



Evaluation of the implementation and use of *My Cancer Care Record*

Consumer summary report

This report provides a summary of the findings of the evaluation and how we will use the information to continue to improve *My Cancer Care Record* and the way it is used.

Who participated?

During the project, *My Cancer Care Record* was introduced to 682 people affected by cancer who accessed treatment from 13 cancer services across Melbourne's north east and the Grampians region of Victoria.

Everybody who received the folder was invited to provide feedback and share their ideas. We wanted to hear from the people who used the folder. Patients had the option to provide feedback themselves, or they could nominate a carer, family member or other support person to participate. We also collected feedback from healthcare professionals.

How did we collect feedback?

While people were welcome to provide feedback at any time, we mainly collected feedback via:

- surveys (sent to people who used the folder and healthcare professionals) to learn how people used the folder and whether it was helpful for people affected by cancer and the healthcare professionals they interacted with
- individual interviews with people who used the folder
- feedback groups with staff who coordinated the project at each cancer service.

Between May 2017 and February 2018, a total of 682 people affected by cancer were introduced to *My Cancer Care Record*.

We sent out 465 surveys to people who had agreed to receive a folder and be part of the evaluation. We received feedback from 270 people including:

- 212 patients aged between 18 and 90 years
- 58 carers, family members and other support people.

We completed individual interviews with 22 people to learn more about their experience using the folder.

Thirty-six healthcare professionals completed a survey about their experience working with people who used *My Cancer Care Record*.

Fourteen staff from the participating sites also shared their ideas about coordinating the project in their services.



The Integrated Cancer Services are supported by the Victorian Government

How did people use *My Cancer Care Record*?

Most people (70%) DID USE *My Cancer Care Record*.

The most common ways that people used *My Cancer Care Record* were to:

- store medical and cancer-related information (92%)
- record information (e.g. about medications, contacts or appointments) (81%)
- remember important medical details and information (66%).

This aligns with the primary purpose of the folder, which is to assist people affected by cancer to manage their health information.

'For me, the whole idea of the folder is to have one central place to store all of our info. We get so many bits of paper and collect info from all sorts of people. Everything goes in the folder and then we never have to think about where things are. This was how the folder was explained to me and this is how I've used it.'

Consumer interview

Fewer than one-third of people (30%) DID NOT USE *My Cancer Care Record*.

Some of the reasons why they did not use the resource were because they had another system in place to organise their information (24%), or that they felt too unwell, overwhelmed or did not have the energy to use it (19%).

Interestingly, one in five (21%) of those who did not use the folder reported that it was a great idea and thought *My Cancer Care Record* would be useful for other people.

Did people receive the information and support they needed to use *My Cancer Care Record* effectively?

The majority of people felt they had received enough information and support to use *My Cancer Care Record* effectively (90% of people affected by cancer and 88% of staff).

Some people suggested that more detailed explanation and support to fill in *My Cancer Care Record* would be useful.

The feedback highlighted that people affected by cancer and the staff they work with need support to make the most of *My Cancer Care Record*. This includes that:

- staff need a solid understanding of the resource, and the knowledge, skills and confidence to introduce and use it with their patients.
- consumers need to be aware that using *My Cancer Care Record* is voluntary and that there is no obligation to accept or use the folder
- systems need to be flexible so that staff can use their judgement to determine if and when it is appropriate to introduce *My Cancer Care Record* to people
- staff working across cancer services would benefit from information and education about *My Cancer Care Record*.

'It would have been helpful for me to know how the folder was going to be used when I received it. The oncologist just gave it to me and then I thought I had to go away and have it all filled in correctly before the next appointment. It was quite a stressful time, but I really needed some clear guidelines about how to use it and why. It has turned out to be useful, but not the way I initially thought. It's very helpful to store information, but if I'd known no one other than me would ever even look at it, I might not have spent so much time filling out every detail.'

Consumer interview



Did people take *My Cancer Care Record* to their appointments?

Forty per cent (40%) of people reported that they always or often took *My Cancer Care Record* to their appointments.

They found it useful to take their folder to appointments to store information and make sure they had relevant information with them. A number of people also found that taking the folder to appointments helped them answer questions and share information with their healthcare team.

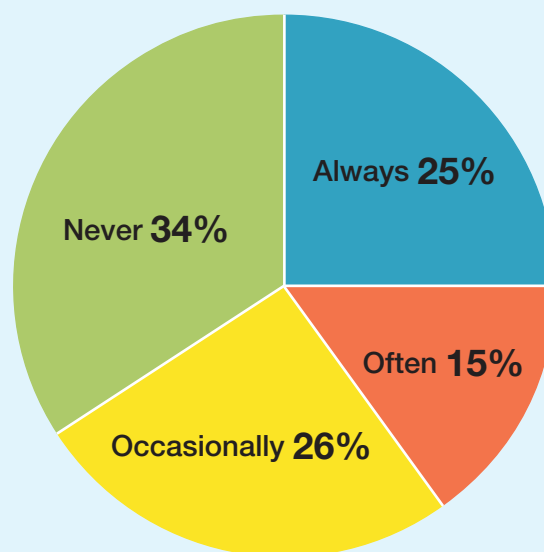
'I would have taken all the information related to mum's condition and treatment regardless, as I wanted to be able to provide all answers any doctors or nurses may ask. Having it all in My Cancer Care Record made it so much easier. It made me feel very much in control of all the information and secure in the knowledge that I had it all with me should any doctor or nurse need to refer to it.'

Consumer survey

Twenty six per cent (26%) of people only occasionally took their folder to appointments, while 34% reported they never took it to appointments. The most common reasons given were because they found it too big or bulky to carry, they forgot it, or they didn't find it necessary to take all of their information to appointments.

The feedback suggests that it may be most useful to take *My Cancer Care Record* to meetings with their healthcare team when they were going to discuss treatment or progress.

How often have you taken *My Cancer Care Record* to your healthcare appointments?



'I took the folder to all of the doctors' appointments and key reviews. I certainly didn't need it for every chemo and radiation session because that was very treatment focused. I think it's very helpful to take the folder to the appointments where you discuss progress. That's where the value is. In the future, it would be helpful to teach people how to make the most of their folders – simple tips, like when it helps to bring your folder, would be useful.'

Consumer interview

Did people visit the *My Cancer Care Record* webpage?

Just 10% of people visited the *My Cancer Care Record* webpage

(www.mycancercarerecord.org.au).

Nearly half of those people visited the webpage to print extra pages for their folder. Some people felt it had not been necessary for them to visit the webpage, while others were not aware of the webpage and were unsure about when or why it would be useful for them to access it.

How did healthcare professionals use *My Cancer Care Record*?

Nearly 90% of the healthcare professionals who completed the survey had been involved in providing *My Cancer Care Record* to their patients. However, according to both staff and people affected by cancer, once they had provided the folders, very few staff had made further reference to or use of the folders.

‘It’s a nice idea to use it to share information with the staff, but that was never explained to me. I took our folder to appointments but none of the team ever asked to look at it, so I guess the idea that we could use it to share information was never demonstrated to me. Now that I think about it, that would be a good way to use it. I think the staff need to take the lead on that and show people what’s possible.’

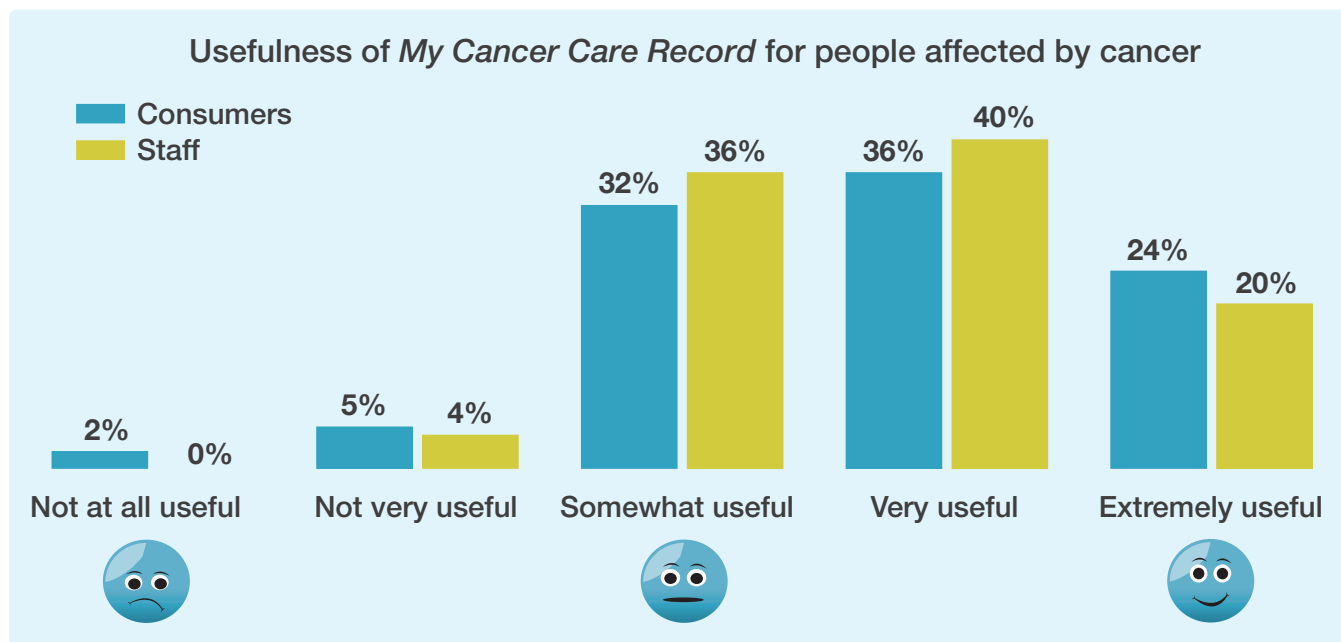
Consumer interview

How useful is *My Cancer Care Record* for people affected by cancer?



Most people (93%) found *My Cancer Care Record* useful. When asked to rate the usefulness of the folder on a scale of 1 to 5, (where 5 was 'extremely useful'), the average rating was 3.8 out of 5.

Most staff (96%) thought that *My Cancer Care Record* was useful for patients and their families, with an average rating of 3.8 out of 5.



'So often, you just can't remember everything and your brain is awash with information. My Cancer Care Record was so helpful because when I couldn't remember things, I could always go and look it up. It was a useful reminder. If you were really having a bad day, you could ask someone to write things in the folder for you; that way it's not all up to you and your broken brain to remember all the details!'

Consumer interview

A number of people provided feedback that they found *My Cancer Care Record* very handy to keep all of their information neat and organised in one place. They also indicated that *My Cancer Care Record* helped them communicate with healthcare professionals and empowered them to ask questions and/or request information from staff.

'It helped me with staying organised and relieving the stress of losing important paperwork.'

Consumer survey

People were also asked to rate how useful *My Cancer Care Record* was for a range of purposes.

People rated the folder as most useful for:

- storing medical information in one place (average rating 4.4 out of 5)
- keeping track of medical and cancer-related information (average rating 4.2)
- recording information that the healthcare team told and/or gave me (average rating 4.1).

'Using the folder gave me a sense of control. It helped me know exactly what was happening and made me feel less overwhelmed and confused.'

Consumer interview

There was evidence that *My Cancer Care Record* was **slightly more useful for carers** than patients who used the resource themselves (average carer rating 4.4 compared to 3.7 for patients).

Most people received the folder at the start of treatment or before treatment commenced. People were most likely to use it when it was provided to them early in their treatment. Even when provided later, most people used the resource and identified it as useful.

Seventy-one per cent of staff survey participants reported that they would like to see *My Cancer Care Record* become routinely available for people affected by cancer. The most common reasons were that they thought the folder was a useful resource for patients to store their information in one place, and it helped people stay organised and communicate with their healthcare team.

‘Knowledge is power, so if the patients are knowledgeable and have information about their disease and treatment plan readily available, it gives them a sense of control over their illness.’

Staff survey

How useful is *My Cancer Care Record* for healthcare professionals?

Most healthcare professionals (86%) felt that *My Cancer Care Record* was useful for them (average rating of 3.5 out of 5).

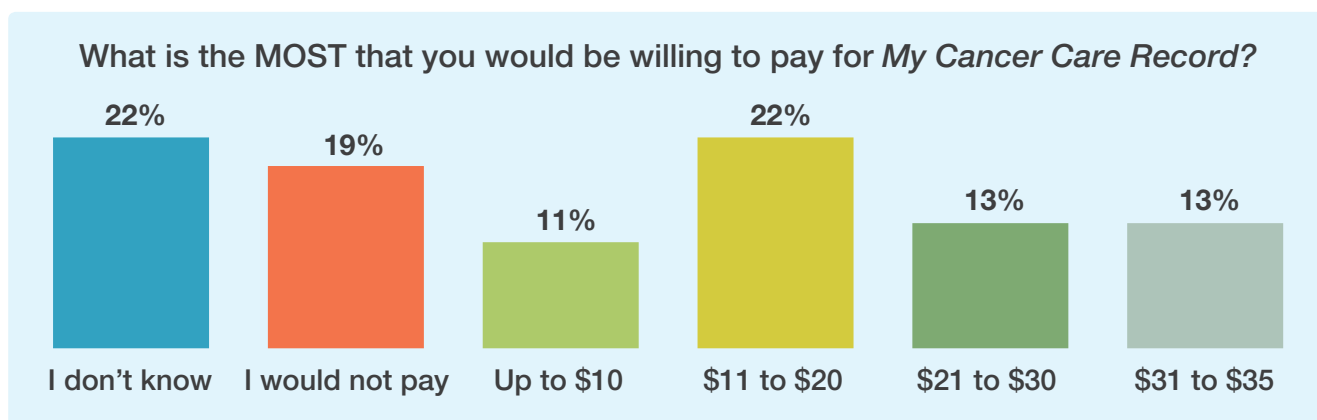
They reported that if people use *My Cancer Care Record* effectively, it has the potential to reduce duplication and minimise the time required to access copies of test results and reports from other health services. This is particularly relevant for people attending multiple health services.

‘So many patients assume that we can access complete patient records from every service and that we all share information automatically. That obviously isn’t the case, which can be frustrating for us and them. If families knew to ask for information and bring it to appointments, that would improve everyone’s experience’

Staff feedback group

How much are people willing to pay for *My Cancer Care Record*?

The consumer survey asked people about how much they would be willing to pay for *My Cancer Care Record* (and were given multiple choice response options between \$0 and \$35). There was a large spread in people’s responses and the existing feedback does not provide a clear indication of an acceptable price point.



It was clear from the feedback provided that both consumers and staff needed to be clear about the purpose and benefits of *My Cancer Care Record* in order to understand its value.



Would people use an app version of *My Cancer Care Record*?

Just under half (45%) of people said they would use an electronic app version of the resource if it was available to use on a smartphone or tablet. Many of these people felt that an app would make it easier to access information because it would be more convenient and portable. A number of staff also thought that an app would be useful and convenient.

'I use my smartphone all the time so if I didn't have my folder I could still access the information if needed.'

Consumer survey

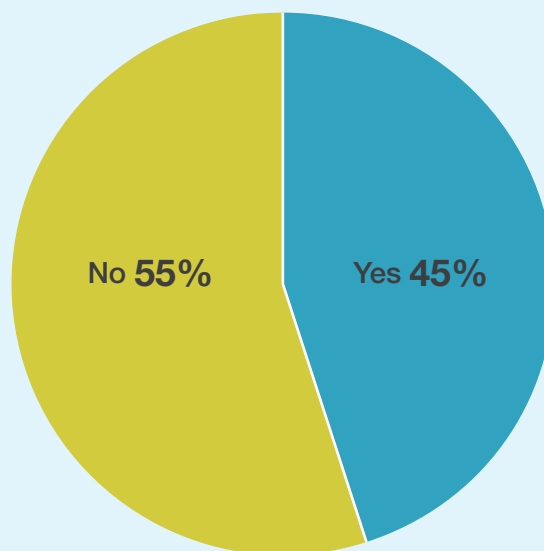
The most common reasons why people reported they **WOULD NOT USE** an app were that they did not use a computer, smartphone or tablet or didn't feel that they were computer literate.

'I am not very technologically savvy so I would struggle with scanning in reports, etc.'

Consumer survey

Some people reported that they preferred to keep hard copies of their information and an app would not allow for information to be stored in the same way.

Would you use *My Cancer Care Record* if it was available as an app?



'If I used an app I would still keep the hard copies so would still need somewhere to store everything. It would be good to offer both options.'

Consumer survey

Overall, people affected by cancer and the staff they worked with felt that *My Cancer Care Record* was a useful tool that was easy to understand and use. A number of people highlighted that *My Cancer Care Record* was a great idea and described how much they liked or appreciated the resource.

Opportunities for improvement

How can we improve the design of *My Cancer Care Record*?

Consumers and staff provided a number of recommendations about how the design and layout of the folder could be improved. Overall, the findings supported the existing literature and previous patient-held record evaluations, which demonstrate that there is not a single size, design or format that is appropriate for every consumer.

Suggestions about how we can improve *My Cancer Care Record* folder design related to:

- **Revising the size and format of the folder**

Twenty-three per cent of people affected by cancer and 45% of staff found the folder too bulky and suggested that a more compact folder would be easier to carry and use. Other people liked the layout of the folder and found the A4 size useful to store information.

How can we improve the use of *My Cancer Care Record*?

Suggestions about how we can improve the use of *My Cancer Care Record* related to:

- **Supporting people to personalise their folder**

The feedback reinforced the diverse ways that people used (or wanted to use) *My Cancer Care Record* and highlighted the potential benefit of being able to personalise the resource. People also described the value of staff providing ideas and encouragement for consumers to personalise the way they use *My Cancer Care Record*.

- **Providing *My Cancer Care Record* at the time of diagnosis or at the beginning of treatment**

- **Encouraging staff to be more actively involved in using the folder.**

The most common suggestions about ways we could improve *My Cancer Care Record* and how it is used were:

- Revise the size and format of the folder
- Support people to personalise their folder
- Provide the folder to people at the time of diagnosis or at the beginning of treatment
- Encourage staff to be more actively involved in using the folder.

Next steps

This project has provided valuable insights about how people have used *My Cancer Care Record* and how to maximise its value in the future. Now that the project is complete, the project team will share the findings with other services and use this information to make important decisions about the resource and how it can be used to best support people affected by cancer.

We thank everyone who helped in the evaluation of *My Cancer Care Record* for your contribution and interest.