



My Cancer Care Record A consumer driven initiative

Issue:

Consumer members of the North Eastern Melbourne Integrated Cancer Service felt people affected by cancer should be:

- **More informed and actively involved in their own care**
- **Provided with more of their personally-relevant health information**
- **Better equipped to recall and communicate their cancer and other health-related information with health care professionals**

The group were keen to develop a resource to meet this purpose and also to drive the initiative.

Approach:

Consumers engaged on this initiative were supported and involved in all phases of resource development and implementation, including:

- **Initial identification of needs via consultation meetings**
- **Developing the program logic/work plan to identify project goals and intended outcomes**
- **Developing the terms of reference to engage clinicians on an advisory and implementation group**
- **Chairing the advisory and implementation group meetings**
- **Assisting in the preparation and revision of resource content**
- **Deciding on the overall folder design, logo and name - My Cancer Care Record**
- **Assisting in the evaluation of the resource and determining the relevant next steps**

Outcomes:

My Cancer Care Record folder has been developed.

The folder provides people affected by cancer with:

- **A place to organise and keep their medical and cancer-related information**
- **Tips on questions and information they might like to ask of health professionals**
- **A place to record and recall important details that are frequently asked.**

100 folders have been piloted with oncology patients across seven health services in north eastern Melbourne and four hospitals in the Loddon Mallee region of Victoria.

Surveys were disseminated to people who received the resource, to obtain their feedback and suggestions for improving the resource.

Feedback confirmed the resource is useful to patients and families for storing information and to help remember important medical details. Respondents also confirmed that it is ideal to receive such a resource before starting cancer treatment. Work is currently underway to address design aspects that will further improve the resource, before the next phase of implementation.

This initiative was driven by consumers who through their personal experiences, recognised the need for such a resource, advocated for its development and contributed their ideas, time and passion at every stage.

