

## MY HEALTH MATTERS PILOT PROJECT

### SUMMARY OF THE CANCER SOCIETY SOCIAL BEHAVIOURAL RESEARCH UNIT EVALUATION REPORT<sup>1</sup>

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In its ‘National Report: Preliminary Results from the 2009 Cancer Care Survey in NZ’ the Cancer Control Council of NZ reported on patient’s cancer care experience with the intention of using it to improve services in the future. The survey findings included support for the concept of a toolkit that could encourage patient involvement in their own care, contribute to an increase in a patients self-management of their condition, optimize their relationship with their health care team, and improve their understanding of the health information that they are given.

In response to this the Cancer Society of New Zealand developed ‘My Health Matters’, a patient diary toolkit that we piloted across the CSNZ Central Districts Division over an 18 month period that ended late in 2013.

In a parallel process we asked the Social Behavioural Research Unit (SBRU) at Otago University to undertake a formative evaluation of the toolkit to inform the ongoing development of this or any other patient diary toolkits in the future. While the evaluation provides some positive insights into the MHM toolkit, CSNZ does not intend to continue producing this resource for distribution as it considers there are a number of alternative resources available to patients at considerably less cost.

A summary of the SBRU report on the formative evaluation of ‘My Health Matters’ (MHM) follows.

The full report is available from the Cancer Society New Zealand, National Office or by emailing [admin.cancer.org.nz](mailto:admin.cancer.org.nz)

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<sup>1</sup> Evaluation of ‘My Health Matters’ report to CSNZ – Jean Simpson and Richard Egan, SBRU, Dept of Preventative and Social Medicine, University of Otago, March 2014

## Conclusions

Creating a toolkit such as MHM to engage people with cancer in their own care is a constructive concept and one that is supported in the literature. MHM is not, however, and was not designed to be, a resource appropriate for all patients.

In this evaluation we found that there is evidence to suggest:

- A patient diary toolkit can assist a person in self- managing their cancer care
- Dependent on the content of the toolkit, health literacy and confidence can be improved
- The diary had greater uptake than the journal, but those that used the journal, did so extensively
- The inclusion of storage capacity in the toolkit on the one hand, enabled patients to keep information in one place but conversely, but on the other, made the toolkit heavy and bulky. This can make it less desirable for those who were fatigued, ill, or would want something less obtrusive
- The toolkit was used by the patients' spouses, partners, children, grandchildren and friends.
- There is potential for an electronic or web based system.
- A functional relationship and good communication between the person with cancer and support services who provided the toolkit could facilitate better use it.

Cost versus the benefits of the toolkit should be considered in any future development.

## Key findings

People used MHM according to their own characteristics and circumstances. How people used the toolkit depended upon:

- Personal coping strategies, past experience and their personality
- The stage and severity of the cancer or the treatment
- Being fatigued in pain, or being very busy with treatment, reduced the engagement
- Information requirements ranging widely for newly diagnosed.

Most participants used MHM for a while then stopped:

- Nearly all evaluation participants used the MHM initially at least to some degree.
- Most participants were through their initial treatment within six months and did not use the MHM for long.
- Partners, significant others, family and friends also used the toolkit.

Some sections were used more than others:

- The information was usually read thoroughly but some felt that the information was too general and that they received better, more relevant information from CSNZ directly
- The section on questions for the medical team was valuable.
- The diary was usually used, sometimes very extensively.

Engagement with MHM:

- The toolkit was used for a relatively brief period in most cases.
- At six months post diagnosis very few were still using MHM as their treatment had stopped.  
Content of the Toolkit
- Overall MHM was considered a positive tool, the information was nearly always read, the content was considered good and should be retained if changes are made.

- Users of MHM need to be relatively literate.
- Some gaps in information were identified and there was overlap with other information provided by the Cancer Society and other agencies.
- MHM is a paper and pen-based resource, but many participants noted that they, or their significant other on their behalf, used the internet for further information.

#### People liked the design but not the format (size and weight)

- The overall pocket that held the diary and the journal was considered to be a good feature. There were some favourable comments about the ability to keep lots of other relevant papers in the folder.
- On the other hand, the size and weight of the folder was criticised by a number of participants.

#### The best time to get a copy of MHM was at diagnosis:

- The timing of the delivery of the toolkit to a patient was important. The best was at the time of, or soon after, receiving the initial diagnosis and before engagement with treatment services started.
- Having an ongoing contact available for the patient from where they received the toolkit was helpful.

#### MHM is largely a useful and empowering toolkit:

- It supported people to ask questions and gave them a sense of gaining control and being empowered.
- People could keep track of the medication and test results and did not have to remember this
- People could write their own experience and thoughts.
- Health professionals were mostly supportive of the concept of the toolkit as a good fit with patient-centred care.

#### A few changes to content, format and 'look' would improve MHM:

- Change the size and weight of the MHM and have choice in size of diary (and journal perhaps).
- Expand to using an electronic or web based version was considered worthy of further investigation.
- Content additions included information about surgery, pain management, recipes, hopes and fears, depression, perhaps palliative care and expand the audience to friends and family, especially children and grandchildren
- Make it look 'less posh' as this can be a barrier to some patients and could reduce the cost of production of the toolkit.

#### My Health Matters Pilot Project– the toolkit and its evaluation

CSNZ worked with a group of people who have experience of cancer to develop 'My Health Matters' (MHM) - a patient diary toolkit that includes features identified as important to patients and their carers in both the Cancer Control Councils survey and our own review of international literature. These features include a glossary of terms, a journal, a diary and information about cancer and related issues.

SBRU's evaluation of MHM was designed to:

1. Provide information on the extent to which the toolkit was able to make a positive contribution to the patients cancer care experience and
2. Gather feedback that could inform the ongoing development of either MHM or any other patient diary toolkit.

### **What the literature search told us**

The first stage of our (SBRU) evaluation was a comprehensive search and review of the international literature associated with patient dairies. Very quickly, the overarching concept of patient-centered care emerged as a priority focus in this work.

The concept of patient-centered care is widely discussed in the literature we examined but the complex nature of it means that there have been relatively few evaluations of strategies used to foster it. There are discussions about the complexity of the patient-health professional relationship, the variable use (and misuse) of medical jargon, and issues associated with the ownership of an individual's health information.

We found a number of evaluations on the use of diaries among people with cancer or other serious and/or chronic illnesses. Mostly these are not about diaries that are self-managed by the patient, but rather, those kept by others such as carers or health professionals on behalf of the patient when they are seriously unwell.

We found a correlation between a patient's level of health literacy and the uptake of patient dairies; we also found discussions on the role that diaries such as MHM can play in improving health literacy.

### **How we undertook our evaluation**

The evaluation was an 'improvement oriented evaluation' so it was aimed at identifying strengths and weaknesses of the MHM pilot toolkit to inform the development of this or any similar resources in the future.

We decided that a formative evaluation of the MHM was best addressed by using qualitative methodology that would provide information from cancer patients who had experience of using the toolkit.

The perceptions and experience of people with cancer were sought using an open-ended semi-structured interview schedule. This method ensured that critical aspects that we had not identified in our planning could be incorporated into the evaluation of the toolkit's performance.

This qualitative study was not designed to have its findings generalised to the population of people who have experience of cancer; nor to reflect a consensus view; nor assess the efficacy or effectiveness of the toolkit itself to achieve outcome measures for self-management, relationships with health professionals, or quality of life.

### **Distribution of MHM and selection of evaluation participants**

There were 250 toolkits available to be distributed across the Central Districts Division.

Potential evaluation participants were identified by staff that with the person's permission passed on contact details to the research interviewers. Responses were obtained from 18 participants who had cancer.

Approximately three months after receiving the MHM toolkit, individuals participated in an interview. After a further three months, a second interview was conducted by telephone with the majority of these participants. We asked the evaluation participants about the extent to which MHM contributed to their access to, and use of, cancer related information, their ability to self-manage their condition, and their relationships with their health care team.

We conducted individual interviews and had a discussion with a group of 12 health professionals across allied health, oncology, treatment services and community based organisations. The aim of this was to gauge their perceptions of the MHM, its value in their practice and the advantages and limitations they saw. We asked them what they thought was missing from the toolkit, or alternatively unnecessarily included in it.

Interviews were recorded, transcribed, then coded deductively from an initial set of items, then inductively based on the participants' narratives. Analysis generated a set of themes from which the findings have been drawn.

### **Ethics approval**

Ethical approval was granted through the Department of Preventive & Social Medicine by the Ethics Committee for the University of Otago.

### **Limitations of the evaluation**

The limitations of this study were partly set by the original scope of the evaluation. The aim was to investigate the value of the toolkit to people with cancer, and ascertain how they thought it did or did not contribute to their ability to engage positively in decisions about their treatment and to the management of their care. It was not to quantify the number of changes or measure the clinical outcomes resulting from the use of the toolkit.

As a qualitative study the findings do not claim to be representative of cancer tumour types of other 'populations'.

These findings give reliable and considered positions from the evaluation participants, providing valuable insight into the strengths and weakness of the MHM toolkit.

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