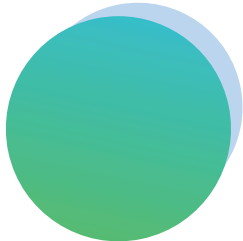


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Background

Our Cancer Our Way is a project all about improving cancer services for children, teenagers and young adults (CTYA). We have gathered feedback from CTYA and their parents/carers about their experiences of cancer care. We asked them to tell us what was working well, what wasn't going so well and what improvements they would make if they could. We received a lot of positive feedback and also heard about things that could be done differently to improve the experience of children and young people with cancer.

Younger children were invited to share drawings, pictures, a story or poem, a song or photos, or talk to us. Teenagers and young adults were invited to share blogs, artwork, poetry, video diaries, mind maps, songs, posters, photo diaries and stories, or to come to an online focus group. Adults were invited to come to an online focus group, have a telephone interview or share their feedback via email.

The priority issues for people were:

- Clarity and consistency of communication.
- Support when leaving hospital and at the end of treatment.
- Waiting for medication.

We asked people to choose their top priorities from each of these areas, telling us where they wanted us to start with improvements. The hospital team sent a survey out to all those affected which also helped us see what mattered most to people. Younger children were involved by being asked to put stickers onto worksheets which were specially designed for this project so they could say what matters most to them.

Thank you to all the people involved in the project so far – it has been true coproduction in action!

Summary

Theme:

1) Practical Issues

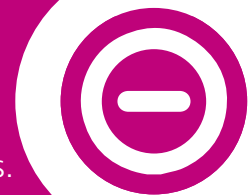
a. Positive

- i. Charities and support groups advice and help was much appreciated and welcomed.



b. Negative

- i. Transport and travel was an issue, especially at weekends.
- ii. There was a lack of information about charities and support groups.



2) Understanding Treatment and Side Effects

a. Positive

- i. Well informed by a range of staff once in treatment.



b. Negative

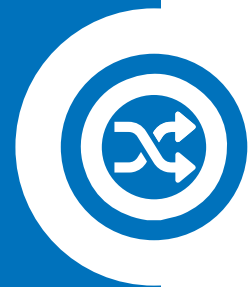
- i. Information was sometimes unclear or contradictory with a lack of continuity.
- ii. Need to ensure young people are told about the future impact of treatment and they have the right support on decisions (e.g., storing eggs and sperm).



3) Communications

a. Mixed

- i. Shared care works well for some but not for all (there were mixed views).
- ii. For some, communication was extremely positive, for others it was very negative. No consistency or continuity.
- iii. Being listened to as a parent. In some areas it's good, in some not, again a lack of consistency or best practice across areas.



b. Negative

- i. Information may be given out along the way, but staff/clinicians need to ensure that people actually take it in and understand it.



4) Time on the Ward

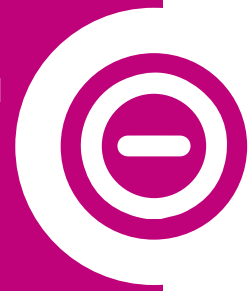
a. Positive

- i. Staff interaction, support and care.



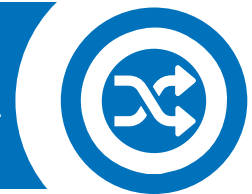
b. Negative

- i. General wards are not child friendly. (Other specialist units received positive comments.)
- ii. Not enough provision for younger children (play, support).
- iii. Food is often not child friendly.



c. Mixed

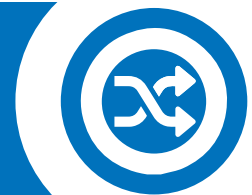
- i. Play facilities. Some comments were positive and some negative.



5) Psychological Support

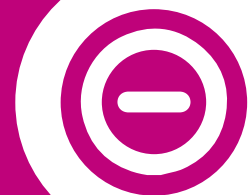
a. Mixed

- i. Where families had received support it was welcomed and appreciated. However, availability of support is not consistent or equitable.



b. Negative

- i. Lack of support post treatment
- ii. Lack of support for siblings.



6) Looking after children at home

a. Positive

- i. Charities, support groups, community nurses and specialist units.



b. Negative

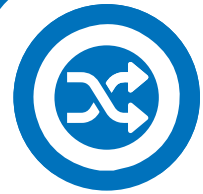
- i. Lack of support out of hospital environment.
- ii. Dealing with aftereffects.
- iii. Not explaining things in a way young people can understand.



7) Education

a. Mixed

- i. Some schools were helpful with continuing studies but not all.



b. Negative

- i. More support needed for children going back to school.



8) Connecting with other parents

a. Positive

- i. Help to link with other parents (especially through social media).



b. Negative

- i. Having to ask for links to other parents rather it being something that is offered/provided.



9) Pharmacy

a. Negative

- i. Long waits for medication (both within hospital and at discharge).



Suggestions for Improvement

The following suggestions came from participants in the project:

- Reduced price or free parking.
- Ensure parents/families receive a list of support groups and charities in their area.
- Have an overall co-ordinator of care/treatment - the one person who holds it together and knows you and your child, can explain the plan and what you need to do.
- If someone just popped in to see how everyone was on the ward. And said take a break, do you need someone to cook for you or things like that.
- An information pack relevant just for people with babies as well as one for older children would have been brilliant.
- Friends and family need a bit of a guide about how they can support you.
- Could there be a “parent buddy” system?
- Zoom calls for parent groups so you can ask questions to a consultant and/or nurse might be useful.
- Use a variety of ways and methods to keep gathering feedback on services from parents and families throughout their journey.

Our Cancer Our Way - Always

The project, Our Cancer Our Way has ended now, but the legacy of the work, continues to help shape discussions in Wessex between patients, staff and the Cancer Alliance. The CTYA cancer services in our hospitals, proactively seek feedback from their patients, parents and caregivers, on an ongoing basis and we refer to this as Our Cancer Our Way – Always. Seeking views to help make improvements has become part of the process, rather than a single project with a beginning and end. Clinical staff from the CTYA ward and Wessex Cancer Alliance’s engagement team, meet regularly to ensure there is alignment and that any feedback that needs further exploration, can be done effectively and with clear outcomes.

We are very grateful to the project team that codesigned Our Cancer Our Way and helped to shape the way these cancer services and patients work together, to bring about change. Special thanks also, to those with lived experience who contributed so much to this piece of work.

The challenges and successes of coproduction in Our Cancer Our Way

Description of the project

This was a project to find out from patients and parents/carers what worked well, what worked less well, and what needed to improve in relation to children, teenager and young adults cancer services.

The work involved several stages:

- planning the project - setting up a steering group and designing communications
- seeking feedback from patients and parents/carers, using a variety of mechanisms
- theming and summarising what people told us
- prioritising the issues raised
- codesigning service improvement

On the next pages are our thoughts, including things that went well, things that went less well, and what we might have done differently.



Project planning	<p>We planned the work as logical and “linear” (see the bullet point list above) but, it got “messier”. For example, we continued to invite feedback while we were writing up the initial feedback. We invited people to prioritise issues while still seeking feedback. This was simply necessary and didn’t detract from the work, it just added some complexity.</p>
Building a team	<p>The steering group included people from many disciplines, organisations, paid staff, and volunteers. We succeeded in building an effective team recognising everyone’s different skills, experience, viewpoint and workplace cultures.</p> <p>Although the project was run through virtual meetings, our occasional face to face meetings were enjoyable and really helped us work better together. Some things can’t be done on-line! And relationships develop better face to face.</p>
Inviting people to provide feedback and engage with the work	<p>When inviting people to give feedback, it was clear that it wasn’t the flyers, webpages or social media that drew anyone in. People mainly got involved as a result of a personal invitation – from a discussion with staff they knew, from a direct email or text. Being asked directly, by someone you know, makes a huge difference.</p> <p>Some parents who were interviewed then got involved in the steering group, feeling more connected.</p> <p>We ended up with more feedback from parents – but the project was about young patients. So we had to bear this in mind when theming and summarising the responses.</p>
Different methods for different age groups	<p>We had to devise many different methods for our different age groups – from zoom interviews for adults, to “wishing wand” sheets for children. No one method works for all.</p> <p>We thought we would run focus groups, but it was impossible to get busy people with caring commitments to meet at same time – so we had to adapt and went instead for one-to-one zoom calls.</p>
Summarising the feedback	<p>Adults were very happy to talk / take part in interviews - people like to tell their stories – but this resulted in a lot of information, perhaps more than we could manage. It was challenging to summarise it.</p> <p>On the other hand, this approach had positives as many participants found it helpful to tell their stories in full – they had not been asked before.</p> <p>We didn’t think through clearly enough in advance how we would summarise or analyse the insights we received. We received feedback in many formats and in great volumes making this a complicated and time-consuming piece of work.</p> <p>Coproducing the feedback summary was worthwhile, but volunteers did not have the time the “paid staff” had – they helped us theme the feedback, and we had to break the task down to suit everyone.</p> <p>In the summary we just wanted to reflect – not decide what was most important, not jump to solutions – which is surprisingly hard. But necessary if this is coproduction.</p>

**Coproduction
- working
with people
with lived
experience on
the steering
group (our
expert
advisers)**

Coproduction developed slowly and was not fully in place from the beginning of the project. Young people initially helped develop the logo and webpage, then joined the steering group. It took longer to involve parents/carers (this followed them giving feedback). There are pros and cons of getting volunteers involved later – once they joined there was clarity about the project and tasks but missed the opportunity to help shape the early stages of the project.

Coproduction means accepting delays – it's complex and hard to do unless everyone can join in. And you must take in many different viewpoints, so decision making can be more time consuming, but richer.

Coproduction meant doing the feedback summaries and prioritisation took longer, relied on input from many, and involved a workshop style event. It was more complex, and more rewarding.

We asked expert advisers what they felt about their involvement. They said:

- we made it easy for them to be involved, being flexible and kind (it didn't matter if someone missed meetings, arrived late, forgot to reply to communications)
- they felt pride in their involvement, something good coming out of a previously difficult situation
- they were committed to being and hearing the voice of service users – wanting to make changes to benefit all and to give back to the NHS

At one point we weren't clear with an expert adviser when we asked for views on the communications – this caused real disappointment and we had to apologise and learn to be clearer. This reminded us to be 100% clear about expectations!

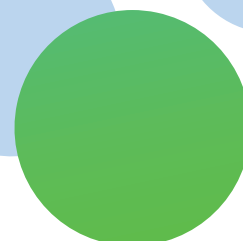
**Learn as you
go**

We offered good thinking space in our steering group meetings – learning and recording lessons as we went along – and were honest with each other, able to discuss, challenge, change tack, and say what wasn't working.

We accepted we didn't know it all and would make mistakes. We were learning as we went along – especially in relation to co-production, the nature of which meant we had to change tack a lot, when things didn't work or needed to be rethought.

Because as a team we were passionate about and committed to doing this work well, and accepted we were learning along the way, no set back felt like a failure. We just found a way around.

Speed	Moving at pace, especially at the beginning, helped us feel we were achieving. When delivery slowed down (mainly due to covid and the complexities of co-production) this could feel frustrating.
The impact of covid and the lack of face to face	<p>Covid had both a positive and negative impact on the work.</p> <p>On the negative side, not being able to do any direct engagement work on the wards was challenging, so we relied on those working on the wards to connect us to patients. This limited the feedback we received and put extra demands on staff teams.</p> <p>However, meeting virtually as a steering group made it easier for volunteers on our project team to take part – geography was irrelevant with no travel necessary, and coming to meetings was less time consuming.</p>
Working with the service	<p>Feeding back positive messages that we heard to clinical staff was reassuring and motivating.</p> <p>We didn't embed the work as fully in the service as we should have, resulting in a need to "handover" the work at the end of the project. We needed more internal leadership from the beginning.</p>
Acting on feedback	Although some of the straightforward issues raised have been acted upon, so far this has not been feedback to patients and parents/carers.
Coproducing solutions	For a variety of reasons, we have not managed to get to the stage of coproducing solutions to the prioritised issues raised. This stage will have to become the responsibility of the staff team as the project closes, hence the need for a clear handover.





Special thanks to Involving People for their support in delivering this project.

