up onto the wall shortly afterwards. The success of ideas like this can be transferred to consultation processes. If art work, ideas or comments that are submitted can be publicly displayed (projected in waiting rooms or put up on websites) then it gives an immediate sense of recognition that your comment or idea has been seen.

Top tips for involving younger representatives in Clinical Reference Groups

“I feel as though maybe having an actual young person who is going through it or who has been through it on the group to talk about their experiences and what they feel could have been improved from services or what they particularly liked and offer that other point of view, I think that would be really helpful for them” (young man, Teenage Cancer Trust Unit UCLH)

“We had two young people on the Clinical Reference Group. It was fantastic. As a chair I made sure that they were invited to say something and they had something to share.

It felt like it was a genuine engagement process” (Chair, Teenage Cancer Clinical Reference Group)

“I feel like a lot of other methods, things can get lost in translation so if you have that direct person to person contact (by a young person attending the Clinical Reference Group) then it is just easier for you to get straight any thoughts and air out everything...you can clarify it” (young man, Teenage Cancer Trust Unit UCLH)

“Clinical Reference Group, I feel like that would be probably top of my list to be honest because we can go directly to the people that are actually going to be making the changes. Yeah so until then it’s just hear say but this one is really like just getting to the point and going to the people who would be making the changes” (young man, Teenage Cancer Trust Unit UCLH)

Clinical Reference Group meetings can be intimidating forums. Clinical discussions are highly technical, experts are keen to ensure their points are heard, conversations about budgets may be tense and it can be fast paced. However, they are one of the key advisory and decision making forums in the specialised commissioning process, and children and young people have said that they want in! Including younger Patient and Public Voice representatives in this process needs to be done sensitively if the Clinical Reference Group is really going to create an atmosphere where they benefit from hearing the younger service users perspective directly.

How can children and young people be directly involved in Clinical Reference Groups?

- Establish or link with an existing children's or youth forum; share the Clinical Reference Groups agenda in advance; allow children and young people to decide what agenda items they would like to discuss and feedback on. Support children and young people to add their own agenda items for discussion at the Clinical Reference Group and encourage representatives from the forum to attend and present key points from their forum discussions.
- Develop video, photography or creative arts projects around key issues around the commissioning of services. Support children and young people to explore their experiences through these mediums and to present and discuss them with Clinical Reference Groups.
- Invite children and young people from established groups (within charities and support groups) to attend and present on key issues that are important to them

- Develop working groups that work much more flexibly on issues. These working groups could meet with local groups of children and young people (forming a buddy or partner relationship) to hear directly the experiences of the service either as a regular meeting, a children and young people's voice meeting or by visiting local groups where and when they meet
- Hold a two way Q & A session where they can ask more about the work of the Clinical Reference Group and you can ask about their experiences / views – this could be as a speed networking session, a meet the decision makers lunch or in another informal and child/young person friendly way
- Encourage children and young people to apply to become Public and Patient Voice representatives on Clinical Reference Groups.

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

Case study: Young Patient and Public Voice representatives on Clinical Reference Groups

Between 2013 and 2015 the NHS England Clinical Reference Group for Teenagers and Young People with Cancer had two younger representatives who participated in the group. Tom Grew, was one of these Patient and Public Voice representatives and reflects on his experience.

“I was diagnosed with Cancer when I was 18 years old. When I was first diagnosed I felt really alone and like I was the only young person with Cancer. I was initially approached to get involved when I attended a Macmillan conference. It was the personal approach that encouraged me to initially sign up. Having been involved in representing young people with cancer, I discovered the late effects service – 6 years after diagnosis.

I had already done quite a lot of patient voice volunteering before I applied to be on the Clinical Reference Group. I had been involved in the NCRI (National Cancer Research Institute) clinical studies group for 3 years beforehand as part of the Core Consumer group. We would assist with different research projects and also helped to dip into larger group of young people to get their views. I had a fantastic experience. The benefits for me were many but I have to say it was probably the social benefits that were most significant for me. Meeting others with shared experiences and making friendships through this group was amazing. I realised that I wasn't the only young person going through this. We became very close as a group and did a lot of activities together. We spoke at conferences, helped with research and really felt appreciated. We also got paid for some of the work and had our travel expenses

covered.

The way this group ended wasn't ideal as there wasn't clear closure. We became aware that we were not in the group any more when we saw the adverts for new people to join the group. I was quite disappointed and felt that I still had more to give. This is when I applied to join the Clinical Reference Group as a Public and Patient Voice representative. I was 28 at this stage.

The Clinical Reference Group meetings were a mixture of face to face meetings and conference calls. The meetings moved around the country which made it fair for people to attend. I had met some of the people who attended through my work with NCRI. Knowing some of the people already helped. There were also representatives from Clic Sargent and Teenage Cancer Trust who were used to working with young people and they were good for support. Rachael Hough was the Chairperson of the Clinical Reference Group and I always appreciated the fact that she asked me "what do you think?" directly in the meetings and gave me space to answer.

I attended every meeting for the first year. During my second year on the Clinical Reference Group I started working and found it difficult to attend the weekday meetings. It really helped that travel was paid and lunch was provided for meetings but in the end time was the main barrier to my attendance.

Personally I wish that I had got involved in patient participation earlier. The opportunity to connect with other young people with cancer earlier on when I was feeling really lost and still going through treatment would have been good. I also learnt so much and it changed my direction in terms of career. I have gone on to train as a doctor and am now specialising in psychiatric medicine.

A short animation of Tom's experience can be seen here:

<http://www.invo.org.uk/thisismystory/>

Case study 3. Young Patient and Public Voice representatives on Clinical Reference Groups

Section 7: Developing participation and co-production

You are now in the exciting position of embarking on a project that has more of a focus on co-production or participation (moving beyond a consultative model). This section explores some of the options for methods and approaches. The starting point should always be one of accessibility so keep the age, needs and abilities of the children and young people that you want to reach in mind and wherever possible work alongside children and young people to shape the project from the outset.

Why would children and young people get involved?

"I wouldn't want someone else in my situation to go in and feel like they have been palmed off as well, cos it is, it does feel, a bit crap at the time" (young man, Teenage Cancer Trust Unit UCLH)

Often the biggest struggle people have with child and youth engagement is getting children and young people to engage with the activities. The Kaizen Partnership (Kaizen, 2013) use the model of intrinsic (personal and internal) and extrinsic (external) motivation to help think through why people might get involved in participation activities. Sometimes these motivations are directly linked to the intended outcomes of the project but often they are not.

During the development of this guidance, children and young people shared why they had, or would, get involved in participation activities. The illustration below demonstrates how much of their motivation relates to indirect intrinsic and extrinsic motivators. It highlights that when service user voice activities are narrowly focused on gathering opinions and feedback, they will not appeal to many children and young people. The most successful participation project and activities will incorporate the things that children and young people would like to get out of the project as well.

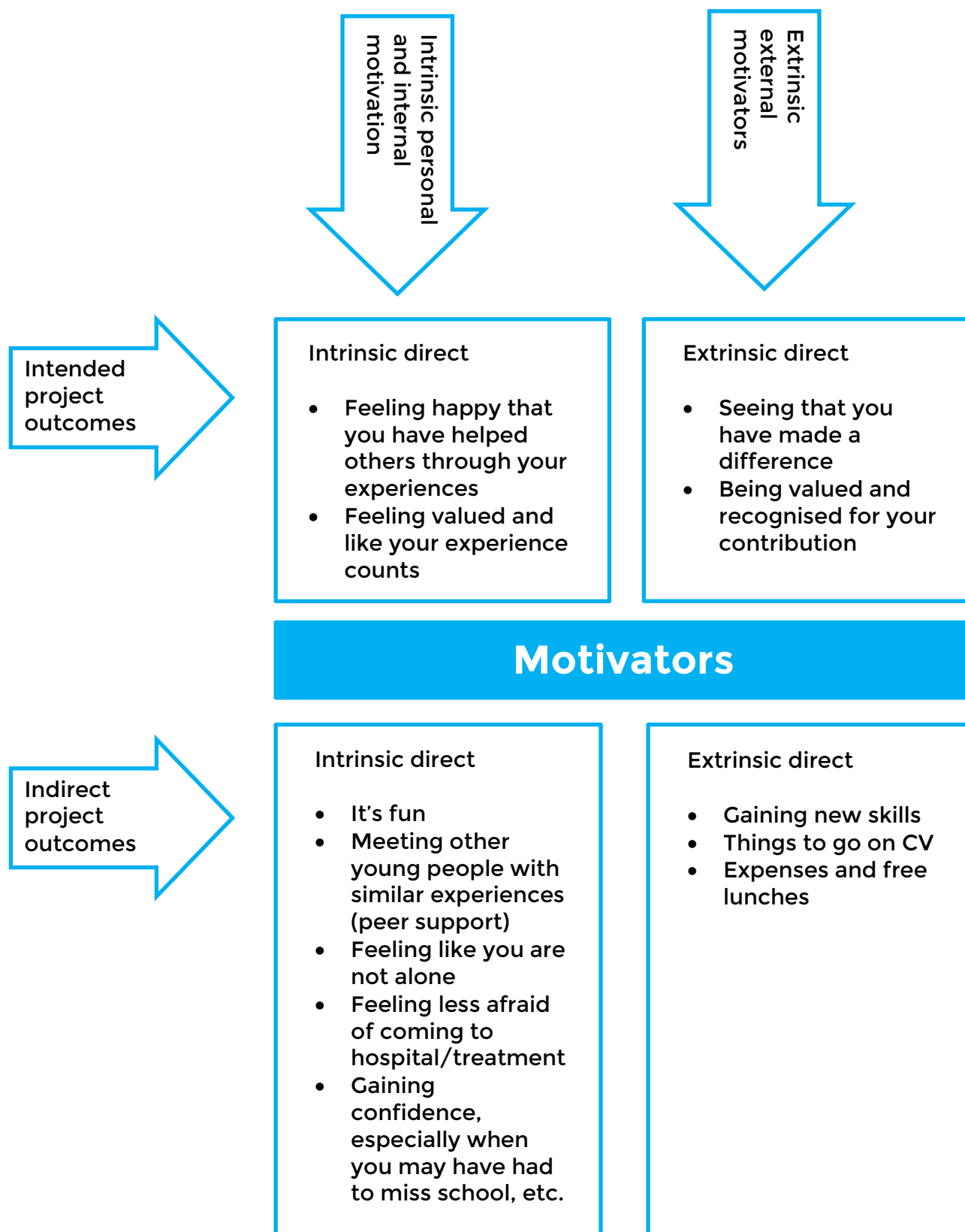


Fig 3. Motivators for engagement

"I am definitely less afraid now I have been involved with the forum. There has been so many times that I have been ill and stuff like even since the forum just like I am a lot less afraid now cos I know what is going on behind the scenes from the forum. Not so much confident but reassured that there is always someone there that you can say something to" (young woman, Alder Hey Youth Forum)

The RCPCH *&Us* programme looks to balance all engagement project work between three factors – fun and social (ice breakers, creative participatory methods, food and social time), children and young people led agenda (their priorities, their topics that are link to child health) and being clear and transparent on the RCPCH led agenda (topics and priorities from RCPCH that need child or youth feedback).

Case Study: Peer led consultation: Alder Hey Youth Forum, developing this guidance

The Royal College of Paediatrics and Child Health contacted the Alder Hey Youth Forum when they began thinking about how to develop this guidance. The support worker for the forum asked the young people if and how they would like to be involved in one of their regular meetings. The feedback was that they were interested in developing an app or doing an activity where they could learn some new skills and work with other children and young people. An app was slightly outside the scope of the project but designing a process that was more interactive, where the young people could take some control and gain new skills was an interesting idea.

The idea of peer consultation emerged and six young people signed up to a two day project. During the project, the young people received training on the project outputs and outcomes (what is specialised commissioning and what is the role of a Clinical Reference Group), active listening, team work, consultation, review/analysis and how to develop a peer consultation. They practised interviewing each other and got used to using Dictaphones. They formulated the questions that they wanted to ask and in the afternoon of day 1 and the morning of day 2, they went out to speak to other young people in out-patients waiting rooms and on the wards.

The young people were supported by staff and volunteers from Alder Hey Hospital and RCPCH. As health care experienced young people, they were very sensitive to

the needs of children and young people that they spoke to on the wards, working with ward staff who would do a quick round to see who was awake, well enough to talk and to see if they were interested before the young people approached. They managed to speak to 16 children and young people during their two sessions asking questions about relocation of services, who do you tell when you are not happy with something about your health care, do you feel like you get listened to when you are talking to a nurse or doctor and the different ways to share voices and views.

The programme wrapped up with a workshop where the young people looked at the themes that emerged from their discussions with other young people and fed into what they felt should be in the guidance. All of the young people fed back that they felt they had learnt new skills around listening and working in a team. When asked what they enjoyed most they said

“Getting to interview people and spend time with my friends doing things I enjoy and making a difference”

“Learning about new skills and going onto the wards”

“Gathering views from more patients”

“Meeting other patients”

They all also said that they were keen to do more! Three months later a follow up workshop happened to share the draft guidance and support the young people to write up their experience for their CV and future work applications. The Youth Forum will be writing a blog of their experiences to share and have received a full report of all comments, suggestions and ideas from Alder Hey children, young people and families which has been shared internally to support service design.

Case study 4. Peer led consultation: Alder Hey Youth Forum, developing this guidance

Simple ideas to start a dialogue with children and young people

- Think of three simple questions that would inform your decision making. One week every quarter, ask clinicians associated with your Clinical Reference Group to “ask *their clinic*” and record responses, sharing them with the group. Questions could be – tell me an example of the best care you have received, tell me your wish for the care you receive, and if you were in charge of all the money for this condition – what would you do?

- Create an opportunity for groups of children and young people who use your specialised service (from service user groups, hospital forums, charities etc.) to feed in on a termly basis by setting them one question or theme a term to look at in their established meetings. Capture the feedback and report back your findings
- Create a hashtag and use social media to engage and build followers for quick fire feedback. An example of successful social media engagement is Neomates UK with over 300 parents with previous neonatal experience engaging online through a closed Facebook group on UK service planning for neonatology
- Spend time once a term to visit a clinic waiting area or ward and speak to the patients and their families. Face-to-face is great and using your time as a resource keeps the costs down.

Think bigger...

Bigger and more creative projects for participation cannot be added on to people's existing workloads. At a certain point you will need to ensure adequate resources are allocated to develop this work in an inclusive way. Making use of external funding will support development in this area, you could apply for some project funding to kick start your programme. Work with children and young people to apply to O2 Think Big, speak to NIHR, and contact your local funding advice bureau (Council for Voluntary Services) for support in identifying relevant local and national funders.

What method?

To help you with the next step, young people during the course of developing this guidance, have created an overview of methods for engagement and their views on the pros and cons.

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

Method	Why it is good	What's not so good about it
	<ul style="list-style-type: none"> It's almost like having that same face to face meeting but you are going to them. <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> 	
Video (big brother style booth)	<ul style="list-style-type: none"> Feel more comfortable, free to express feelings. Don't have to worry about things getting back to people Good if there is someone actually interacting and interviewing you like in Big Brother 	<ul style="list-style-type: none"> Camera shy Might not be accessible for wheelchair users Might not feel that comfortable; feel awkward You have no connection with other young people
Drama	<ul style="list-style-type: none"> Good if you get it right can give ideas It's really interesting <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> 	<ul style="list-style-type: none"> How would you get their feedback Some people might have issues interacting
Parent / carers as advocates	<ul style="list-style-type: none"> They are often the first person you talk to about experiences. Younger children / children with communication difficulties might find it easier 	<ul style="list-style-type: none"> Parents / carers might panic Views can go through playground whispers / 'parent filter' and not be

Method	Why it is good	What's not so good about it
	to talk to parents / carers in the first instance.	shared accurately. <ul style="list-style-type: none"> Don't always share difficult stuff with parents / carers - want to protect them a bit.
Online daily log - Young people do a daily update about their wellbeing and the service.	<ul style="list-style-type: none"> As long as it was confidential it could work Anyone can access it People might be used to doing this sort of thing at school / college Large numbers of young people could give feedback 	<ul style="list-style-type: none"> No access to the internet No form of dialogue or sense of being involved in decisions Just sending through your experiences
Youth Forum	<ul style="list-style-type: none"> Can be honest about opinions, more comfortable, relate to other young people Get to discuss and debate ideas. Get to see if other young people have had the same experience as you Face to face is better for building relationships and trust. Made good friends and got a lot of support. 	<ul style="list-style-type: none"> Some people don't like to share information. It would be a bit harder for really sick patients. Time consuming You can't go if you are very unwell
Social media posting (Facebook / twitter / snapchat)	<ul style="list-style-type: none"> A place to vent. Anonymity can give you a chance to open up confidential Issues. A closed Facebook group has wide outreach and is less intimidating. Closed group is good if you want to share personal / intimate stories. Could be promoted to young 	<ul style="list-style-type: none"> 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. A closed Facebook group doesn't work for recruiting people Not very co-ordinated

Method	Why it is good	What's not so good about it
	<p>people on the ward</p> <ul style="list-style-type: none"> • Easy way of connecting with people across country 	<ul style="list-style-type: none"> • Shyness on social media - You might wonder where my words are going. • Online communication is great in theory but hard to build relationships, when we are in one place we are forced to talk
Forms (smiley face, traffic lights)	<ul style="list-style-type: none"> • Good for younger children, colourful • Might feel comfortable expressing yourself in writing • Less time consuming 	<ul style="list-style-type: none"> • Can be boring for older children and hard for younger children • <i>"So long as it is not this huge long thing and you are sitting there forever writing on it."</i> • <i>"What if you have more to say than just what is on the questionnaire?"</i> • Form many not give an honest picture of how you are feeling
Email	<ul style="list-style-type: none"> • Easy to put together thoughts in writing • Less time consuming • Would be better if you knew you were going to get a reply • If it was actually someone senior asking for your opinion who was going to read it 	<ul style="list-style-type: none"> • Younger children often don't have email and older ones sometimes don't check it • Not a two way dialogue

Method	Why it is good	What's not so good about it
Talking to doctors / nurses (staff advocating for young people within Clinical Commissioning processes)	<ul style="list-style-type: none"> • <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> • Normally first point of contact so easier to share stories / experiences 	<ul style="list-style-type: none"> • Don't want to seem critical or ungrateful • Difficult to tell them what you think • 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 • Brought up not to be rude to adults (criticising them can feel like being rude) • Some young people may feel shy and uncomfortable about a certain condition they have. This is negative
Attending Clinical Reference Group meetings	<ul style="list-style-type: none"> • Speaking straight to people in charge • An opportunity to get feedback and have a discussion about your ideas. • Learn more. You know things haven't got lost in translation and they can ask us questions • Direct and professional opinions • Would need good facilitators • Face to face is important because it gives ability to bounce ideas with young people and really be able to get the conversation going 	<ul style="list-style-type: none"> • Might be scary • Might be boring • Hard to get decision makers and young people together at a time that suits both • Will they be able to explain things without going into jargon? • They need to get more than one point of view from young people

Method	Why it is good	What's not so good about it
Petitions	<ul style="list-style-type: none"> • If you get a certain numbers of signatures they have to discuss it in parliament • You could ask if people want to just fill out form or whether they want to get involved further and or leave a personal story / testimony. • Can be youth led 	<p>Can be confrontational rather than collaborative</p> <p>Wouldn't be able to share experiences</p>

Res 7. Involvement – what methods can you use?

Thank you to the peer interviewers from the Alder Hey Youth Forum for their suggestions and comments.

“I would send an email to someone if I knew I was going to get a response if it was someone that I knew was in charge and valued my opinion” (Young Man, Teenage Cancer Trust Unit UCLH)

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

For more support and guidance on these areas, please contact your local engagement lead, use resources from <https://www.england.nhs.uk/participation/> or join the Engagement Collaborative by RCPCH at www.rcphc.ac.uk/and_us

Case Study: HIV Clinical Reference Group.

Some Commissioning processes and Clinical Reference Groups straddle both adults, young people and children. This can create additional challenges for hearing the voice of children and young people as they may only be one small segment of the service user population. One of these areas is HIV. Children and young people born with HIV in the UK are a low prevalence, high need group who face extreme social isolation and stigma. 70% are from Black and Minority Ethnic Communities; many have been through or are still in the asylum system. They live in families who are often marginalised, with many living in poverty (CHIVA, 2017). However as a percentage of the total number of people living with HIV in the UK they are small and a reducing number.

In the past CHIVA (Children's HIV Association) sat on the Clinical Reference Group as a Patient and Public Voice representative. Abi Carter, Participation Officer from CHIVA who attended the meetings also facilitated the CHIVA Youth Committee. This provided a direct link to a group of young people and a wider network of groups. Abi would take the Clinical Reference Groups agenda items back to the Youth Committee to discuss. She would then feedback their views at follow up meetings. On one occasion a young person volunteered their experience of services to be discussed as a case study and provided his recommendations about how it could have been improved. This model functioned well in that it allowed young people to speak up and discuss the agenda of the Clinical Reference Group in a forum where they were comfortable and could also discuss other issues of interest to them but the model also faced some real challenges.

Dr Ian Williams, Chair of the Clinical Reference Group reflected that although it was

really useful to have a Patient and Public Voice representative from a children and young people's organisation, much of the agenda related primarily to adult services. This raised the question about how much of the meeting and agenda was relevant to CHIVA and the Youth Committee.

Abi also felt that some of the highly technical discussions about drugs were very difficult to engage with. The issues that the young people raised were often more focused on aspects of service delivery relating to communication, transition to adult services and to the stigma of living with HIV.

The highly technical discussions and small overlap of agendas between the Youth Committee and the Clinical Reference Group presented one issue. Another was the format of the meetings which were often telephone conference calls. These were not child or youth friendly, "it was quite intimidating for me to engage in and I am a professional, I think it would be really challenging for a young person" said Abi.

The recent restructure of the Clinical Reference Groups and the reduction of the number of Patient and Public Voice representatives on the group has seen CHIVA step down as Patient and Public Voice representatives. Dr Ian Williams highlighted a lack of applications from young people or children / youth organisations to become Patient and Public Voice representatives in the recent round of recruitment, raising questions about accessibility and whether young people are getting to hear about the opportunities.

Going forward the Clinical Reference Group will be establishing a Paediatric working group. This will allow for more flexible engagement focused on children and young people's agenda, building on lessons learnt from their experience to date.

Recommendations

Even when children and young people are a relatively small number of the service users, it is important to ensure that their experiences are heard. Especially when their experience of being young with this diagnosis intersects with other forms of disadvantage and social exclusion.

- A more flexible approach should be taken. Where the majority of a

commissioning process focuses on adult services, working groups or partner initiatives could be established to feed in the views of young people on specific issues (rather than asking children or young people's representatives to engage with the full agenda of the Clinical Reference Group). These groups could then attend and present to specific agenda items at meetings.

- Scan the agenda and upcoming issues for Clinical Reference Groups for issues particularly relevant to children and young people.
- Ensure that Paediatric services and groups supporting children and young people are aware of the role of the Clinical Reference Group, are on the registered stakeholder lists and are invited to engage in consultations.

Case study 5. HIV Clinical Review group

Ideas for starting discussions with services users

The following activities are designed to be useful at the point where you have established contact with your young service users and are beginning to work together.

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 and sharing knowledge with children and young people

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:

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

Res 10. Setting the agenda

This activity helps to recognise the knowledge and experiences that all parties bring to the table. The areas of knowledge that is exclusive to each group present an opportunity to learn from each other. The quadrant that both know is agreed and public knowledge and the area that neither group knows represents the area to collaborate, explore and learn together. This activity is adapted from Johari's window (created by Luft and Ingham, 1955).

Other voice engagement activities available at www.rcpch.ac.uk/and-us-resources

Section 8: Trouble shooting: Your dilemmas solved and myths dispelled by young people!

A number of fears and concerns are commonly expressed about engaging children and young people in strategic decision making. Many of these fears emerged during interviews with those working in specialised commissioning that took place during the development of this guidance. These dilemmas were put to young people for their advice to help problem solve...

The advice below comes from young people aged 13 to 25 years (from Alder Hey Hospital, Teenage Cancer Trust Unit UCLH, RCPCH *&Us* workshop) all of whom had used specialised services.

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!

Conclusion

Throughout developing this guidance and speaking to children and young people, the message was clear for how to involve them in specialised commissioning and Clinical Reference Groups

- *Inform* children and young people about what Clinical Reference Groups do and how they can get involved in sharing their voices and opinions
- *Consult* with children, young people and families about their experiences, wishes and needs for specialised services
- *Involve* children and young people in decision making for specialised services. Do this through Clinical Reference Group meetings, challenge days, one off shared meetings or other creative ways
- *Represent* children and young people's needs and wishes in decision making to ensure they are able to influence and impact commissioning.

Section 9: 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
- Association of Young People's Health www.youngpeopleshealth.org.uk/
- British Youth Council www.byc.org.uk
- Council for Disabled children <https://councilfordisabledchildren.org.uk>
- Children's Rights Alliance for England www.crae.org.uk
- Generation R: Young people improving health through research
<http://generationr.org.uk>
- National Children's Bureau 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 Royal College of Paediatrics and Child Health www.rcpch.ac.uk/and_us
- Save the Children England www.savethechildren.org.uk
- UK Youth 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
- Kaizen Engagement Models – Engagement Strategy & Planning (2013) Kaizen <https://docs.google.com/file/d/0B5jf1s5B703TWkJUN3ZZbXpTTWc/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 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 www.rcpch.ac.uk/andus-participation
- Participation Works www.participationworks.org.uk
Participation Works provides policy updates, resources, information about innovative practice and links to key organisations and networks across the UK.

Reports and references

Arnstein, S., 1969. A ladder of citizen participation. *Journal of the American Institute of Planners*, 35:216–24

Blades, R. Renton, Z. La Valle, I. Clements, K. Gibb, J. and Lea, J (2013) *“We would like to make a change”: Children and young people’s participation in strategic health decision-making* (2013)

Coyne, I. (2008) Children’s participation in consultations and decision-making at health service level: A review of the literature. *International Journal of Nursing Studies* 45 1682–1689

Coyne, I. (2005) Consultation with children in hospital: children, parents’ and nurses’ perspectives. *Journal of Clinical Nursing* 15, 61–71.

Department of health: (2015) Children and Young People’s Health Outcomes Forum: 2014 to 2015. <https://www.gov.uk/government/publications/children-and-young-peoples-health-outcomes-forum-2014-to-2015>

Hart, R, and (1992) Children’s Participation from tokenism to Citizenship: Innocent essays no 4, Unicef https://www.unicef-irc.org/publications/pdf/childrens_participation.pdf

Kaizen Partnership Ltd (2013) Strategic Engagement Models –
<https://docs.google.com/file/d/0B5jfls5B703TWkJUN3ZZbXpTTWc/edit>

Lewin, R. Kendall. L. Sloper, P. Parsons, J. (2003) The views of young people with congenital cardiac disease on designing the services for their treatment. *Cardiology in the Young*, 13: 11–19

McLaughlin, H. (2015) *Involving Children and Young People in Policy, Practice and Research*.

NCB London

<https://www.ncb.org.uk/sites/default/files/field/attachment/report/Involving%20Children%20and%20Young%20People%20in%20Policy%20Practise%20and%20Research.pdf>

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

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

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



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