



Continuous  
Improvement in  
Care *cancer*

# CIC Cancer Annual Report December 2018



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### Abbreviations

DoH	Department of Health
FSH	Fiona Stanley Hospital
HREC	Human Research Ethics Committee
HSS	Health Support Services
KEMH	King Edward Memorial Hospital
PROMs	Patient reported outcome measures
RPH	Royal Perth Hospital
SJoG	St John of God
VBHC	Value based healthcare
WACaPCN	WA Cancer and Palliative Care Network

The Continuous improvement in Care – Cancer (CIC Cancer) Project is progressing well and successfully achieving early outcomes and work is underway towards achievement of mid-range outcomes. This report will outline the progress to date, in detail, against both the desired outcomes and the milestones/KPIs and reporting requirements listed in the funding agreement. In summary, however, the results (Table 1) are as follows. Items marked with a tick are completed or achieved.

Table 1: Results ladder

	Activity theme	Achieved	In progress	Expected
Short term outcomes/ Outputs	Stakeholder engagement	<ul style="list-style-type: none"> <li>✓ 5 sites</li> <li>✓ 5 tumour types</li> <li>✓ 8 clinical champions</li> <li>✓ Consumer Ref. Group</li> <li>✓ Website</li> <li>✓ Steering Committee</li> </ul>	<ul style="list-style-type: none"> <li>✓ Survey/focus groups for PROMs development in ovarian cancer</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Priorities are set for ongoing clinical research work and improvements</i></li> </ul>
	IT system	<ul style="list-style-type: none"> <li>✓ Discussions with senior informatics personnel in WA Health, Cancer Registry and SJoG</li> <li>✓ Evaluation of commercially available PROMs systems</li> </ul>	<ul style="list-style-type: none"> <li>✓ Under construction – beta version in place</li> <li>✓ Request for site integration underway</li> <li>✓ Testing has commenced with colorectal cancer at SJoG Midland</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Linkages with current hospital data capture systems</i></li> <li>• <i>Effective and efficient capture of data</i></li> </ul>
	Research/ Funding/ Students	<ul style="list-style-type: none"> <li>✓ 5 sub-projects commenced</li> <li>✓ Additional \$1.19 m secured (27% ↑ CRT\$)</li> <li>✓ 1 student; 1 fellowship</li> </ul>	<ul style="list-style-type: none"> <li>✓ Advocacy activities to secure further funding</li> <li>✓ Register of potential opportunities for students</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Enhanced access to funding for VBHC</i></li> <li>• <i>Health outcomes specific capacity and collaboration enhanced</i></li> </ul>
	Ethics	<ul style="list-style-type: none"> <li>✓ HREC approval</li> </ul>	-	-
	Collaborations	<ul style="list-style-type: none"> <li>✓ 13 different groups</li> <li>✓ COSA Think Tank</li> <li>✓ ICHOM, All.Can, OECD</li> </ul>	<ul style="list-style-type: none"> <li>✓ All.Can Aust Steering Committee</li> <li>✓ Early discussions with BUPA</li> <li>✓ Discussions with GIRFT</li> </ul>	<ul style="list-style-type: none"> <li>• <i>WA results enhance ICHOM standard datasets</i></li> </ul>
	Publication	<ul style="list-style-type: none"> <li>✓ 2 publications and 3 conference presentations</li> <li>✓ 3 Citations + 1 mention</li> <li>✓ 12 seminars</li> </ul>	<ul style="list-style-type: none"> <li>✓ Communications plan</li> </ul>	<ul style="list-style-type: none"> <li>• <i>International VBHC conference held</i></li> </ul>
Medium term outcomes	Outcomes measurement and analysis	<ul style="list-style-type: none"> <li>✓ 4 cancer datasets in place</li> <li>✓ Project concept for patient pathway mapping project</li> <li>✓ Baseline data from involvement in international patient experience survey (All.Can pilot in WA)</li> </ul>	<ul style="list-style-type: none"> <li>✓ Dataset for ovarian cancer in development</li> <li>✓ Integration with existing clinical registries underway</li> <li>✓ Investigation of WA lung registry underway</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Benchmarking to inform care provision</i></li> <li>• <i>New interventions are identified/researched to address deficits/gaps/unmet need</i></li> <li>• <i>Comparison of outcomes to optimal care pathways</i></li> <li>• <i>Patient assessment of service</i></li> </ul>
	Economic analysis	<ul style="list-style-type: none"> <li>✓ QALY Instrument identified</li> </ul>	<ul style="list-style-type: none"> <li>✓ Health economics discussions in place</li> </ul>	<ul style="list-style-type: none"> <li>• <i>Cost effectiveness measured</i></li> </ul>
Longer term outcomes	Implementation as best practice	-	-	<ul style="list-style-type: none"> <li>• <i>Outcome datasets adopted as best practice</i></li> <li>• <i>Measurable improvements in care and cost effectiveness</i></li> </ul>

# Measurement of the success of the project - achievement of desired outcomes

The desired outcomes for the project reflect the impact sought as a result of the work implemented. These outcomes, together with the required inputs and outputs, have been diagrammatically represented in a summary logic model (Figure 1). As some of the phases of the program sit across 5 years, these are not logically mapped against the outcomes. As such, the relevant phase has been noted alongside the outcomes listed below.

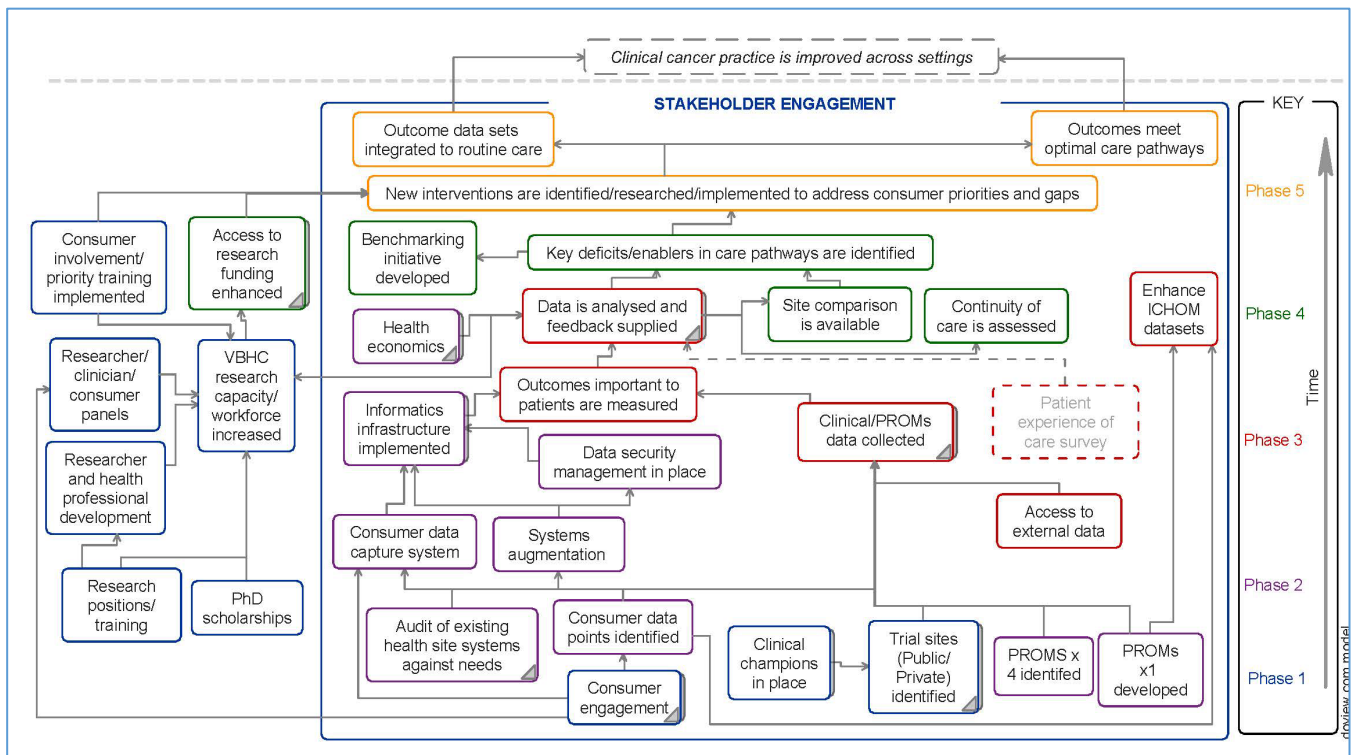


Figure 1: CIC Cancer Logic Model

## 1. Short-term outcomes/outputs (1-2 years)

The outputs, or short-term outcomes, of the project are:

- Clinician and consumer engagement and input informs data collection and research needs. (Milestone/KPI Phase 1)
- 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. (Milestone/KPI Phase 2)

Additional outputs of the project include:

- Inclusion of additional projects within the overall program of research and access to additional funding.
- A definition of datasets for each nominated tumour type (Milestone/KPI Phase 2)
- Human Research Ethics Committee approval for the work (Milestone/KPI All Phases)
- Collaborations locally, nationally and internationally (Milestone/KPI All Phases)
- Publications, presentations, including scientific, policy and consumer (Milestone/KPI All Phases)
- Students trained (Milestone/KPI All Phases)

## 1.1 Stakeholder Engagement

A Communications Plan has been developed to inform effective stakeholder engagement activities. This is a dynamic document that will be updated and amended as required. The plan outlines the planned communication activities designed to:

- 1) engage and involve clinicians, trial sites, and consumers in the CIC Cancer Project and associated program of research;
- 2) ensure that the work of the project contributes to the body of knowledge and encourages new research; and
- 3) contribute to improvement in clinical practice through routine capture of outcomes important to patients, their families, and significant others.

In order to ensure consistency of the 'look and feel' of the program and maintain the narrative, branding guidelines have also been developed and circulated to investigators and project partners.

### **1.1.1 Service/clinician/tumour stream engagement**

Five hospital sites have been engaged: St John of God (SJoG) Subiaco (a private hospital), SJoG Midland Hospitals (private/public partnership) and Royal Perth, Fiona Stanley, and King Edward Memorial Hospitals (tertiary public hospitals). All nominated tumour streams have been engaged. Meetings have been held with both clinical and key senior health service management personnel at each site or health service group.

Eight lead clinicians working across the five sites are involved in the project at this time (Figure 2). They have each taken on the role of 'clinical champion' for the cancer type under consideration at each site. Regular communication is in place to ensure that these clinicians are informed of progress and key documentation has been supplied to them for review and comment. Each of the clinical champions has been named in the HREC applications as an Associate Investigator.

A series of meetings have been held with Dr Mary Theophilus, colorectal surgeon at RPH and SJoG Midland, and her team to identify data needs and prepare for commencement with colorectal cancer as a 'test bed'. Colorectal cancer at SJoG Midland will be the first site and tumour type to collect data with collection commencing in late 2018.

Several meetings have also been held with Dr David Manners and his team at SJoG Midland to integrate the CIC Cancer work with that of the pilot study into a clinical quality registry for lung cancer.

To date 70 introductory or engagement activities/events/meetings/presentations have taken place. The most successful presentation to date was provided to clinicians at Sir Charles Gairdner Hospital during Research Week. A lot of interest in the work was generated; with one group requesting further information about how they can measure outcomes for a pilot clinic they are setting up to serve adolescents with complex multisystem disorders without clearly mapped transition pathways. On hearing about the CIC Cancer work they are very keen to work together so that learnings can be maximised, and duplication minimised.

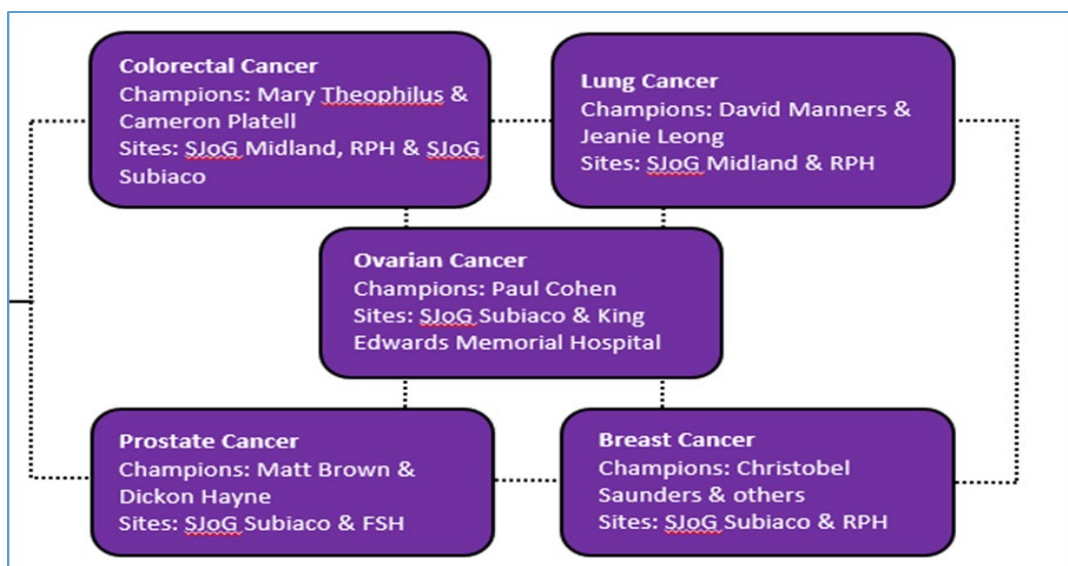


Figure 2: Sites, champions and tumour types

### **1.1.2 Consumer engagement**

A consumer engagement model is in place. This will consist of a Consumer Reference Group and 'research buddies'. Invitations have been called and applications received and vetted ready for commencement of the group. Their first task will be to provide input into the patient reported outcome measurement (PROMs) data capture system and the consumer related key messages and communication pathways incorporated into the draft Communications Plan.

A 2.5 hour long 'community conversation' was held with participants from the WA Ovarian Cancer Support Group on 27/08/18. The purpose of this event was to understand the 'lived experiences' of women with ovarian cancer and their carers, so as to inform the development of a dataset for ovarian cancer. There were eight attendees (6 ovarian cancer survivors and 2 spouse carers) across two tables of facilitated discussion with notes taken for a report of key themes from participants. These themes will be used to formulate focus group questions for the next step. Participants also provided input into the content, delivery timing, and mode as well as the preferred format of the survey planned for a series of focus groups planned for early 2019. An ethics application for this additional work is underway.

### **1.1.3 Other engagement activities**

A series of activities have been undertaken to enhance engagement with all stakeholders.

#### **Promotional and Marketing collateral**

A dedicated CIC Cancer website ([www.ciccancer.com](http://www.ciccancer.com)) is in place. This provides targeted information for consumers, health professionals, and researchers. The website is a work in progress and we will continue to make changes as the project progresses.

Promotional collateral such as information flyer has been produced and is available for download via the website.

#### **CIC Cancer Steering Committee**

A CIC Cancer Steering Committee has been put in place with meetings held every three months. To date four meetings have been held. The committee is primarily made up of investigators on the

project. Additional expertise is invited to attend committee meetings as required. Terms of reference are in place.

As advised, the initial membership of the committee has altered with Dr Andrew Yeates stepping down as an investigator due to a change in role. Andrew's involvement in the CIC Cancer Steering Committee has been taken up by Dr Alexius Julian, Chief Medical Information Officer. Grahame Bowland of Murdoch University has taken the committee place previously held by Dr Kathryn Napier, following her resignation from Murdoch University.

A change of position for one of the investigators subsequently required changes to the multi-institutional agreement between partner universities. This necessitated additional legal review across all sites and resulted in deferrals in invoicing processes. Work was unaffected, and activities continued during this period but processes to transfer funds between partners were delayed.

## 1.2 ICT system development

### 1.2.1 System design and creation

Deployment of an informatics system is underway, based on an open source clinical and patient-centred registry framework. This will collect clinical and patient-reported outcomes data for people with cancer. This includes a 'site system' that is housed within the site intranet, providing a repository for clinical information to be captured. This will be linked to an external entity that allows patients to record their patient-reported outcome measures - 'PROMs platform'. This information will be securely transferred into the 'site system' regularly to allow for discussion with patients during consultations. This connection of information not previously captured will allow clinicians to have a much better understanding of what matters to patients about their care and its outcomes. The last part of the system is a database for use by the research team. De-identified data will be securely transferred offsite to this 3rd component to allow for analysis and evaluation of the data. Figure 3 depicts the interaction between CIC Cancer system components themselves and current health information systems. A short video of the beta version (as at mid October 2018) of the system is also available at [https://www.youtube.com/watch?v=Og3hqNC\\_kVA&feature=youtu.be](https://www.youtube.com/watch?v=Og3hqNC_kVA&feature=youtu.be).

The aim is to obtain access to relevant data within current hospital systems in order to minimise duplication of data entry. Successful meetings with system architects from both Health Support Services (HSS) and St John of God Healthcare have been held and documentation for concept approval has been submitted to both sectors. Successful meetings have also been held with senior health informatics personnel at:

- Department of Health – Patient Safety and Quality Directorate;
- East Metropolitan Health Service – Area Director Data and Digital Innovation;
- WA Cancer Registry; and
- WA Cancer and Palliative Care Network.

Some slight delays were also experienced with the informatics system architecture following the resignations of key personnel from Murdoch University. However, the use of 'sprint' episodes of development and completion of tasks in a parallel, rather than linear, mode has addressed these delays. Work is focusing on the PROMs collection component first as this is considered the largest gap in information currently available.

Planned work on the informatics system over the next 12 months includes:

- refinements to the PROMs Platform;
- enhancement and further development of notifications and scheduling system in the Site System;
- development of 'skip logic' and conditionality in the Site System;

- development of the CIC Cancer Research Database;
- export of the ICHOM data elements to the CIC Cancer Research team;
- beginning integration of the CIC Cancer system to the current hospital systems and other relevant systems such as the Cancer Registry; and
- refinements as required.

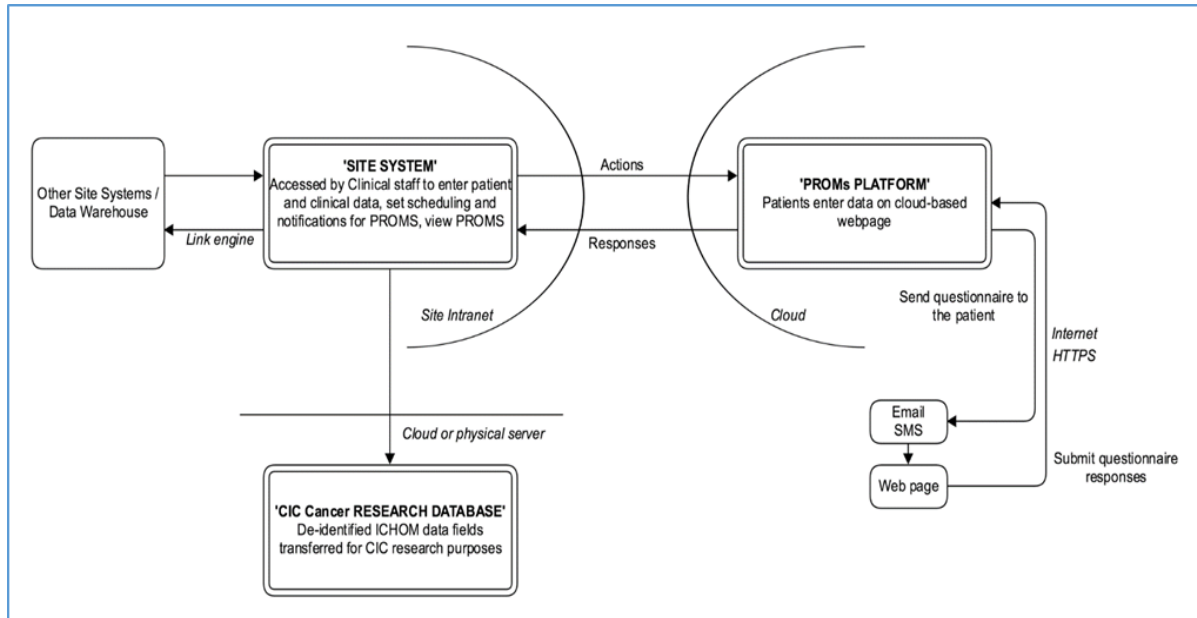


Figure 3: CIC Cancer Informatics system components

### **1.2.2 Market review**

It was recognised that there are a number of commercially available ‘off the shelf’ PROMs systems on the market. In order to ensure that internal development of this component of the system was an effective course of action, a formal review of the use of commercially available systems was undertaken. This evaluation, however, found that these didn’t easily meet the complex tailoring, integration and linkage requirements of the project and would generally be much more expensive. A formal report is available should this be of interest.

### **1.2.3 Defined datasets for each nominated tumour types**

The standard datasets for colorectal, lung, breast and localised/advanced prostate cancer developed by International Consortium for Health Outcomes Measurement (ICHOM, [www.ichom.org](http://www.ichom.org)) are in place. These have been developed by an international group consisting of leading physicians, measurement experts and patients and consist of questions related to disability of health, degree of health, survival and disease control, and quality of death.

Work is underway to define a set of relevant and appropriate patient reported outcomes for ovarian cancer using a qualitative approach. This will be achieved through an extensive literature review and a series of focus groups to be conducted with women and their significant others who have experienced ovarian cancer. The focus group data and subsequent findings will inform a set of patient reported outcomes for ovarian cancer based on what is important to patients, their carers, and clinicians. The workings of the research team is guided by the process developed by ICHOM to establish standard sets for the other four cancer types in the project. It is hoped that the work undertaken for ovarian cancer will inform ICHOM and form the basis for an internationally recognised standard set.

Additional data items – over and above those included in the ICHOM datasets – have been requested by some of the clinicians, particularly in relation to national clinical surgery audit requirements. The aim



is to ensure that the system meets the needs of the clinicians and, where feasible, is tailored to their requirements so additional clinical items are being added where appropriate. Work is underway to map these additional data variables for colorectal cancer and integrate these with ICHOM dataset. Testing of the datasets and informatics system has commenced at St John of God Midland Hospital in colorectal cancer.

### 1.3 Additional Research Projects/Funding

#### 1.3.1 Sub Projects

In addition to the overarching project, within this program of research there are now a further five sub-projects underway. These include:

- *Implementing ICHOM Breast Cancer Dataset - Feasibility Pilot Study.*  
This is a sub study that will undertake pilot testing of the uptake of patient-reported outcomes measurement (PROMs) by women with newly diagnosed breast cancer at Perth Specialist Breast Care (PSBC) clinic at St John of God (SJoG) Subiaco Hospital.
- *Continuous Improvement in Care - Cancer: moving towards the first Western Australian lung cancer Clinical Quality Registry.*  
The primary aim of this sub-project project is to conduct a pilot study into the use of the ICHOM Lung Cancer Standard Set in a Western Australian population in order to develop a clinical quality registry that has utility both for improving patient care and enabling further research. This was one of 6 clinical fellowships offered for 2019.
- *Continuous Improvement in Care – Cancer: Identification of WA specific data variables for colorectal cancer.*  
This short-term project seeks to work with the Continuous Improvement in Care (CIC) Cancer investigators, informatics experts, clinical champions, and consumer groups to identify clinical data requirements and Patient Reported Outcome Measures (PROMs) specific to colorectal cancer within WA in preparation for completion of data capture tools and data collection across Royal Perth Hospital, St John of God Healthcare - Midland and Subiaco Campuses.
- *Patient Reported outcome measures (PROMs) in Colorectal Cancer Surgery*  
This sub-project enabled purchase of laptop computer hardware and tablets for use by clinicians and patients for data entry into the web-based registry.
- *CIC Cancer - Ovarian Cancer Focus Groups*  
This sub-project has been implemented to inform the development of the ovarian cancer dataset through distribution of a survey and conducting focus groups in WA and interstate to access consumer input.

#### 1.3.2 Grant Funding

These additional projects have also attracted additional external grant funding with more than \$180,000 secured from the WA Cancer and Palliative Care Network (WA Department of Health) since June 2018.

Table 2: Grants awarded

Funder	Funding (\$) excl GST	Period	TOTAL
WACaPCN DoH	\$18,029.35	2018	\$18,029.35
WACaPCN DoH	\$10,454.55	2018	\$10,454.55
WACaPCN DoH	\$150,000	2018	\$150,000

In addition:

1. Two grants were applied for and not awarded.

- a. 2017 Research Impact Grant from UWA
  - b. 2017/18 Collaborative Cancer Grant Scheme for early to mid-career investigators from Cancer Council WA
2. A further 10 opportunities have been carefully considered and a decision made to not to apply as it was deemed that an application would have very limited chance of success or the project is not yet progressed enough to identify a sufficiently robust project concept for the application.
  3. Advocacy activities have been undertaken on 4 occasions this year. This involved written responses to consultative opportunities (e.g. Medical Research Future Fund, Future Health Research Innovation Fund) or involvement in priority setting events (e.g. Digital Health Co-operative Research Centre Funding).

### **1.3.3 Funding from sources other than CRT**

In addition to the CRT grant, total 'matched funds' of \$1,190,000 (excluding in-kind) have been accessed from all partner organisations.

This, combined with the additional grants secured as at the time of reporting, equates to 27% increase on CRT funding.

*Table 3: Additional funding secured*

<b>Funder</b>	<b>Funding (\$) excl GST</b>	<b>Period</b>	<b>TOTAL</b>
Cancer Council WA	\$50,000 pa	5 years	\$250,000
UWA Research Office	\$50,000 pa	5 years	\$250,000
Cancer and Palliative Care Research and Evaluation Unit (UWA)	\$50,000 pa	5 years	\$250,000
Notre Dame University	\$20,000 pa	5 years	\$100,000
Murdoch University	\$20,000 pa	5 years	\$100,000
Curtin University	\$20,000 pa	5 years	\$100,000
St John of God Subiaco	\$28,000 pa	5 years	\$140,000

## **1.4 Ethics Approval**

A delay in seeking ethics approval for the project led to a variation from desired timeframes across several aspects of the project resulted. This impediment in ethics submission resulted from unavoidable delays in recruiting the Program Manager, a pivotal position in preparation and submission of the ethics applications. This has had a flow-on effect with resultant delays to participant recruitment.

Ethics approval was obtained from both the public and private sectors in late 2018 and colorectal cancer participant involvement will be trialled in November/December 2018, to ensure that any unforeseen issues are identified and managed prior to a rollout to lung cancer patients.

### **1.4.1 CIC Cancer - WA Health**

Ethics approval has been received from South Metro Health Service Human Research Ethics Committee (HREC) for the overarching program of work. This approval excludes the use of opt-out consent. In addition, requests for Governance approval have been submitted.

### **1.4.2 CIC Cancer - St John of God Health Care**

HREC approval has been received from St John of God (inclusive of opt-out consent) subject to receipt of the required legal agreement.

### **1.4.3 Implementing ICHOM Breast Cancer Dataset - Feasibility Pilot Study sub-project**

Ethics approval has been obtained for this sub-project, subject to receipt of the required legal agreement.

#### **1.4.4 Development of Ovarian Cancer Dataset sub-project**

Ethics documentation for this sub-project has been submitted.

### **1.5 Collaborations locally, nationally and internationally**

Nineteen opportunities for in-depth collaboration have been realised. These have included areas such as:

- local liaisons with sites not currently involved and research/health policy groups with areas of expertise that can inform the project (e.g. HUB - Health Research and Data Analytics);
- discussions and contribution to activities for national bodies such as Australian Commission on Safety and Quality in Health Care, Aust. Healthcare and Hospitals Association, Bowel Cancer Australia, and Clinical Oncology Society of Australia (COSA), Ovarian Cancer Australia, and Cancer Council WA;
- early discussions with BUPA about how we can collaborate;
- meetings with 'disease leads' in the NHS Get It Right First Time (GIRFT) project about shared learnings; and
- meetings and contribution to activities for international groups such as ICHOM and All.Can.

#### **1.5.1 All.Can**

All.Can is an international patient-focused initiative that aims to gather insights from the cancer community and sharpen the focus on delivery of care truly of value to patients. The Australian chapter (1 of 9 around the world) plans to identify improvements to the cancer patient care pathway through the healthcare system. The overarching goal for All.Can is to help contribute to sustainable resource allocation in cancer care so that funding is directed to interventions which create the most value for patients. This reflects the global reforms in healthcare that are moving away from volume-based care and focusing on improving patient outcomes.

A survey was distributed to 10 countries to identify common issues cancer patients experience and gain patient's perspective on how the cancer care experience could be improved to shape recommendations to improve care in Australia. The CIC Cancer project sought a targeted link so that results could be attributed to WA to provide a baseline (also see section 2.1).

Discussions are in place about CIC Cancer joining the Steering Committee for All.Can Australia.

#### **1.5.2 COSA**

Input was provided to the Clinical Oncology Society of Australia (COSA) Survivorship Group in August 2018 Think Tank – a workshop undertaken to start the process of developing a roadmap to support implementation of patient-reported outcome (PRO) monitoring into clinical cancer care in Australia. The Think Tank brought together 32 participants, representing clinical, research, consumer and policy perspectives from across Australia; providing an opportunity to review available evidence, identify considerations for implementation at patient, service and policy levels, and highlight opportunities for collaboration and action. A report will be made available shortly.

#### **1.5.3 BUPA**

Early discussions have been held with Cindy Shay, Director of Health Partnerships and Innovation and Zoe Wainer, Head of Public Health Customer Experience, Health Insurance at BUPA. Further discussions will be held when they travel to WA in December 2018.

#### **1.5.4 GIRFT**

Meetings have been held, both in Australia and the UK, with senior clinical leads (Dr Fiona MacNeill, Dr Maire Morton, and Prof Tim Briggs) involved in the NHS Improvements' GIRFT program. This is a national program designed to improve the quality of care within the NHS by reducing unwarranted

variations. By tackling variations in the way services are delivered across the NHS, and by sharing best practice between services, GIRFT identifies changes that will help improve care and patient outcomes, as well as delivering efficiencies such as the reduction of unnecessary procedures and cost savings. They have not yet implemented PROMs in the program so we hope to share learnings across both programs.

## 1.6 Publications, presentations, both scientific, policy and consumer

In addition to capturing the level of engagement undertaken, a register has been implemented to measure promotion of the project through publications and presentations.

- Johansen NJ, Saunders CM. Value-Based Care in the Worldwide Battle Against Cancer. Muacevic A, Adler JR, eds. *Cureus*. 2017;9(2):e1039. doi:10.7759/cureus.1039.
- Slavova-Azmanova, N., Johansen, N., Saunders C., Ives, A., *Patients First: The Continuous Improvement in Care Cancer Project in Western Australia*. The Health Advocate, Iss. 45, Dec 2017, pp. 34-35.
- Poster presentation at the International World Hospital Federation World Hospital Congress in Brisbane in October 2018 – ‘Placing Patients First - The Continuous Improvement in Care - Cancer (CIC Cancer) Project’
- Poster presentations at the Clinical Oncology Society of Australia annual scientific meeting held in Perth in November 2018.
  - ‘When is ‘enough’ data really too much? Data capture in the CIC Cancer Project’ and
  - ‘Measuring what’s important to our patients: The Continuous Improvement in Care - Cancer (CIC Cancer) Project’

A further 13 seminar style presentations have been given to events such as Science on the Swan; Royal Australian College of Surgeon meetings; Value based Health care Summit; Cancer Council WA public lectures; hospital research week functions; COSA pre-conference workshop, and Australian Health Care Association events.

### 1.6.1 Citations

A review of citations for peer reviewed journal articles indicates three citations to date.

Table 4: Citations

Article	Citations as at 31 October 2018
Johansen NJ, Saunders CM (2017)	3

An article was published in the Australasian Society for Breast Disease Update (*Measuring outcomes that matter to patients – ICHOM and Value-based Health Care*, Elder, E., Ed. No. 14, August 2018) by the head of research at the Westmead Breast Cancer Institute in NSW that referred to the CIC Cancer project work as a solution to the issue of effective outcomes measurement in cancer.

## 1.7 Students trained

There is currently one fellowship position and one medical student involved in the CIC Cancer program of work. A bank of potential projects is being set up for efficient access and uptake as student-based opportunities arise.

## 2. Medium term outcomes (2-5 years)

### 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. (Milestone/KPI Phase 3)
- The ICHOM standard datasets are enhanced and improved through the results of WA trials.
- Consumer input informs priority setting for ongoing clinical research work and improvements in the value of 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. (Milestone/KPI Phase 4)
- Access to research funding is enhanced through improved understanding of value-based health care and increased capacity and collaboration of the health outcomes specific research workforce.

### Additional outputs of the project include:

- ICT systems and personnel operating at each hospital in each nominated cancer (Milestone/KPI Phase 3)
- Capture of relevant PROMs for each nominated tumour type at each hospital (Milestone/KPI Phase 3)
- Data captured on patients treated at nominated institution p.a. (by treatment) (Milestone/KPI Phase 3)
- Numbers of patients with the nominated tumour types involved in the study across participating hospitals (Milestone/KPI Phase 3)
- Full documentation of clinical tumour stage (Milestone/KPI Phase 3)
- Evidence of treatment based on relevant optimal care pathway (Milestone/KPI Phase 4)
- Patient assessment of service in place (Milestone/KPI Phase 4)
- Novel interventions, positive results and translations into clinical care demonstrated in each tumour type at each hospital (Milestone/KPI Phase 4)
- Improvements in care demonstrated including disease-free survival after primary treatment, decreased rate of in-hospital death from surgical complications, demonstrated improvements in areas of unmet need (Milestone/KPI Phase 5)
- Cost effectiveness measured (Milestone/KPI Phase 5)
- International conference hosted (Milestone/KPI Phase 5)

### 2.1 Outcomes Measurement

ICHOM datasets will be used for lung, colorectal, breast and prostate cancer. The fifth dataset (ovarian cancer) is under development as part of this project.

Following any required modifications from the colorectal cancer trial at Midland hospital, data collection will be rolled out across the remaining cancers and sites. Ongoing modifications will be made as each site and tumour type is brought on.

#### **2.1.1 Dataset for ovarian cancer**

A review of previous work and currently available instruments has been undertaken, a consumer representative who has lived experience of ovarian cancer has joined the sub-team, collaboration with Ovarian Cancer Australia has been initiated, and initial discussions with a wider group of consumers have been completed. Work is underway to conduct focus groups held in February/March 2019 in Perth, Mandurah, and Bunbury to build on the information gained during the initial Community

'Conversation'. Collaboration with CCWA is underway to maximise access to these groups. These will further explore the issue of importance to patients prior to discussions with clinicians and selection of appropriate clinical and patient reported outcome measures for trial in late 3rd quarter 2019 (also see Section 1.1.2).

### **2.1.2 Integration with clinical registries**

Work to prepare for the initial testing of the data collection system in colorectal cancer at SJoG Midland includes review of how to best integrate data capture for the Bi-National Colorectal Cancer registry and how this dataset maps to the ICHOM dataset.

Additional funding has been obtained to develop a WA clinical quality register for lung cancer that has utility both for improving patient care and enabling further research (also see Section 1.3.1). The feasibility of collecting this data on all patients with suspected lung cancer across two sites will also be sought.

## **2.2 Patient Assessment of Care**

As noted in section 1.5.1 a baseline level of data has been captured via WA involvement in the All.Can patient survey conducted internationally (<http://www.all-can.org/patientsurvey-en/>). The All.Can survey was designed to ask patients to share their perspective on how the care experience could be improved; focusing on what matters most to patients. The results will be used to inform discussions with policymakers on how to improve cancer care; thereby bringing the voice of the patient into the decision-making process, in an effort to ensure cancer policies focus on meaningful outcomes for patients above all other considerations.

A WA specific link to the survey was created so that our responses could be isolated from those across the world. An email notification of the availability of the survey was distributed to a base of approximately 1,000 current and previous patients within the Perth Specialist Breast Care Clinic at SJoG Subiaco Hospital. An unknown number of these were lost due to 'bounce backs' because of invalid/out of date email addresses. Other opportunities to promote the survey were also taken up via Cancer Council WA (CCWA), accessing clients of the 131120 Information and Support line and those visiting the Regional Support Co-ordinators.

Issues with the survey were experienced on the day immediately following distribution when the survey link was found to be 'broken'. This was traced back to an IT malfunction in the UK organisation hosting the survey but time differences meant that Australia was most affected by this issue. Despite this, as at 31/10/18 (4 weeks from first involvement) a total of 220 responses had been received (response rate is unknown but exceeds 20%).

This pilot can be used to inform the patient experience of care survey to be undertaken by WA Cancer and Palliative Care Network. Learnings from this pilot include:

- ensuring, where possible, that IT systems consistently remain in operation whilst undertaking work involving online surveys;
- limiting delays exacerbated with time differences by hosting work locally;
- implementing reminder alerts to increase completion rates over time;
- ensuring different media are available (e.g. handouts) to promote the survey as use of email alone doesn't capture out of date or invalid details; and
- identifying and accessing opportunities for distribution across many different channels (e.g. regional offices at CCWA or cancer treatment centres).

## 2.3 Cost effectiveness

Discussions to implement a health economics component have been had with key personnel at Health Systems and Health Economics Unit at Curtin University. This had identified the need to incorporate an instrument that allows for measurement of quality-adjusted life years so that a change in value for money resulting from the work of the CIC Cancer project can be measured. Funding for a full health economic analysis will be sought.

In order to identify current patient pathways and the processes along those pathways, a sub-project is to be implemented that will undertake mapping of these pathways across cancer types, sites, and treatment types. Identification of potential sources of additional funding for this sub-project is underway.

## **3. Long-term outcomes (5+ years)**

Given that current funding agreements only guarantee funding for 5 years, attainment of these outcomes may be beyond the scope of the project if further funding is not accessible.

- The use of outcome datasets is recognised and adopted as an important component of routine/best practice cancer care within the clinicians managing the tumour types at the health services sites involved in the project. (Phase 5)

## **4. Ultimate desired outcome**

The much longer-term desired outcomes, beyond the guaranteed funding, include:

- Measurable improvements in care and cost effectiveness are demonstrated.
- Local, national, and international collaboration leads to further successful funding opportunities such as a Program Grant or Centre of Research Excellence.