

 **Picker**

 **Wessex Voices**

local healthwatch 
working together


Wessex
Cancer Alliance

Our Cancer, Our Way—Always!



Why co-produce improvements?

Wessex Cancer Alliance is responsible for overseeing the delivery of cancer care across Wessex by supporting two Integrated Care Systems; one covers Hampshire and the Isle of Wight, and the second covers Dorset. It was recognised that a co-production approach to identify areas for improvement was needed for cancer services to better meet the needs of children, teenagers, and young adults (CTYA) and their families. Wessex Cancer Alliance was keen to work in partnership with CTYA and their families using creative and varied engagement activities. The aim was to explore CTYA and family experiences of the whole cancer journey and to work together to understand how cancer services could be improved.

Engaging with patients and their families

Recruitment

As there were no established CTYA or parent involvement groups, different approaches were used to both invite feedback about services and to recruit CTYA and their families to the project group:

- Frontline staff and clinical teams directly asked CTYA and their parents/carers whether they would like to be involved in the project.
- Staff designed an initial flyer to publicise the project more widely. Once some young people became involved in the work, they re-designed it into three different age-appropriate flyers to encourage a greater response.
- Facebook groups for young people with cancer, managed by the hospital, shared information about the co-production project and a request for participation.
- Text and email messages were sent to young people and their families.



Initial engagement

Staff initially engaged with CTYA to explore their experiences of the care received and understand what is important to them. An independent project group member conducted interviews with 25 parents, and feedback was also sought from CTYA via surveys and Facebook. This engagement work was essential for highlighting the positive aspects of people's experiences and areas where improvements could be made. The relationship built up with parents during the interviews was important for encouraging their continued involvement.

"I really got to know those parents because the interviews were very long and detailed. So, when they were approached with, 'Actually, do you want to get involved now?' I think they felt really connected."

(Project Manager, Wessex Voices)

Many practical improvements were suggested from CTYA, such as the hospital food, boredom whilst waiting around for treatment and a lack of play specialists at the weekends. Parents of children receiving cancer care raised communication as a critical issue, particularly how much information they can absorb on diagnosis and about the cancer treatment pathway.

Problems with communication between different hospitals and healthcare professionals were also noted, specifically between the main hospital treating the child and any other hospitals involved in their care and the GP and district nurse. Emotional support for the whole family, particularly after the completion of treatment, was another key area highlighted for improvement.

Actions

The engagement with CTYA and parents highlighted many different areas for quality improvement. The next stage was prioritising these issues to identify a focus for this project. The approaches used were tailored to the different stakeholders:

- Teenagers and young adults preferred an online tool. A short survey was developed for this group, allowing respondents to prioritise the importance of five issues.
- The project group designed a colourful worksheet for the younger children allowing them to vote for the area they thought was most important by using stickers or drawing a smiley face. A playworker or youth worker shared the worksheet with children on the wards.

The project group has gone through a long process of condensing the insight gained through the engagement work into themes. An online survey will be conducted to ask patients and their families to prioritise these themes to identify the key areas for improvement.

"Having parents and young people onboard while we're having that discussion is clearly really valuable because I think none of us feels able or qualified. We haven't walked in those people's shoes."

(Facilitator for engaging CTYA)

The project group shared a poll on their Facebook group for CTYA to decide on the name for this project. The most popular title was **'Our Cancer, Our Way'**. Children and young people were instrumental in developing the logo for this project.

What has helped?

- Partnering with voluntary sector organisations, **Wessex Voices** and **Healthwatch Dorset**, to draw on their skills and experiences in co-production and working with CTYA.
- Support from the communication lead at the Alliance.
- Involving a facilitator who has experience in engaging with children and younger people.
- Using alternative methods to co-production to accommodate the needs of CTYA, such as encouraging engagement through drawings, artwork, blogs, video diaries and songs.
- Building relationships with parents at the start of the project to encourage their continued involvement in the work.

"The fact that we've managed to sustain the co-production and the input of young people who are on the project team despite all the restrictions and the challenges that Covid have put upon us says something really important about how important those young people feel it is to be part of this project because they feel like they can make a difference."

(Clinical Advisor on CTYA, Wessex Cancer Alliance)





Key challenges and learnings



Staff engagement. It was essential to share the many positive aspects of cancer care that patients and their families highlighted to ensure staff did not feel overly criticised. The project group regularly communicate with staff about their work to help with engagement.



Challenge of remote working and visibility of the project. The requirement to work remotely during Covid-19 enabled some people to participate who previously would have struggled. However, it negatively impacted the approaches that could be used to engage CTYA. It also affected the visibility of the project as steering group members could not go on to the wards to develop relationships with staff.



The need for a **flexible approach** to co-production, recognising the direction and focus of the work can change and, at times, be uncertain due to it being based on the needs of CTYA and their families.



The need to be **flexible in methods of engagement and working with CTYA.** Those who were less comfortable joining meetings were involved in different ways, such as contributing via WhatsApp.

“Having to flex how you work with people, change things as you go along, and learning to be comfortable with that degree of unplanning is, I think, certainly for people who manage health services a really new discipline.”

(Clinical Advisor on CTYA, Wessex Cancer Alliance)

Next steps

Once the prioritisation exercise is complete and there is a clear focus on the aspect of care to improve, the steering group will work collaboratively with staff to co-produce solution(s). The team is consulting people on whether they prefer face to face or online meetings.

The aim is to have a wider group of CTYA and their families involved in co-designing the actions to drive improvement and change to services.

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