



Case Studies from “*Guidance on involving children and young people in specialised commissioning*”

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..



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.



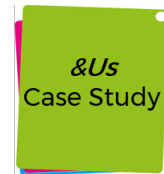
Case study: Young Patient and Public Voice representatives on Clinical Reference Groups

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

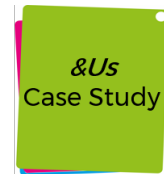


Case Study: Peer led consultation: Alder Hey Youth Forum, developing this guidance

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

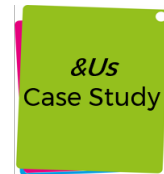


Case Study: HIV Clinical Reference Group.

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.