

Co-design Partners in Care case study

Understanding the experience of discharge from hospital as part of the ‘Cancer Journey’ (Bay of Plenty District Health Board)

Context

The ‘C’ word...The Big C...CANCER. A word no one wants to hear. But sadly many people are affected by it – either as a diagnosis they receive themselves, or a member of their family/whānau, or a friend has received.

Bay of Plenty District Health Board (BOP DHB) wants to ensure consumers/patients diagnosed with cancer are well prepared and have the knowledge and support they need on being discharged from hospital, to help them have the best possible experience throughout their ‘cancer journey’.

Aim

Everybody’s cancer journey is different and unique to them. However, it is a journey they do not take alone. There are usually many individuals and organisations involved, including their family/whānau and friends, their general practitioner, hospital staff, and specialists/consultants.

Not all journeys are simple or go smoothly and it is the aim of this project to help ensure that when a consumer is discharged from hospital after being given a cancer diagnosis or treatment, they have the tools and information they need to assist them on their journey.



Engage

A cancer journey involves many people, so it was important for this project to capture perspectives from all stakeholders involved in the consumer cancer journey.

The project engaged with the following stakeholders:

- Consumer/patient.
- Family/whānau and friends – these people are often on the journey with their loved one and also have their own journey and questions as they walk beside the consumer/patient. While they may not be undergoing treatment, they are often supporting the person who is.
- Staff – including nurses, doctors and specialists in oncology, radiotherapy and chemotherapy wards, and possibly palliative care. There is also the possibility of social workers, dieticians and other staff being involved. Each person has different needs and their journey and treatment options vary, depending on a number of individual factors surrounding their diagnosis.
- Kathleen Kilgour Centre – provider of radiation treatment in the Bay of Plenty.
- Cancer Centre Chemotherapy Unit.
- Cancer Society.

Capture

We collected information from 130 people:

- **BOP DHB complaints:** We reviewed three complaint reports.
- **Consumers:** We held informal coffee conversations with 50 patients who were in the transit lounge waiting for their discharge papers. A further 35 patients agreed to take part in follow-up phonecalls, when we ran out of time to talk to them in the transit lounge. We made notes after discussions and during follow-up calls.
- **Patient/consumer questionnaire:** We distributed 150 questionnaires through the Kathleen Kilgour Centre, the Cancer Centre and the Cancer Society. We received 24 completed questionnaires.
- **Staff questionnaire:** We distributed 76 questionnaires to doctors and nursing staff, and received 8 completed questionnaires.
- **Focus group:** We attended a coffee support group organised by the Cancer Society where we explained the purpose of the project, and got eight volunteers who agreed to take part in a focus group.
- **Feedback:** We sought feedback from patients on the High Suspicion Cancer Lung, Faster Cancer Treatment pathway.

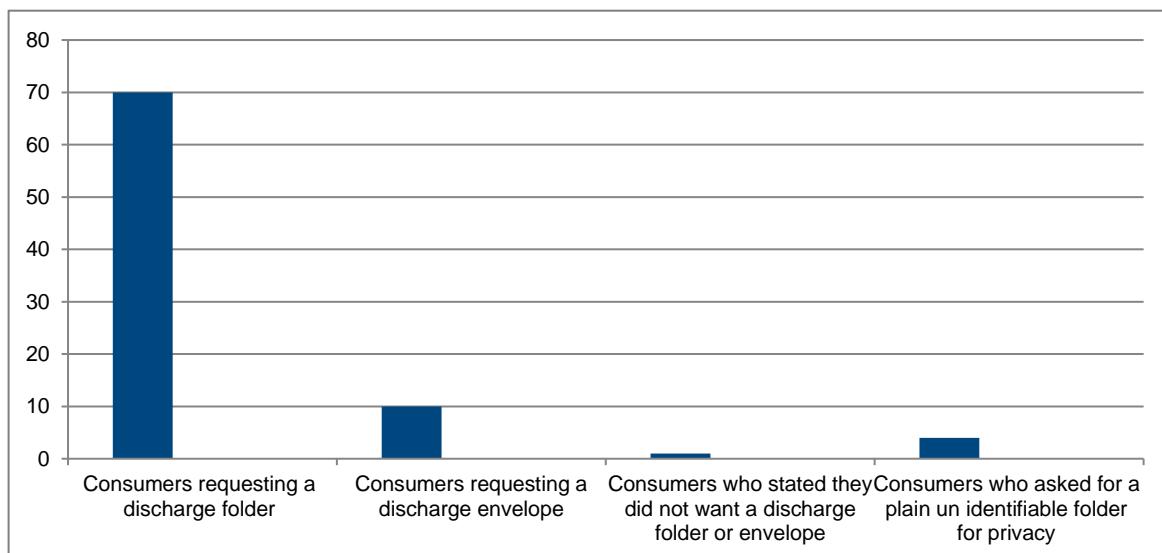


Figure 1: Consumer feedback on the discharge process.

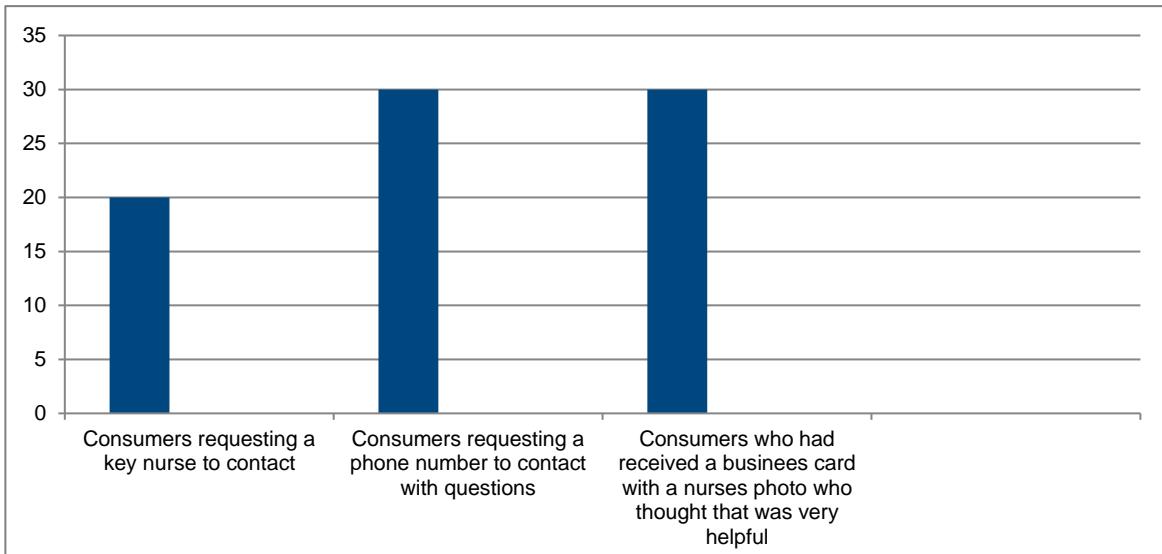


Figure 2: Consumer feedback on having a hospital 'point of contact'.

We used a range of different methods to capture consumer experiences, including:

- informal coffee conversations with patients/consumers
- phone conversations with patients after their discharge from hospital
- questionnaires given to patients/consumers and staff to complete
- patient stories
- focus group feedback
- complaints made to BOP DHB
- staff corridor conversations
- consumer home visits.

All information was collected on an anonymous basis. This was explained to everyone we contacted to assure them their privacy was protected, and to reassure patients that any information given would not affect their treatment in any way.

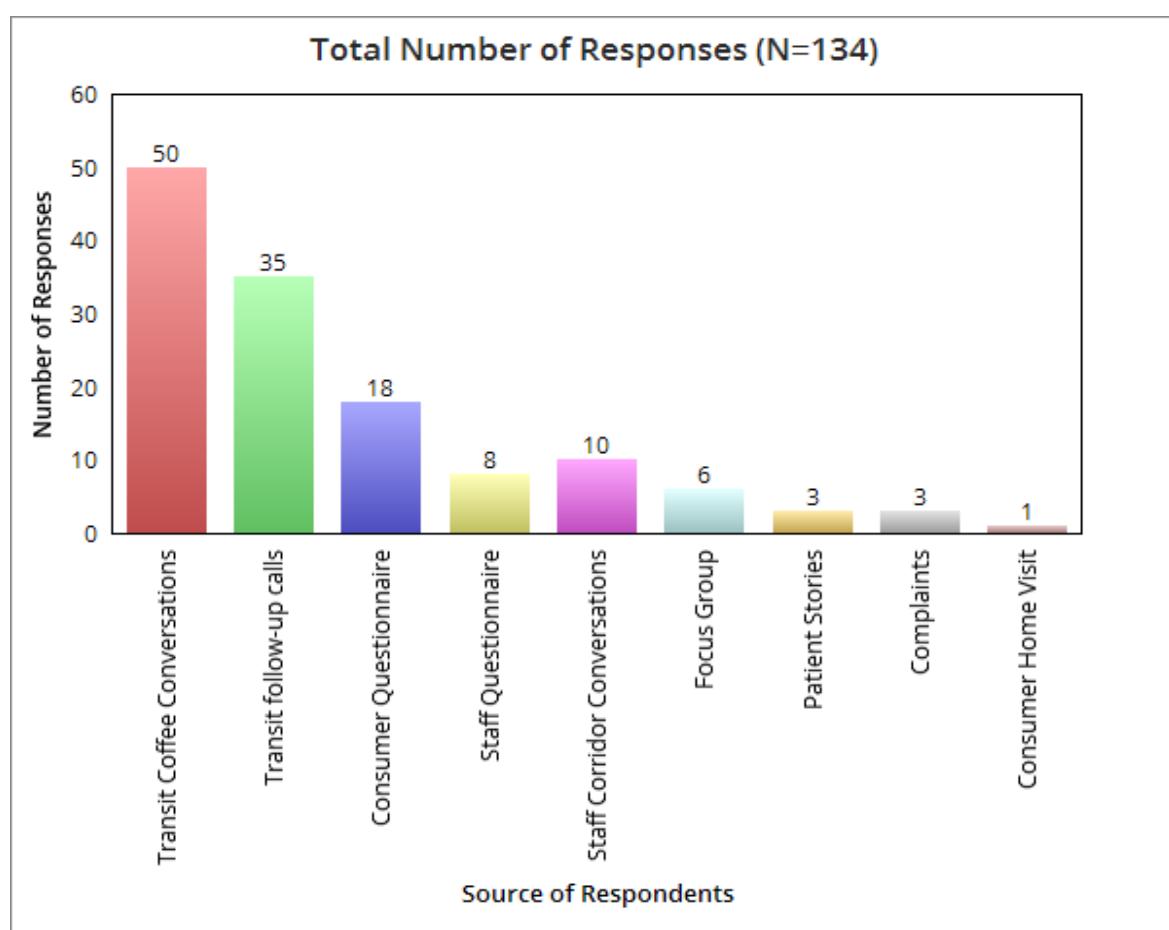
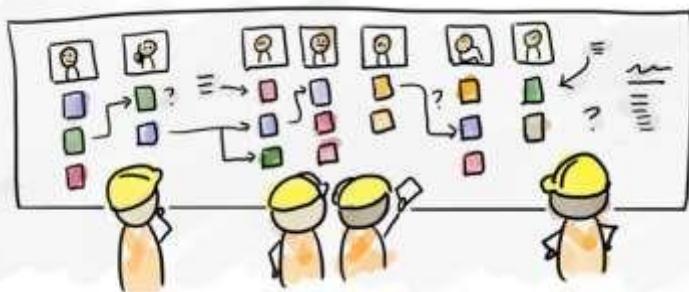


Figure 3: Number of interactions with people when capturing their experiences.

Understand



The project identified key points/themes that had been highlighted by consumers and staff throughout the information gathering process. This included collating questionnaire responses – both closed and open-ended questions.

Staff responses

The key themes highlighted from staff responses were as follows.

Q.1 What support do you need?

- Access to a 'point of contact' for patients to call with any questions – all staff responses asked for an easy way to find contact details of the relevant hospital specialist staff that they could give to patients. It was from this information, and discussion with our sponsor, that the 'easy to find contact list' was developed.
- Training – more training/in-service training.
- Resources – more access to written information about cancer treatments and services for patients and family/whānau.

Q.2 What obstacles do you face?

- Resources/information – unsure where to access relevant information and what to give to patients.
- Timeframe – need to have a full diagnosis before referral to cancer services, so there is pressure to get all the information together in time.
- Staff confidence – lack of experience in discussing cancer, feeling insecure.
- Patient responses – how to deal with the myriad of patient responses/questions.
- Responsibility for giving information – doctors often rely on nursing staff to provide information and nursing staff rely on medical/surgical team to provide information. Internal access via OnePlace computer system is available for contact details of specific cancer nurses where contact is difficult, and information is not easily accessible otherwise for staff in wards.

Q.3 What information do you give patients?

- Verbal discussion with patient about their treatment.
- Written information – hospital pamphlet, Cancer Society pamphlet.
- Hospice details/referral, if required.
- Hospital outpatient referral.
- Social worker referral.
- Hospital 'point of contact' to get further information and/or ask questions.

Consumers/patients (family/whānau)

There has been some very positive feedback. However, it appears when the process/journey goes wrong, it goes very wrong, and it is difficult to change the process quickly.

Key themes:

- The need for consumers/patients to have access to contact details for a hospital staff member they can contact if they have questions.
- The need for an early referral to the Cancer Society. Because of privacy issues, the Cancer Society is unable to actively contact people within the hospital system.

Improve

- The BOP DHB internal computer system (OnePlace) now allows staff to type 'cancer' into the search engine and a link to a cancer nurse coordinator page pops up. This page includes details of those who specialise in each cancer stream and their contact details. It also includes a link to the cancer nurse coordinator's email address, which has made it quick and easy for staff to access, and refer patients.
- A new cancer nurse coordinator team leader has been employed and will start in July 2018. If staff are unsure of who to refer patients to, they can send an email to this team leader. Cancer streams that do not have an allocated cancer nurse coordinator can also be referred to the team leader.
- We are in the process of working on adding other contact details to the cancer coordinators page, such as the Cancer Society, hospice and the hospital palliative care team, with a quick-link to refer patients. We are yet to identify a point-of-contact for urology patients. We will share with the Kathleen Kilgour Centre that patients are not sure who their point of contact is post-treatment.
- In-service training sessions for staff have been arranged for later in the year.
- The Cancer Society nurses will give feedback on the service they provide and how to refer patients. We will provide advice about the new easy-to-access cancer nurse coordinator link and how to email with referrals. Details will be added about where to find resources and what information to give to patients.
- We are in the process of working with the Cancer Society and BOP DHB's IT team about simplifying the Cancer Society referral document. This is being developed through the document committee.
- We are working with our focus group to develop an information folder to give patients. This will include information they identify as helpful in their journey after initial cancer diagnosis and discharge from hospital including a single point of contact, and the name of the senior medical officer providing care. The folder will be trialled initially through Tauranga Hospital.

Measure

- Contact list on OnePlace – staff will be contacted to assess whether the changes made to the internal computer system have made information easier to access.
- Patient information folder – we will continue to work with consumers to measure the usefulness of the folder and adapt it as needed.
- Planned in-service training will be given for staff at all levels.

Working as a co-design team

Sharon: 'As a consumer I have been fortunate to be working with two excellent BOP DHB staff members. We have worked well as a team and collaborated well together throughout the project.'

Mel: ‘Working as a co-design team has been fantastic and energising. I feel very lucky to have been invited to participate on this project with Mary and Sharon. The process of working with staff and consumers has been very positive. As a “floor nurse” I feel very privileged to have had the opportunity to engage with consumers out of the hospital setting with no time constraints. Colleagues have commented that being given the opportunity to give feedback and input into changes and what they need, will make a big difference.’

Mary: 'I have thoroughly enjoyed this experience. It has been wonderful to engage with our consumers and listen to their stories. Their feedback has been so informative and it has been so rewarding to be able to improve our cancer service. Mel and Sharon have been awesome – we have gelled well as a team and have built up a great relationship with each other which will last long after this project.'



The project team

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