

Abstract Form

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Title of abstract: Patient Information: helping people affected by cancer find the information they need

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Background:

People with cancer need appropriate information to address their concerns and help them be involved in their care.

While there is high quality cancer information available from reputable organisations, there is also a lot of less reliable information that people can find online. Poor health literacy can make it difficult for people to know the difference.

Aims:

The Cancer Institute NSW Patient Information site was developed to provide a portal to help people with cancer find trusted and reliable information relevant to their situation.

Key requirements included: informing users about optimal cancer care and the role of multidisciplinary teams; guiding them to existing quality information rather than replicating this; and mapping content for use with patient-reported measures programs.

It also provided an opportunity to bring together key resources for priority groups, including Aboriginal and Torres Strait Islander, multicultural, and rural and remote communities.

Method:

Preliminary steps included a literature search, and discussions with patients, carers and health professionals, to understand the information needs of people affected by cancer.

An iterative process was used throughout design and development, with personas, user journeys and a messaging architecture used throughout. Content review, usability testing and general feedback was provided by key stakeholders, including people affected by cancer and health professionals.

Partnership with the Cancer Council NSW was key to ensuring that users could be directed to appropriate information and support services.

Results:

The Cancer Institute NSW Patient Information site was launched in October 2018. It provides people affected by cancer with introductory information for particular situations, encourages them to ask questions and be involved in their care, and guides them to in-depth information from other reputable organisations.

Implications that impact on your project:

It is hoped the Patient Information website will assist people affected by cancer to understand their treatment options, feel more confident talking to their cancer care team, and be able to find the information and support they need.

Patient Information will also support the Cancer Institute NSW statewide patient-reported measures program, allowing cancer patients to receive tailored information in response to concerns identified in their survey responses.