

Welcome to the Spring Edition of the newsletter. Two pieces show the outcome of a number of years of planning, developing, reviewing and finalising a My Cancer Care Record. The first attempts I remember of developing such a resource was started by Southern Health's Patient Held Record. The My Journey Kit developed for breast cancer patients was developed by Breast Cancer Network Australia. In this newsletter are reports of the latest iteration developed by North Eastern Metropolitan Integrated Cancer Service (NEMICS) and Grampians Integrated Cancer Centre (GICS). Many other such records have been developed but hopefully this version will be useful across all cancers and all areas of Victoria.

Also included in the newsletter is a report of the opening of the Victorian Comprehensive Cancer Centre (VCCC). It is an interesting building to visit.

Cancer in Victoria Statistics and Trends 2015 was launched on 5th December at the Victorian Cancer Council – a short report is included.

Please send in articles, ideas, requests, views ... for inclusion in the next newsletter in preparation in February 2017.

Committee for 2016-17

President - Marilyn Dolling

Secretary – Dr Pamela Williams OAM

Treasurer – Sandra Anderson

Members – Denise Horsey, Sandra Oriander, Barbara Latham.

We thank Marie Craw for her work as Treasurer in 2016.

Dr Pamela Williams OAM

My Cancer Care Record

Recently a My Cancer Care Record folder was launched in Ballarat. The My Cancer Record is a joint initiative between North Eastern Melbourne Integrated Cancer Service (NEMICS) and Grampians Integrated Cancer Service (GICS). The Record will help store and record medical and health-related information in one place. The Record aims to connect the information and people involved in your care.

Following are edited versions of two presentations made at the launch on 4 November 2016. An Oncologist also spoke passionately about the need for such a record and emphasised that he was promoting it to all his staff and colleagues.

My Cancer Care Record

My Cancer Care Record is an initiative of the North Eastern Melbourne Integrated Cancer Service Consumer group.

It is a resource designed for people affected by cancer and seeks to help store, record and organise their cancer and other related health information.

Our group recognised the importance of supporting people affected by cancer:

- to be **more informed, involved** and in **control** of their care;
- to be provided with more **personally relevant information**;
- and
- to be **better equipped to recall and communicate their medical information** with health care providers.

Via our own personal cancer experiences, we recognised the value of maintaining our own records:

- to help communicate our medical issues;
- to help recall dates and names of medication and treatment

- how helpful keeping this sort of information can be not only for us, but also our families & carers.

The needs we had identified were aligned with those that other consumer consultations had also found, that is:

- that people affected by cancer seek to have more information about their own specific cancer type;
- they want to be provided with the details of the treatment they are having;
- they want to know what questions to ask;
- and often feel that because of issues with sometimes poor or slow communication between doctors and hospitals, and the number of people involved, we as the patient or family, can be the ones with the full and accurate story - but these details are not always easy to remember.

Clinicians in our region were also advocating for the development of a similar resource to help patients keep track of the various aspects of their care and treatment, especially because cancer care can be provided by many different people and often over long periods of time.

Our consumer group undertook a review of existing, like resources and we recognised that many of the other resources were either specific to a cancer type or to specific treatment types; or were designed in a way that didn't allow for information to be added or removed. So we got started on developing our own.

The project was formally prioritised by North Eastern Melbourne Integrated Cancer Service stakeholders at the 2013 annual planning workshop. Development of all aspects of the resource was led by the North Eastern Melbourne Integrated Cancer Service Consumer Reference Group, in collaboration with clinicians from public and private cancer services across the north eastern Melbourne region as well as Cancer Council Victoria.

Having a good representation of areas ensured we included links to all key aspects of cancer care such as clinical trials, palliative care and the optimal cancer care pathways.

Working alongside clinicians, consumers participated in all aspects of the design and development of the resource.

This included:

- preparing and revising content pages

- involvement in determining the folder design, including deciding on the logo and a name for the folder.

The outcome of this process, and all the hard work, was that in August 2014, the first version of *My Cancer Care Record* was produced.

The resource is a ring-bound folder, which allows for information to be easily added.

It is applicable to any person affected by **any** cancer and not specific to a particular treatment type and it is also applicable for use by any health service.

A small, proof of concept pilot was conducted in late 2014. This involved 100 folders being distributed to people affected by cancer, across health service sites in the north eastern region of Melbourne as well regional sites in the Loddon Mallee, including Mildura and Bendigo. This initial pilot was run over three months and feedback was provided via a survey.

The feedback was very positive and users confirmed that it was a useful resource. Based on the feedback, further enhancements were made to the resource. We also determined that a larger and longer implementation pilot would be required.

In November 2015, we were approached by the consumer advisory group of the Grampians Integrated Cancer Service to share our learnings from the development and pilot of *My Cancer Care Record*. This was because Grampians consumers had also identified the need for a similar resource.

We are very pleased that consumers from the Grampians region have shown such interest in the resource and have been so willing to partner with us in this next pilot phase. We recognise the increased difficulties that regional cancer patients face, not only having to see many different cancer doctors, but often with the added difficulty of accessing those services across regional and metropolitan areas.

Our aims for the second pilot are to:

- **confirm that people affected by cancer need, use and value *My Cancer Care Record***
- and that **health care professionals, value, promote and advocate use of *My Cancer Care Record*.**

For the North Eastern Melbourne Integrated Cancer Service Consumer Reference Group, it is very satisfying to know that the issues we have input to and involvement in, are making improvements to the way cancer

services are delivered and we hope this leads to better outcomes and experiences for others.

As far as my personal experience with cancers are concerned, I would have given anything for a resource like this, especially during my mouth cancer. In that situation I had involvement with two surgeons, numerous X-rays and scans, private hospital admission and surgery, radiation at Peter McCallum, dieticians, speech therapists, orthodontist, dental mechanic, dental surgeon and hyperbaric treatment.

I either had to remember all the details or keep my own notes.

The following is a quote from someone who was provided *My Cancer Care Record* as part of the initial pilot and sums up perfectly, how valuable such a resource can be:

“I think the folder is a great idea for collating all relevant medical cancer information – be that for a personal reference tool and/or benefitting family who may need to refer to a medical history at some point; to aid GPs in the identification of a family genetic predisposition to an increased cancer risk.

Additionally, have found the folder very helpful as a resource when trying to complete an income protection claim.”

I have mentioned the time and effort put in to the *My Cancer Care Record* by the consumers involved in this project. However, we could not have achieved what we have without someone managing the project. Much time and effort has been expended by the *My Cancer Care Record* Project Officer from North Eastern Melbourne Integrated Cancer Service to edit the document, obtain ethics approvals, arrange the required contracts and communicate with the various hospitals. I am sure I speak on behalf of all consumers associated with the *My Cancer Care Record* project in acknowledging all the hard work put in by Anna Mascitti.

The vision, both the North Eastern Melbourne Integrated Cancer Service and Grampians Integrated Cancer Service consumer groups share, is that in the near future, *My Cancer Care Record* will be available and offered to any person diagnosed with cancer in Victoria.

Ray Kelly, Consumer Representative NEMICS

My Cancer Care Record Launch

It is six years since my wife died from her cancer and it was only 17 months from her initial diagnosis to her death. In that time we had to embark on a very steep learning curve that involved:

- Learning about the nature and progression of metastatic melanoma.
- Pondering on whether or not to undergo any treatment at all.
- The efficacy of each of the treatment options that were part of the medical response to her condition.
- Learning about palliative care and when it might be appropriate.
- Finding out where there might be some support for us.
- Understand living and dying.

And much of this was done on our own because there was no procedure or mechanism in place to provide some ongoing assistance.

Some experiences in the process will remain ever fixed in memory:

Being told that the biopsy at stage 2 showed that Vera was in the clear.

Having a further test later that showed that she had an aggressive looking mole that needed to be looked at urgently.

Being told by the surgeon after removing 25 lymph nodes that he had removed every tumour cell that he could see.

Deciding on chemotherapy and palliative care.

The moment of Vera's death.

Our experience was unique, as all cases of cancer are. There are many cases of cancer but the individual experience of the tumour and what happens during the treatment process is different for everyone. The *My Cancer Care Record* addresses that in some way, each record book is patient specific.

In 2015 GICS and the Consumer Advisory Group conducted Cancer Conversations whereby it sought to gain first-hand information and ideas from patients and providers about how we could improve the patient experience in our region. In this process there were 56 ideas generated; these were voted on to see which were the most important so that these could be acted upon. The three most important areas for improvement were:

- Support and assistance

- Communication and information
- Facilities

What was interesting was that these concerns were virtually identical to those identified in the 2010 research, They Don't Call Us Patient for Nothing.

This time both GICS and the CAG knew that they had to act to make an improvement. But just how do you do that? How do you focus on the whole person rather than just the cancer? How do you improve information sharing practices? How do you get clinicians to offer greater information to patients?

We came to the conclusion that the My Cancer Care Record, which had been through a proof of concept stage with NEMICS was the most efficient way to do this, we formed a partnership and here we are.

What has to be understood is that the MCCR is just a tool but it is capable of making a significant difference to current practices. It empowers patients and their carers to make informed decisions about their treatment options. It is something that allows clinicians and their care teams to develop information specifically for their patients. Patients can take copies of their test results, medications can be recorded, visits can be documented, questions for their next visit to an oncologist can be prepared in advance. Already we have visited every specialist in the GICS area so that the distribution of this MCCR will be used in Bacchus Marsh, Ballarat, Ararat, Stawell and Horsham. Its use will become embedded in the treatment practice of each oncologist and that should guarantee its sustainability.

Where to from here? If an evaluation affirms what we believe to be the value of this project then we should be moving to have its use adopted on a state-wide and national basis. We can move on to having it formed into an app for digital use.

For the present my hope is that is MCCR proves to be a useful tool in improving communication and information sharing between patients and treatment teams and that it empowers patients to play a more active role in the decision making that is part of their treatment process.

Ian Kemp, Consumer Representative GICS

Stepping into the world of Cancer Action volunteering

I discovered a wonderful team of current and aspiring volunteers at the CAV skills development course in July. Over two consecutive Saturdays, Dr Pamela Williams introduced us not only to the skills needed as a Cancer Action Volunteer, but also to a group of volunteers keen to share information about potential activities for involvement and education.

This led to me registering for a public event – and breakfast – later that month. The event was held at the new Victorian Comprehensive Cancer Centre (VCCC) in Parkville. It was entitled “Patient and Public Involvement: Building Partnerships across the VCCC.” It provided further networking opportunities for volunteers and some real-life examples of successful partnerships between the expert - researchers, clinicians, academics – and volunteers from the community.

It was exciting to be at the new VCCC in the same month as its opening and the visit by the US Vice-President Joe Biden. I was very impressed by this one billion dollar building. The open plan of the building around a central atrium meant that it was a place of light and modernity. The architecture was not dour or depressing, but rather, a place presenting opportunities for hope and happiness.

There were breakout spaces too. There was an indoor/outdoor café on the ground floor, apparently shared by patients, specialists and the public. The 7th floor café, The Loft, was even more impressive with its beautiful outdoor rooftop and joyful sculptures.

The attendees at this event were in the meeting and conference area of the building, also on the seventh floor, and the facilities were excellent. The VCCC is in the Peter Mac building and on this occasion we didn't visit the hospital itself. However if the hospital facilities match the other VCCC facilities that I saw, I think I would find any necessary stay at Peter Mac far less daunting than otherwise.

Marjie Courtis

Views of the VCCC



Clockwise from Top Left: Entrance to VCC, Atrium, Inside panel, Rooftop garden



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