

Co-producing a factsheet to support people living with cancer



What needed improving?

The rates of cancer in the East Coast are high so Lincolnshire Integrated Care System (ICS) wanted to ensure the voices of people living in this region were heard and improvements could be made. Along with Macmillan and Every-One charity, Lincolnshire ICS started this co-produced quality improvement project.

Engaging with people with lived experience

Recruitment

A steering group consisting of members of staff from a range of partners and people with lived experience was set up to oversee the co-production project. The group spoke to many healthcare professionals from the Primary Care Network (PCN), neighbourhood teams and the GP Practices in the area to explore what they considered to be the key areas for improvement. The project leads also approached people in the street in the East Coast area to understand what their main priorities were for improving cancer care. The town of Mablethorpe was specifically highlighted as a key area for quality improvement, so this became the focus of the project.

To recruit people with lived experience to the steering group, posters were distributed throughout Mablethorpe and the project leads also reached out to the local community. Only one person with lived experience of cancer joined the first meeting. However, through word of mouth, numbers increased and there have since been five people who have consistently attended meetings.

Gathering initial feedback

One of the members of the project team facilitated the group and created a neutral space to bring people with lived and learned experience together with staff to enable initial conversations. The people of Mablethorpe felt isolated as services are a long way from their hometown. The group became a space where they were able to share these grievances. Although it took time, giving the group space to voice their upset enabled the project to progress.



Allow time and space for people with lived experiences to share previous negative experiences.

How was a solution co-produced?

Development of a local factsheet was the focus of the co-produced improvement, which aims to help residents of Mablethorpe to navigate the cancer support in their area. The factsheet informs people on a wide range of services and help that is available to them.

Topics include:

- Information on transport/ parking/ blue badges
- Financial support
- Aftercare/ Emergency care
- Prescriptions
- Mental Health and well-being
- Physical activity post treatment
- Charity/ hospice support
- Spiritual/ Faith
- Physical appearance- dental treatment and wig services
- Housing
- Volunteering
- Support for carers

The wider county co-production group contributed to a Lincolnshire-specific cancer website. The steering group provided input into the website to ensure it contained relevant information for people living on the East Coast. Details about the website will be included in the factsheet.

People with lived experience highlighted that they struggle to find out about services or support that might be available to them. They noted a preference for learning about services through posters rather than other approaches. Posters will therefore be displayed in places specified by them, to advertise services that could be of benefit or interest to them.

Key Learnings

- **The importance of recognising local needs and differences.** The East Coast was recognised as an area that was underrepresented in the system-wide co-production steering group. The initial plan was for the newly formed East Coast Cancer steering group to eventually join the county-wide co-production group, but it became evident that the needs of this group were very different to the wider community.
- **The need to manage expectations.** There were several improvements that were suggested by the group, but some were not achievable within the funding and time constraints of this project. It was key for the project leads to manage the expectations of the group members to keep people engaged.
- **The need to change focus.** The staff members recognised the people with lived experience had a very different view on the project's focus. Allowing shared control within the group created space for co-produced improvements.

“Co-production is around that balance of power. It's about having that equal space in the room for people, that they have the skills, knowledge and confidence to be able to contribute and to make a difference.”

(Staff interview)



Challenges



Recruitment of people to join the steering group was challenging. Staff engaged with many people from the Mablethorpe area, however, they were resistant to joining the group as they believed it would have little impact.



Working remotely. It was felt remote working hindered progress of the group: face-to-face meetings would have allowed a more relaxed conversation style.



The need to educate people about co-production. People with lived experience were typically older and challenges were highlighted around creating a behaviour change. The approach to co-producing improvements with staff was explained to the group, along with the benefits of this way of working.



Impact. Although the group are not yet at a point in which they are able to measure the impact of the factsheet, they are unsure of a suitable way to evaluate its success and already foresee challenges around the measurement.

“Trying to kind of talk about, create some behaviour change, is quite a challenge.” (Staff interview)

Next steps

- **Distribute factsheet.** The team plan to integrate the factsheet into general practices in the area to ensure they are accessible to anyone who might need them.
- **Engage with GP Practices.** It was felt that the group need to engage with staff from GP practices to further support understanding of the difficulties that those with lived experience face.
- **Continued engagement.** The people with lived experience and the team would like to continue the co-production work, so the feasibility is being explored.

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