



Our Cancer Our Way – Always
Wessex Coproduction: Involving children and
young people in developing cancer care
specification.

Key Learning

- Involving a broad range of people with different lived, and learned experience, clinical and nonclinical specialisms relevant to the area of development provides a strong foundation for good coproduction.
- Take an iterative approach, listening, write share, check again, and so on. This allows large amounts of feedback to be sifted into themes, and then actions, and enables people to feel heard and included even if everything said cannot be acted upon.
- Keep everyone involved and onboard by sharing the positive feedback as well as what needs to change.
- Be creative about ways for people to tell you what matters to them.

Who was involved

This work - about improving and developing cancer care for children, teenagers and young adults, was led through the Wessex Cancer Alliance (WCA), covering the HIOW and Dorset Integrated Care Boards, so affecting a whole system. Services are delivered through a hub and spoke model, a specialist hospital, local hospitals, and community services also delivering to children and young people with cancer across Wessex.

Project summary

The work was of key strategic importance - to inform the delivery of the new specialised commissioning service specification. The partnership delivering this work was wide. The project team originally drawn from WCA, involving young people with lived experience in advisory roles. Parents and families also got involved. A clinical reference group involved members of broader clinical teams from across the area. A youth worker and play specialist contributed additional broader expertise to the work. The breadth of experiences and expertise were key to providing a strong foundation for good coproduction.

The challenges and solutions

The work was carried out across two stages. The first was about seeking people's views, and the second about turning those into actions for change. During stage one, design elements took place and the project group including the young advisors was established. A range of ways to connect with people were set up, from social media - to conversations online and with young patients in hospital. Covid restrictions meant that face to face engagement was curtailed, in particular as many young people with cancer were self-isolating. Creative approaches for young people to engage included writing wish pages, and sharing what matters to them, from food to play, whilst they are in hospital.

In stage two the engagement moved from hearing what people felt, to what needed to change. Transcripts from the original interviews were written up and put into PowerPoint

presentations, and gradually pulled into themes that encompassed all we had heard. The findings included the good, the less good and what needs to be improved. Sharing this with the clinical reference group reassured them how much everyone values what they do, and began to indicate the areas people are looking for some changes.

The Outcome

After lockdown was lifted, the project group could finally meet face-to-face and went through all the feedback, ensuring all comments were noted and used in the process of making the feedback easy to digest and share. The group agreed together that there were three key themes:

- Communication
- Information
- Support and Practical Issues

All the feedback in each theme were turned into statements/questions for a survey to put out again to people to prioritise the areas for action. The Survey went back out to everyone involved, and the priorities for the ICS commissioning specification was informed by these.