

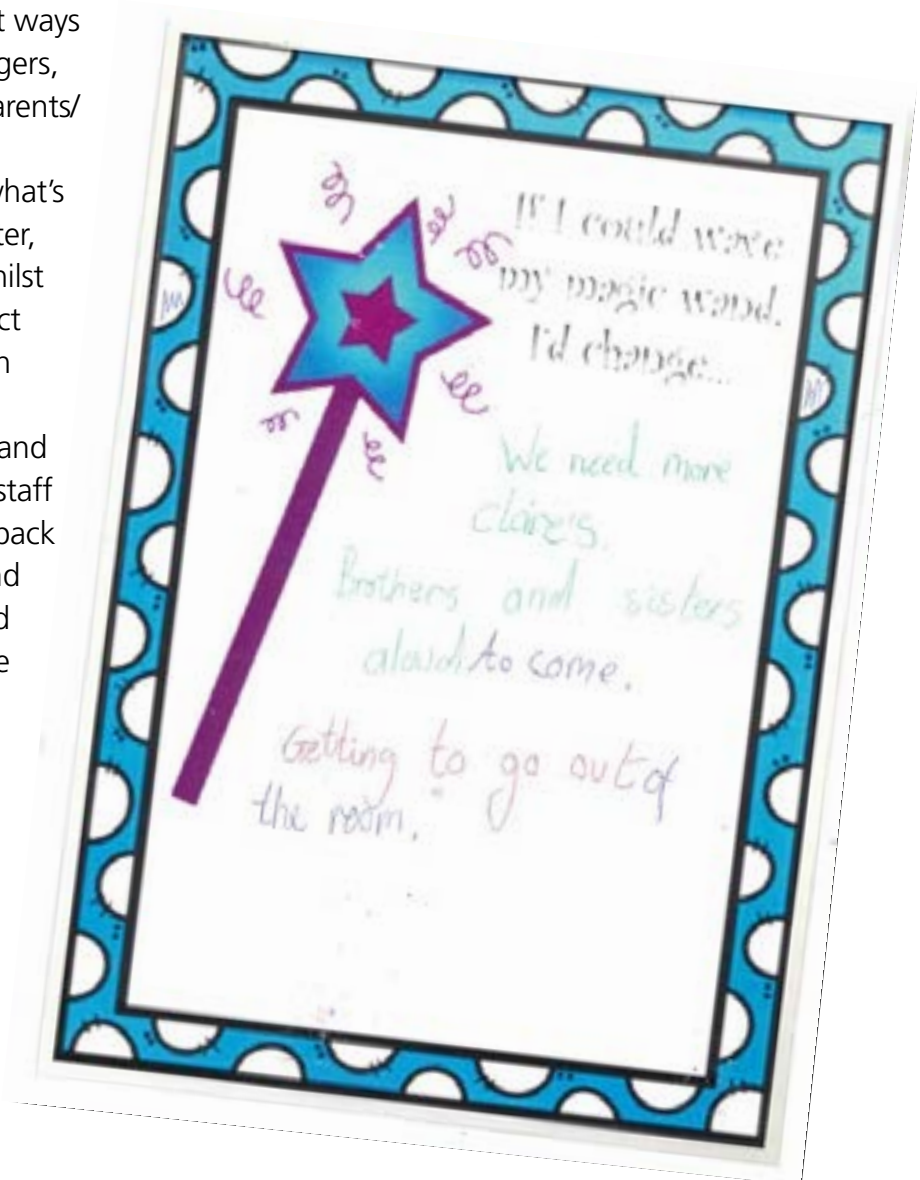
Personalised Care: Our Cancer Our Way

A project to hear about the experiences of cancer services for children, teenagers, young adults and their carers led to some 'quick fix' improvements and will shape future practice

What is Our Cancer Our Way

Our Cancer Our Way (OCOW) was created to hear directly from children, teenagers, young adults and their carers about their experiences of cancer services. From this we aimed to bring about improvements in their care by working together in a co-productive way. Our project team included people from [Wessex Cancer Alliance](#), [Involving People](#), a young person's engagement specialist, [Healthwatch Dorset](#), and people with lived experience – young expert advisors and some parents.

Using a range of different ways we asked children, teenagers, young adults and their parents/ carers what they thought about cancer services – what's good, could be done better, and needs to change. Whilst Covid19 meant the project team could not work with patients directly, the Play Specialist, Youth Worker and Social Worker and other staff were able to gather feedback in the form of pictures and poems, and "magic wand sheets" on the wards. We spoke to parents online.



We heard a lot that was positive

"Lovely staff...
Good facilities...
Lots of space...
Lots of support"

"The group, even down to the people who used to clean his room they did a great job. People like the cleaners and the bloke who did the food...down to the people mopping the floor each day...always friendly and positive"

"They are just the best nurses and staff I have ever encountered in my life...we loved some of our guys and the best thing about them was the continuity of care having the same nurse, the same faces, their training working with young people, it made all the difference"

"Someone was always at the end of the phone"

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We also heard what people wanted to be done differently

"Less waiting for pharmacy"

"Chemo to be ready when you arrive"

"A parent guide to hospital stays"



Making sense of so much feedback

One of our challenges was that we heard so much that we needed to summarise and theme the feedback to make use of it. We held a workshop to do this as a project team.



We then sent out surveys to help us prioritise the areas for improvement. For younger children we developed a “sticky note sheet” asking which was the most important thing to do something about - Food, Being Bored, or Play.

For adults we used an online survey so they could rank the issues in order of importance.

Amongst everything we heard, three issues appeared the most crucial.

- **Communications** - not getting contradictory messages, getting test results quickly, getting the right amount of information at the right time
- **Practical issues** - the wait for medication when coming to hospital for day treatment adds to anxiety and wastes time. Plus, sometimes being given too medication (ones people already have) is wasteful
- **Support** – support in hospital is great, but at home you can feel a bit alone, especially after treatment, when there are challenges about getting back to “normal” life and dealing with what has happened

We developed “scenarios” around these and held discussions between the project group, staff and patients. Collectively we created solutions.

All the feedback we heard was provided to staff teams, who have actioned the “easy to fix” issues. The OCOW feedback is also influencing the ways in which the new service specifications are implemented.

What we learned from Our Cancer Our Way

From working this way, we learnt that:

- To be effective, a range of engagement mechanisms are needed, tailored to different age groups
- Coproduction is complex and time consuming; is built on a respect for everyone's specific skills, knowledge and contributions; and develops over time. It doesn't "just happen"
- Engagement is most successful when invitations to get involved are "personal" and come from known and trusted people
- It's all too easy to try to jump to solutions, without listening to what the problem is and allowing solutions to be co-produced
- To ensure ongoing engagement and co-production, services will need committed resources
- To ensure suggested improvements are delivered, you need to embed the engagement process in the services

All this will influence our future coproduction practice.

For further information

- [Our Cancer Our Way video](#)
- [Our Cancer Our Way - Wessex Cancer Alliance](#)
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