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The Continuous Improvement in Care Cancer Project

Evaluating outcomes that matter most to patients, and improving care.

What is CIC Cancer?

The Continuous Improvement in Care Cancer (CIC Cancer) Project is a multi-institutional program of research that seeks to bring value-based healthcare (VBHC) to public and private healthcare settings in Western Australia (WA), using a model detailed in *The Health Advocate* in December 2017.

The project aims to create value through improving outcomes while containing costs (see www.ciccancer.com).

This is achieved through measuring and acting on variations in outcomes that are important for people diagnosed with cancer.

The results of combined clinical and patient-reported outcome measures will feed back into clinical management processes to:

- improve care;
- help determine needs for clinical intervention; and
- allow units to assess and improve their practices (see Figure 1).

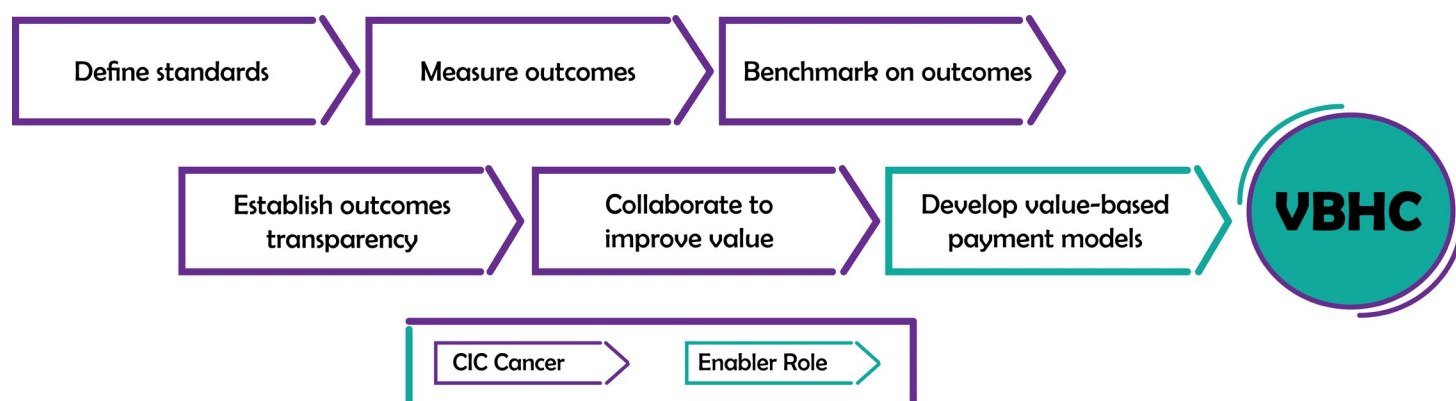
To the best of our knowledge, this is the first time that VBHC processes have been implemented simultaneously across multiple hospitals in both public and private healthcare sectors within Australia.



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“The needs of the CIC Cancer Project are complex and multi-dimensional—and the implementation of an effective engagement and informatics system is integral to successful measurement of outcomes for cancer patients.”

Figure 1: CIC Cancer role in VBHC in WA



The project has been under way for 18 months. In that time, many of the desired short-term outcomes have been successfully achieved and work is under way towards achievement of desired mid-range outcomes.

SHORT-TERM OUTCOMES

- Clinician and consumer engagement and input informs data collection and research needs.
- A secure and effective informatics infrastructure is in place that meets the needs of clinicians and consumers, and links to health services systems where possible.

MEDIUM-TERM DESIRED OUTCOMES

- Outcomes important to patients are measured and the information is used to benchmark and inform care provision across sites and the disease trajectory.
- The International Consortium for Health Outcomes Measurement (ICHOM) standard datasets are enhanced and improved through the results of WA trials.
- Consumer input informs priority-setting for research into improvements in care provision.
- New interventions are identified/researched/translated to practice to address

deficits/gaps and areas of unmet need in care pathways to ensure continuity of care and care outcomes meet optimal care pathways.

- Understanding of value-based health care is increased.

Stakeholder engagement

Five hospital sites, five tumour streams (colorectal, lung, breast, prostate and ovarian cancer), and nine lead clinicians working across the sites have been engaged. Support has also been secured from health care providers, data and information teams, key senior health service managers at each site or health service group, and WA Health.

In addition, a model is in place to successfully involve consumers in:

- the development of ovarian cancer patient-reported outcome measures (PROMs);
- acceptance of the data capture system across all tumour streams; and
- relevance of consumer-related key messages and communication pathways.

Local, national and international collaborations have resulted in increased access to expertise, implementation of associated research; and improved understanding of effective processes.

Data capture system development

A key component of CIC Cancer Project is the implementation of a single informatics system to capture both clinical and patient-reported outcomes (PROs).

A low-cost, easily adaptable, open source system is essential to ensure flexibility to incorporate additional data elements to support clinical and research work, and sustainability, and allow for future long-term uptake and ownership by public and private health services.

Development and deployment of a bespoke informatics system is under way following review

of commercially available applications, and a decision taken to undertake internal development. This builds on a framework currently used for other rare disease registries—the Rare Diseases Registry Framework¹—which allows registry administrators to construct web-based patient registries with minimal software developer effort.

The CIC informatics system will incorporate three components to collect and report on clinical and PROs data:

1. A 'Site System' housed within the health service intranet, to provide a repository for clinical information to be captured.
2. A 'PROMs Platform'—an external entity to complete PROMs. This information will be securely and regularly transferred into the 'Site System' and will allow clinicians to have a much better understanding of what matters to patients about their care and its outcomes.
3. A database for use by the research team, where de-identified data are securely transferred offsite to allow for analysis and evaluation.

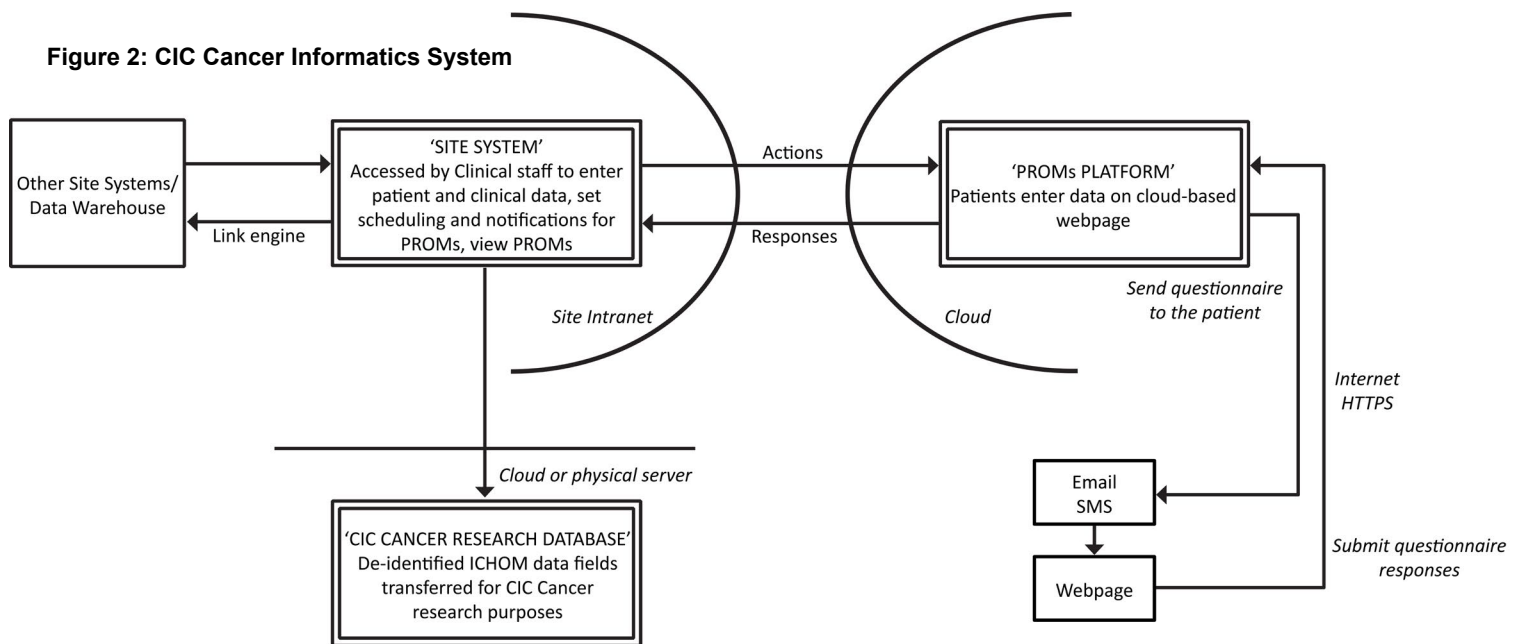
The informatics system is being built to allow functional integration with multiple, differing health services information platforms used within public and private health sectors in WA.

To ensure effective use of resources and long-term sustainability, the informatics system will push/pull data necessary to capture information from across the care pathway, and allow external analysis, while adopting open data standards. This will be achieved by installing it as an enterprise system for both the public and private health service providers involved.

Outcomes measurement

Dataset determination is under way using OECD-endorsed ICHOM standard datasets for colorectal, lung, breast and prostate cancer, amalgamated

Figure 2: CIC Cancer Informatics System



with clinician-requested additions such as mapping and integration with other clinical registries and psychosocial data items.


Both consumers (through focus groups and interviews) and clinicians have been fully involved in the development of a suitable standard dataset for ovarian cancer. The use of the EQ-5D-5L (EuroQol Group measure of health-related quality of life) has also been incorporated to allow for capture of change in quality-adjusted life years as part of the health economics evaluation incorporated into the research program.

Pilot involvement in the All. Can patient survey conducted internationally and within Australia has resulted in an initial understanding of patients' perspective on how the care experience could be improved, focusing on what matters most to patients.

The results, scheduled to be launched in May 2019, will be used to inform discussions with policy-makers on how to improve cancer care. This will bring the voice of the patient into the decision-making process, in an effort to ensure cancer policies focus on meaningful outcomes for patients.

Moving forward

The needs of the CIC Cancer Project are complex and multi-dimensional—and the implementation of an effective engagement and informatics system is integral to successful measurement of outcomes for cancer patients.

Lessons learnt from the initial 'bedding down' of the program are yet to be fully identified. These will be discussed in future updates. 

Reference

1. MI Bellgard, L Render, M Radochonski & A Hunter 2014. Second generation registry framework. Source Code for Biology and Medicine 9:14.

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