



Re- Evaluation for Investing in Children membership: Paediatric Clinic for Cystic Fibrosis

The team within the Paediatric Clinic for Cystic Fibrosis have continued to enter into dialogue with children and young people. They are committed to ensuring children and young people's views are taken into account and that they are involved in decision making. This includes making decisions around their own treatment and also around decisions as to how the clinic's service is delivered. I spoke to Veronica about the changes that have been made over the past year and about how these were led by children and young people. I also had the pleasure of meeting Amber, Shannon, Chris and Liam.

Evidence of Dialogue and Change

Appointment Times

The children and young people I spoke with are happy with their appointment times. Appointments are now given three months in advance. This is in response to young people who expressed concern that appointments during the day meant they were missing important lessons. Now with appointments being planned well in advance, there is an opportunity for young people to have a say and plan their life. Liam said his experiences have been good over the past year. He also told me that if the clinic is ever running late they ring him at home to tell him. Amber said she was happy with the appointment times. When I asked if she ever has to wait, Amber laughed and said "noooo!"

Entertainment

Children and young people previously identified a need for more entertainment in the waiting areas and in consulting rooms. Liam said he is happy with the magazines that are around for him to read. I saw Amber enjoying the drawing and play equipment that are now provided in the consultation room and on the little table that was just the right size for her. Shannon told me "*They do put things in the consulting rooms, but there could be more things for people of my age. But it's ok.*"

Access to a television and video are now available to everyone. These are mobile and can be moved from room to room. Shannon said "*I have watched the TV and some of the video's, but they are a little old.*"

Teenage Area

Some of the older young people asked for their own waiting area. The area is well identified and provides a comfortable space. Again young people asked for the magazines to be age appropriate and current. As a result, the magazines are regularly updated and replaced. However, most of the young people told me because of concerns over cross infection, they do not use the waiting area.

Refreshments

In the previous evaluation the children and young people thought that there should be tea and coffee making facilities around the waiting area. Liam said that he now gets

offered refreshments. Amber said her mam and her had been asked always if they wanted a drink. Amber also enjoys the drinks and biscuits she gets.

Veronica said *“Staff now ask children and young people when they come in if they would like a drink. We ask if anyone wants a tea or coffee.”* Shannon added, *“They always ask me and my mam if we want a drink. They even know now how I like my tea. Loads of milk and three sugars.”*

Staff

The Investing in Children group previously commissioned by the cystic fibrosis clinic highlighted that nurses should be better trained to communicate with children and young people. Veronica told me *“staff very much reflected on these comments and it has given them a higher awareness of how they communicate, and the importance of this. This means that staff now give children and young people the opportunity to make decisions about their treatment. And this is done with children at a younger age than we would have previously done. We are all more conscious that we address the children and young person rather than directing everything to their parents.”*

Shannon said *“They always ask me questions. They’re good like that, they ask what I think and if things are ok. Not so much the doctors but the nurses.”* Liam said, *“I get on with the staff, all of them. Veronica has looked after me from being really young.”*

At every appointment a trolley is put out with lots of leaflets about cystic fibrosis. Shannon said *“We get loads of leaflets but they have loads of writing. You read the first paragraph and then it gets boring. They should be more colourful, not as confusing so you can follow it. More pictures to explain things, like if it was a lot about your lungs, a picture would help.”*

Veronica said *“We are looking at ways we can work together to increase children and young people’s knowledge about cystic fibrosis.”*

The Investing in Children commissioned group suggested that young people would like to feel comfortable to share their health worries with the staff. After discussing these issues with the young people, Veronica set out to find the best way of doing this. One way which Veronica is going to try and then evaluate with the young people, is the use of cards called ‘I can help others learn about Cystic Fibrosis’. These are visual aids which can be easily used by everyone to help explain to the staff how they feel and how much they know.

The action plan create by the Investing in Children’s commissioned group has provided the basis for some of the changes implemented this year. Veronica told me that the team are trying to build on this by looking at new ideas to continue gaining the views of children and young people including putting suggestion boxes or suggestion posters around the clinic area. Another idea could be to ask those previously involved in creating the Action Plan to give their views about the changes.

I would like to thank all the children and young people who helped me write this evaluation. When I asked if they thought the Paediatric Clinic for Cystic Fibrosis should once again receive Investing in Children membership there was full agreement. I therefore recommend that this service once again receives membership. Well done.

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