



**Title** Towards value based healthcare:  
Lessons learnt from implementing outcomes measures

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## Background

Value-based healthcare (VBHC) is an essential step change in how we deliver healthcare. It has been described as achieving outcomes that matter to patients relative to the costs of achieving those outcomes (Porter, 2010). To accomplish this, two key components must be implemented. Firstly, health care systems need to be realigned, and in some cases redesigned, to measure patient-relevant outcomes and capture the costs across the full cycle of care. Secondly, this data captured must be rigorously analysed and interpreted to tailor care to the needs of patients as well as adapt health cost funding models as required.

In Western Australia, we are embarking on a multi-institutional program of research that seeks to bring VBHC to cancer management in public and private healthcare settings. The project, known as The Continuous Improvement in Care – Cancer (CIC Cancer) Project, aims to create value by improving health outcomes while containing costs ([www.ciccancer.com](http://www.ciccancer.com)). The key to success, we believe, is good IT systems that will combine clinical information with Patient Reported Outcome Measurement (PROM) information, with analytics and visual support to ensure quick and easy support for clinicians.

In order to achieve this, the CIC Cancer Project is instituting routine measurement of combined clinical and PROMs which we will:

- feed back into clinical management processes to improve care;
- help determine needs for clinical intervention; and
- allow services to assess and improve their practices.

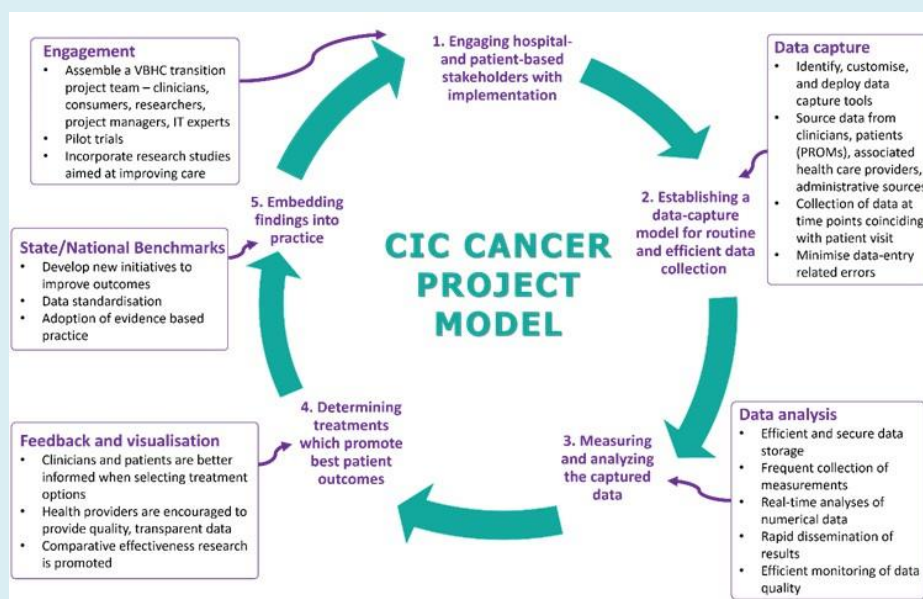
The results of this work will ultimately drive improvements in care and patient outcomes. To the best of our knowledge, this is the first time that VBHC processes have been implemented simultaneously across multiple hospitals in both public and private healthcare sectors within Australia.

The CIC Cancer Project involves a multi-dimensional approach that includes data capture and analysis to support clinical consultation and benchmarking as depicted in Figure 1. Integral to successful measurement of outcomes for cancer patients is effective engagement and development of an informatics system.

Drawing on the experience of the first 18 months of the project, we present our key learnings in four strategic areas which we hope will assist others embarking on the VBHC journey.

1. Planning and governance
2. Engagement and expectation management
3. Data issues
4. Information technology systems

Figure 1: CIC Cancer Project Model



## 1 Planning and governance

The first lesson when embarking on VBHC either as a research project or practice change is that project governance processes are almost always more complex and resource intensive than anticipated!

### *Multi-site issues*

Very few care pathways or indeed patient health experiences are limited to one health provider and site. Similarly, if the project has an academic component, it is likely that not all research expertise will be found at one institution. This means it is important, early in the process, to identify all the potential organisations that have the necessary components required to undertake the project and enter into multi-site project management, funding and legal agreements. These can delay any project for up to 12 months so need to be started immediately.

Equally, if ethics (for example, the Human Research Ethics Committee, HREC) and governance approval is required (as is mandatory for any project which is likely to lead to publication), it is likely that the requirements of public hospitals, private institutions and academic institutions will differ and not all organisations will offer reciprocal arrangements. There may also be differing needs for levels of consent between jurisdictions and institutions. For example, a private hospital may allow “opt-out” consent whilst public hospitals in Western Australia do not.

Furthermore, we plan to use the CIC Cancer information technology (IT) system developed within our project as the key platform for capturing Western Australian data for the national Prostate Cancer Outcomes Registry, which again has differing consent requirements. Understanding of ethics processes and resourcing of the ethics application process will be needed before any project can begin.

At the CIC Cancer Project we utilised logic modelling to identify desired outcomes and required outputs at the outset of the work, and allowed for sufficient mapping of potential work. This ensured that the research protocol and HREC applications addressed the wider potential, and limited need for resubmission for many of the program changes. Embarking on this also leads to unexpected spin-offs and benefits such as identification of multiple areas for collaboration and improvement when sites start to share practices.

## Learnings 1

- A complex and innovative project requires significantly more lead time than anticipated and delays have a ‘snowball’ effect.
- Ensuring adequate time, resources, and expertise are available for project management and good governance is vital, particularly as meeting the differing requirements of different health systems can result in a duplication of effort.
- Logic modelling can assist in providing a basis for program planning.
- Effective communication between the assembled multidisciplinary project team members to highlight issues and rapidly develop mitigation strategies.

## 2 Engagement and expectation management

Engagement of clinicians and health service management is vital to the success of VBHC, both for research and for long-term implementation into everyday clinical practice. Consumer input to the development and implementation phase of the project is also vital. Regular communication and interaction is required to raise awareness and maintain involvement.

### ***Risks to stakeholder engagement***

Moving timeframes and delays are key risks to maintaining stakeholder engagement and require careful management. Delays with ethics and governance, as outlined above, may well delay commencement of the project, risking a loss of engagement from stakeholders and increasing implementation costs. Delays may also occur because of frequent staff turnover within organisations - at the CIC Cancer Project, we encountered this in particular with IT staff.

It is likely at least some project personnel will be on time limited contracts or fellowships and so delays may mean they are unable to fully complete planned projects. While we originally planned to use the previously validated global outcome datasets, developed by the International Consortium for Health Outcomes Measurement (ICHOM) ([www.ichom.org](http://www.ichom.org)), we found we needed to adopt a more flexible approach and customise what data was to be collected. This was for several reasons that reflect the interests and desires of lead clinicians as a mechanism to induce them away from some other limited but pre-existing system, through to customisation required for each health sector and integration with their IT platforms. This was done by deep understanding of the requirements of a clinical unit and iterative manipulations of the dataset to ensure some consistency across tumour streams.

Each iteration requires consistency checks and testing, resulting in much greater development time than anticipated/planned. However, a better, more effective, and user-friendly end-product, with greater buy-in from clinical users who feel it is tailored to their needs will likely result from this additional work.

### ***Consumer engagement***

Consumer engagement needs to be more than lip-service as VBHC has patients at its core. The CIC Cancer Project has attempted this by involving experienced health consumer advocates from the onset of the planning process, and implementing a consumer reference group with sufficient diversity of social and cultural identities to be meaningful. Nevertheless, we experienced a 20% attrition in our groups due to other competing priorities, or the consumers feeling the desire to move on from the cancer diagnosis or in some cases experiencing disease progression and becoming too ill to participate.

Engaging consumers in focus groups can cause distress during discussions so it is important to ensure that mechanisms are in place to immediately address any grief or similar feeling. Linking focus group meetings to cancer support groups would address this but can be seen as contrary to support group principles.

Although often challenging, the qualitative nature of engaging consumers in focus groups has brought about a richness of information that would be otherwise unachievable. Those who participated have expressed a willingness to be further involved in the project depending on their health status. Within the research project, only English language surveys have been used and significant additional work will be required to include other languages for long-term use in everyday clinical practice.

## Learnings 2

- Realistic expectations about the potential for delays and implementation of effective communication streams are vital to maintain engagement.
- Full consumer involvement is ideal but may not be practical or achievable.
- Consumer and external support organisational involvement can be particularly challenging in terms of momentum.
- Formal identification of communication strategies during planning phases enhances efficiency and effectiveness of engagement activities.

## 3 The data challenge

When planning the CIC Cancer Project, we opted to use ICHOM standard datasets for colorectal, breast and lung cancer (Zerillo et al., 2017; Ong et al., 2017; Mak et al., 2016) and the Australia and New Zealand Prostate Cancer Registry database (PCOR-ANZ). In the absence of an ICHOM agreed dataset for ovarian cancer, the CIC Cancer Project is developing our own. The use of ICHOM datasets provides the benefit of internationally developed disease specific minimum datasets that enable comparability and benchmarking internationally.

The utility and translatability in different cultural and linguistic settings is a challenge for any standard data collection tools. Although the ICHOM datasets have included consumers in identification of appropriate and relevant PROMs, their generalisability outside “Western” populations is not known (Rajaram et al., 2018). While some of the questionnaires have now been translated into many languages, this isn’t the case for all the PROM tools that may be used within an Australian context.

The data customisation discussed above, while allowing individual users to accommodate their own interests, carries the risks of creating large and cumbersome surveys and may impact on completion rates. An important component of program evaluation will be to gain an understanding of the minimum number of variables required to adequately measure clinical and patient outcomes.

Clinicians are keen to minimise duplicate data capture and try wherever possible to capture information that will satisfy both the ICHOM standard set and any clinical quality registers in place locally, nationally or internationally. To this end, activities at the CIC Cancer Project have been undertaken to amalgamate and map the clinical variables required for these different databases. The Project opted to customise an informatics system based on an open source registry framework that has been used previously as both a clinical registry and patient-driven registry (Belgard M et al., 2017; Napier et al., 2017). The process of including the ICHOM standard datasets in this informatics system identified the need to:

- include additional date fields so that time periods between episodes can be determined;
- include additional data fields relevant to the WA health system for example whether a screening colonoscopy had been performed;
- modify how the variables were presented, this included moving the variables around so that they followed the patient journey or clinic workflows, thus making the dataset more intuitive to use;
- reword some of the questions and responses to allow for better interpretation while retaining the meaning of the question;
- include fields required for professional bodies audit datasets;
- combine or replace fields to work in with other data registry fields;
- update ICHOM standard sets to accommodate the most recent American Joint Committee on Cancer staging systems. Although ICHOM are doing this themselves this is proving slow; and
- although the PROMS variables from the ICHOM standard set have been adopted as a whole, data mapping identified that the clinical variables across these different data models employed different nomenclature for anatomical location categorisation, surgical techniques, and adjuvant treatment regimes. This will require additional software coding to allow for cross population of databases.

For example, although we planned to utilise the standard set defined by ICHOM at the outset, for colorectal cancer, we also wanted to meet the requirements of the Bi-National Colorectal Cancer Audit. However, neither dataset fully accounted for local process variations and adherence to national or international best practice guidelines. This has necessitated incorporation of even more variables.

Finally, we have had to plan from the outset how we will measure the flip side of the value equation in VBHC – the costs of delivering the outcomes we achieve. In order to facilitate this, the CIC Cancer Project has included the EQ-5D instrument into the PROMs survey.



An understanding of quality-adjusted life years (QALYs) gained will allow comparison of the benefit and cost of health care programs or interventions when undertaking cost-utility analysis and is widely accepted by policy makers. However, this does lead to some duplication with near similar questions in other PROMs, necessitating inclusion of additional text to notify patients of the reasons behind the seemingly repetitious questions.

### Learnings 3

- Flexibility and adaptability are necessary to meet differing information management and interoperability requirements of sites, information flows and clinicians.
- A level of adaptation of standardised datasets is required to meet local conditions and enable practical implementation.
- It is important to work through processes to identify data needs and make any necessary adjustments prior to commencement of data collection. This will assist in maximizing consistent data collection over time, reduce the need for changes to IT systems, minimise re-training requirements and limit potential for errors.

### 4 Information technology systems

Following identification and mapping of data needs and flows, as discussed above, we opted to develop a bespoke web-based informatics platform to collect/extract/integrate data to enable purposeful application of the collected information. This open source solution incorporates the full ICHOM standard dataset, as well as customisation and adaptation to meet specific clinical needs of any tumour stream or site, and potential to be fully integrated into existing health department or private hospital systems. A review of commercially available systems identified that none appeared capable, at the time of review, of fully meeting the complex needs of the project. All commercial systems considered required supplementary work to integrate into the differing needs of sites and information flows, reducing the cost effectiveness or long-term sustainability of any commercially available application.

#### *IT governance*

Differing IT governance requirements between the public and private health sectors have resulted in significant duplication of effort to introduce our CIC Cancer informatics platform as an enterprise system and integrate this to other enterprise systems. Many enterprise systems are unique to the specific environment – public hospital, private hospital and clinician’s private rooms. However, engagement by health service providers and policy makers has been significant, with both private and public health services keen to accept and integrate CIC Cancer into existing systems and infrastructures.



Data custodians of current enterprise systems are willing to share data and work together to improve data collection and limit duplication of effort. Early and thorough preparation of a comprehensive risk management plan is vital in adequately meeting IT governance requirements relating to data protection and privacy.

One key feature of the Australian health system is that patients move between care providers – private diagnostic services, public surgical units, private radiation oncology practices, etc. The best way of identifying patients who move between public and private settings during their treatment and collecting data from diverse places, has not yet been identified.

An understanding that it is impossible for tech-based projects to be concurrently fast, good, and cheap assists in managing the inevitable delays associated with informatics system development. Use of an agile process methodology of building, testing, and learning assists in managing changing needs and adaptations as the work evolves. Effective utilisation of any timeline deferments through ongoing refinements to the usability of the dataset, in consultation with users, has improved the final product and will ultimately save development costs. Clinical knowledge is of significant benefit when preparing the dataset and ensuring the IT staff work closely with clinicians is vital.

## Learnings 4

- Commercial data collection systems may not fully meet complex tailoring, integration and linkage requirements and may therefore be a more expensive option than an easily adaptable, open source system that allows for future, long-term uptake and ownership by the public and private health services.
- Significant timeframes are required to introduce new IT systems to health settings.
- Implementation of good project management practices and involvement of clinical knowledge and health system awareness are important when seeking to develop and introduce new IT systems.

## Conclusion

Implementing VBHC is a long-term commitment that has major change management implications. It takes engagement, planning, succession planning over a long-time course and resources. It is important to be flexible to the needs of the users. Perhaps the most challenging part of implementation is developing and adapting IT systems to allow the collection, storage, analysis and dissemination of data, to ensure this model of care becomes part of our normal clinical pathways.

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