

# Living with and beyond cancer: co-producing a roadmap



## What needed improving?

The information and support given to patients living beyond cancer was recognised by staff and patients as needing improvement. Healthwatch Wirral received feedback from people that it was difficult to move on with their lives after cancer. Staff working closely with people living with cancer also identified that patients lacked support following discharge. Cancer survivorship rates were improving, but the support was not adapting to the needs of survivors. The feedback from staff and people living beyond cancer highlighted a need for change by One Wirral CIC. Co-producing an improvement with people living with and beyond cancer was considered key for ensuring it improved care for patients.

**“Cancer services were designed to detect cancer early and treat cancer but not to support with survivorship. With screening programmes and treatment now advancing, more people are surviving from cancer which means our level of support needs to change.”** (Staff Interview) .....

**“What they said is the pathway for cancer is backwards.”**  
(Staff Interview)



## How was a solution co-produced?

### By recruiting people with lived experience

Adverts were distributed via Healthwatch Wirral and Maggie’s (a cancer support charity), along with advertising throughout the hospital cancer services. Cancer care teams, prehabilitation teams and the Cancer Care Coordinator also assisted in recruiting people for the co-production group. Fifteen people, who had received a cancer diagnosis within the last five years, volunteered to be part of the group.

### Using online meetings

The purpose and value of co-production was explained at the beginning of the group’s first online meeting. In the initial meeting, people with lived experience discussed the reality of being discharged from hospital. Staff were able to assist with some of the issues shared, which built trust within the group. To ensure that people with lived experience were able to confidently voice their experiences:

- smaller groups were facilitated in three online breakout rooms.
- facilitators offered emotional support where required.
- participants were able to leave the breakout room and chat with the project lead if necessary.

The meeting highlighted people with lived experience were given too much information when they were diagnosed, but not enough after their treatment. They needed more support post treatment to navigate changes to their lives and deal with anxiety about the cancer returning.

**“It’s normally me telling people what to do and it’s different now because people are telling me what to do.”** (Staff Interview) .....

## Developing a roadmap

People with experience of living with and beyond cancer agreed that they would have appreciated a roadmap upon discharge. It was felt that there was too little information currently available or that it wasn’t easily accessible. What mattered most was advice about:

- hair loss or altered physical appearance
- how to speak with employers about ongoing side effects
- how to cope with anxiety about relapse

Together with a professional designer, the group created a double-sided leaflet, displayed as a roadmap, to signpost people to various pieces of information and support. After three revisions, the roadmap met the expectations of those with lived experiences. The roadmap contained all the advice needed in one place, rather than being spread over a number of leaflets. It is available in hard copy and digital format.



## Key Learnings



For the work to be fully co-produced, staff had to share control of the content with other group members. They learned to be open minded about the project outcomes.



Budget expectations were set out at the beginning of the project.



One Wirral CIC has started to implement new ways of working using co-production and this approach will be embedded into their strategy.



Due to Covid-19, the group meetings were online. This enabled more regular meetings and some at short notice.



The value of co-production not only ensured the changes reflected what was important to people with lived experience, but it led to unexpected benefits for those involved.



**“Co-production has given me my confidence back - that helped me get a new job.”** (Person with lived experience) .....

## Next steps

- The roadmap will be shared with patients who are being discharged or those who are on active surveillance.
- It is hoped that the roadmap can be shared and used nationwide.
- People with lived experience have been invited to participate in a short film to talk about the usefulness of the new tool.
- The project lead has secured funding for staff training by a Macmillan psychologist. This will be a six-week course to 'Help Overcome Problems Effectively' (HOPE). It will cover areas identified as important in this project and will have people with lived experience facilitating.

**“I have never done anything like this before and it's been so rewarding.”**  
(Staff Interview)

**Picker Institute Europe**  
Suite 6, Fountain House  
1200 Parkway Court  
John Smith Drive  
Oxford OX4 2JY

**+44 (0)1865 208100**

**[picker.org](http://picker.org)**

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