



Continuous  
Improvement in  
Care *cancer*

# Annual Outcomes Report

December 2020



## Contents

Table of Figures .....	3
Table of Tables .....	3
Abbreviations .....	3
Funding Bodies and Partners .....	4
<b>Summary of progress</b> .....	<b>5</b>
Major activities, findings and achievements .....	5
Variation from aims.....	6
Research Foci .....	7
<b>Achievement of desired outcomes</b> .....	<b>9</b>
<b>1. Short-term outcomes/outputs (1-2 years)</b> .....	<b>9</b>
1.1 Stakeholder Engagement (Phase 1).....	10
1.2 ICT system development (Phase 2) .....	12
1.3 Additional Research Projects/Funding (all phases).....	14
1.4 Defined datasets (Phase 2) .....	15
1.5 Ethics Approval (all phases) .....	16
1.6 Collaborations locally, nationally and internationally (all phases) .....	17
1.7 Publications, presentations, both scientific, policy and consumer (all phases).....	17
1.8 Students trained (all phases) .....	19
<b>2. Medium term outcomes (2-5 years)</b> .....	<b>21</b>
2.1 Outcomes Measurement (Phase 3).....	22
2.2 Consumer Priority setting (Phase 1).....	24
2.3 Identification and implementation of new interventions (Phase 4) .....	25
2.4 Enhanced understanding of VBHC/International conference (Phases 4 and 5) .....	25
2.5 Enhancement of ICHOM datasets (Phase 3) .....	26
2.6 ICT systems and personnel operating at each hospital (Phase 3).....	27
2.7 Capture of PROMs at each site (Phase 3) .....	27
2.8 Treatment data capture at each site (Phase 3) .....	28
2.9 Numbers of patients across each site (Phase 3).....	28
2.10 Documentation of clinical tumour stage (Phase 3) .....	28
2.11 Comparison with optimal care pathways (Phase 4) .....	28
2.12 Patient Assessment of Care (Phase 4) .....	28
2.13 New interventions and clinical translation (Phase 4) .....	31
2.14 Improvements in care (Phase 5).....	31
2.15 Cost effectiveness (Phase 5).....	31
<b>3 Long-term outcomes/outputs (5+ years)</b> .....	<b>33</b>
3.1 Long-term outcomes (5+ years) .....	33
3.2 Ultimate desired outcome .....	33

## Table of Figures

Figure 1: CIC Cancer Logic Model.....	9
Figure 2: No. of visits to CIC Cancer Website from Jan 1 – Oct 28 2020 .....	11
Figure 3: Visits by Country from Jan 1 to 28 October 2020.....	12
Figure 4: CIC Cancer Informatics System components.....	13
Figure 5: Proposed summarised Patient Assessment of Care project activities .....	29

## Table of Tables

Table 1: Milestones as at time of project commencement.....	6
Table 2: Publications for reporting period .....	17
Table 3: Posters and presentations provided during reporting period.....	18
Table 4: Media releases and stories .....	18
Table 5: CIC lung cancer pilot EORTC Domain scores compared to the Australian general population	22
Table 6: Data analysis to be undertaken on CIC Cancer clinical and PROMs data.....	23
Table 7: PROMs data capture per site and tumour type .....	27

## Abbreviations

CAR	Concept Approval Request
DoH	Department of Health
FSH	Fiona Stanley Hospital
HREC	Human Research Ethics Committee
HSS	Health Support Services
KEMH	King Edward Memorial Hospital
OCP	Optimal Care Pathway
PCOR	Prostate Cancer Outcomes Registry
PROs	Patient Reported Outcomes
PROMs	Patient reported outcome measures
RPH	Royal Perth Hospital
SJoG	St John of God
SJoGHC	St John of God Healthcare
VBHC	Value based healthcare
WACaPCN	WA Cancer and Palliative Care Network

## Funding Bodies and Partners



*Acknowledgement:  
This work was carried out with the support of the  
Grant provided by the Cancer Research Trust*



Western Australian Health Translation Network

Funded by the Western Australian Health Translation Network's  
Health Service Translational Research Project Grant and the  
Australian Government's Medical Research Future Fund.



## Summary of progress

The Continuous improvement in Care – Cancer (CIC Cancer) Project is progressing well. Whilst there has been some slippage of timelines, all collaborators and stakeholders are focussed on minimising the impact of delays and moving the project forward. This report outlines the 2020 progress against both the desired outcomes and the milestones/KPIs.

### Major activities, findings and achievements

Key activities in 2020 have focussed on:

- integration of the CIC Cancer IT system;
- managing implications of the COVID-19 pandemic;
- seeking new funding and implementing new projects;
- commencement of evaluation processes;
- preparation for the VBHC Conference to be held in 2021; and
- student involvement.

Data collection is underway at three sites and across three cancer types with the IT platform now in place at SJoG Midland and Subiaco hospitals. Current users have indicated that data collection via the platform is working well. Patient-reported outcomes data has been collected for 226 patients and patient-reported experience measures have been collected for a further 149 patients.

Delays experienced to date are related to introduction of the platform across all sites. Reasons for the slower than desired progress have centred on organisational restructures, changes to site-based IT security and management systems, changing information management environments, and multi-level approval processes. Strategies have been put in place to manage these delays and offset the impact by re-prioritising activities and value-adding to the product at an earlier time than might otherwise have been possible.

The flow-on effect of these is the postponements in data evaluation and identification of potential areas of improvement. Opportunities have been taken, however, to make arrangements for work that was to form part of later phases (e.g. ways to provide feedback of data to stakeholders, patient assessment of service, and health economic analysis models). Commencing these projects earlier than expected has meant that an enhanced level of data is being collected from the commencement of data collection rather than incorporated at a later date, improving final results. Another positive consequence is the opportunity to collaborate fully with new software to be implemented by WA Health for data capture at the point of multidisciplinary team meeting discussions about patients with cancer before either of the applications are fully integrated in to WA Health.

It has also been possible to commence innovative value-based healthcare specific sub-projects such as the Bundles of Care project and the impact of COVID-19 on patient experiences that had not been identified as a possible option when planning CIC Cancer. Access to opportunities will continue to be sought as the project progresses; allowing CIC Cancer to act as an effective enabler for introduction of VBHC into WA.

As with all other areas of life, the COVID-19 situation has had an impact on CIC Cancer. Reduced attendance at hospital clinics during the pandemic; a switch to telehealth appointments; dispersal of research personnel to other sites and clinical areas as part of the COVID-19 response; and suspension of cancer screening programs (e.g. BreastScreen WA) affected the number of new patients referred to the clinics and access to those patients. The change to the way patient consultations were held had a positive effect, however, with several clinical champions incorporating patient-reported outcomes into their telehealth consultations.

A key element of long-term sustainability of the work of CIC Cancer is the incorporation of the research into the WA Cancer Plan and collaboration initiatives are underway for implementation and evaluation of the Plan. This, combined with work underway to integrate with health service systems, will assist in long-term uptake and assimilation of patient-reported outcomes into standard care.

## Variation from aims

As a health services implementation research study, the CIC Cancer project needs to be flexible to changing system and stakeholder environments, and adaptable to shifts in stakeholder engagement and the evolving acceptance of value-based healthcare. This adaptability has demonstrated positive outcomes – for example, incorporation of custom data fields to better meet WA clinicians’ needs and involvement in international work undertaken by All.Can – through taking up opportunities during the unavoidable delays to implementation of the IT system.

The timeline identified at the time of initial project proposal has proved to be unrealistic in some areas with delays in early key activities resulting in unavoidable delays in subsequent phases; the most significant being the development of the informatics system.

*Table 1: Milestones as at time of project commencement*

Milestone	Year 1	Year 2	Year 3	Year 4	Year 5
All Phases: Obtain Human Ethics Approval	x				
Phase1: Engagement of stakeholders	x	x	x	x	x
Phase 2: Development and Identification of data capture tools	x	x			
Phase 3: Data evaluation		x	x		
Phase 4: Feedback revise and review including start of service improvement research projects			x	x	x
Phase 5: Program roll out			x	x	x
All Phases: Statistical analysis/Manuscript preparation/Publications		x	x	x	x

The IT environments within which the CIC Cancer informatics system will sit have shifted several times, mostly because of changing technology and security concerns. This has necessitated several changes to development work for the team.

Use of an agile process methodology of building, testing, and learning has assisted in addressing changing needs and adaptations as the project evolves. Effective utilisation of the timeline deferments has also allowed opportunities for ongoing refinements to the usability of the dataset, in consultation with users. These resulted in improvements to the final product, and will ultimately save on development costs.

Whilst awaiting full implementation of the informatics platform, data collection has commenced using manual processes. Access to additional funding for one of the sub-projects assisted in providing staff resources to implement this, with unexpected benefits being that site-specific processes have been fully identified and effective methodologies considered prior to introduction of the IT platform.

Delays have also allowed the team to collaborate fully with a new software, WA-QOOL, to be implemented by WA Health for data capture at the point of multidisciplinary team meeting discussions

about patients with cancer. This application has been under discussion for several years but has only recently been approved for tender processes (anticipated purchase date of March 2021). The close connection between the data collected via this system and CIC Cancer (Professor Christobel Saunders sits on governance committee of new DoH cancer IT systems) will assist in clinical data collection and ultimately improve utility of both systems. The resultant potential for development of better long-term products will improve acceptance and uptake by clinicians and foster effective integration into routine care.

IT delays flowed onto postponements in data evaluation and identification of potential areas of improvement. Opportunities have been taken, however, to make arrangements for work that was to form part of later phases (e.g. ways to provide feedback of data to stakeholders, patient assessment of service, and health economic analysis models). Commencing these projects earlier than expected has meant that an enhanced level of data is being collected from the commencement of data collection rather than incorporated at a later date, again improving final results.

It has also been possible to commence innovative value-based healthcare specific sub-projects such as the Bundles of Care project and the impact of COVID-19 on patient experiences that had not been identified as a possible option when planning CIC Cancer. Access to opportunities will continue to be sought as the project progresses; allowing CIC Cancer to act as an effective enabler for introduction of VBHC into WA.

One of the key effects of the delays will be an inability to demonstrate improvements in care including disease-free survival after primary treatment, decreased rate of in-hospital death from surgical complications, within this current 5-year funding period. This will require several years of data collection and will be an area that will be a focus of any extension to the funding period.

### **COVID-19 Specific Issues**

As with all other areas of life, the COVID-19 situation has had an impact on CIC Cancer. Reduced attendance at hospital clinics during the pandemic; a switch to telehealth appointments; dispersal of research personnel to other sites and clinical areas as part of the COVID-19 response; and suspension of cancer screening programs (e.g. BreastScreen WA) affected the number of new patients referred to the clinics and access to those patients. The change to the way patient consultations were held had a positive effect, however, with several clinical champions incorporating patient-reported outcomes into their telehealth consultations.

The CIC Cancer project has always worked to ensure flexibility and adaptability in site-based processes and data collection methods and so new processes and innovative ways were sought to manage the impact that the changed circumstances had on individuals, the team, and research activities. The obstacles encountered were quickly identified and mitigated through implementation of new processes (and associated additional ethics approvals) for:

- research personnel working from home with inherent data access requirements and associated security management;
- phone recruitment of participants, given the high number of telehealth appointments and telephone assessments;
- capture of verbal patient consent with follow-up for written consent at earliest opportunity; and
- short-term additions to research personnel to assist as staff within other clinical trial projects were unable to be fully utilised during the lockdown.

## **Research Foci**

Key aims for 2020 are listed below, together with a summary of the status at the end of the reporting period. Further details about each item have been included throughout this report.

- Implementation of the informatics platform into SJoG Subiaco hospital – **achieved for breast cancer**
- Integration to the WebPas enterprise system at SJoG – **this is not possible until we have the platform in full operation at both SJoG sites (see section 1.2)**
- Completion of the process to obtain approval for CIC Cancer to be integrated into WA Health – **this has been achieved and awaiting completion of WA Health upload processes**
- Approval for interoperability with at least the enterprise systems identified in phase 1 of the agreed integration – **approval has been secured but implementation is not possible until the system is in full operation**
- Development of the CIC Cancer Research Database component of the informatics platform and export of the ICHOM data elements to the CIC Cancer Research team – **the development of this third component of the platform is complete and is being tested**
- Identification of funding and implementation of planning for the advanced analytics and visualisation component of the CIC Cancer informatics platform – **work to secure additional funding has been undertaken a further time with early work completed external to any additional funding in case funding is not secured via this second grant application (see section 2.1)**
- Uptake of at least 50% of the sponsorship opportunities for the CIC Cancer hosted VBHC conference in 2021 - **achieved**
- Development of draft program for VBHC conference and securement of keynote speakers - **achieved**
- Consider requirements and opportunities to employ a research assistant to help with the next phases of the project – **processes to employ a research assistant are underway**
- Once sufficient data is available, consider options for implementation of structured quality improvement strategies – **major data analysis has not yet commenced**
- Implementation of a pilot project with GenesisCare to test use of bundles of care for women with early diagnosed breast cancer – **underway (see section 2.15)**

The work of the CIC Cancer project in 2021 will focus on:

- Uploading the CIC Cancer informatics platform to WA Health.
- Integration of CIC Cancer platform with at least the WA Health enterprise systems identified in phase 1 of the WA Health approval for interoperability (i.e. WebPAS).
- Piloting the ovarian cancer dataset in an external project undertaken in collaboration with CIC Cancer – *Getting the MOST out of Ovarian Cancer Follow-Up* and refining the CIC Cancer ovarian cancer dataset based on results of this pilot.
- Development of the integrated capture of prostate cancer data.
- Implementation of a pilot project, in collaboration with GenesisCare, to test 'bundles of care' for women with early-diagnosed breast cancer.
- Dependent on access to funding, implementation of the advanced analytics and visualisation component of the CIC Cancer informatics platform.
- Hosting a VBHC Conference with minimum of 300 delegates.
- Data extraction and commencement of data analysis processes.
- Dependent on successful attainment of funding, commencement of the WA Health Experience Survey.



## 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 summarised 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.

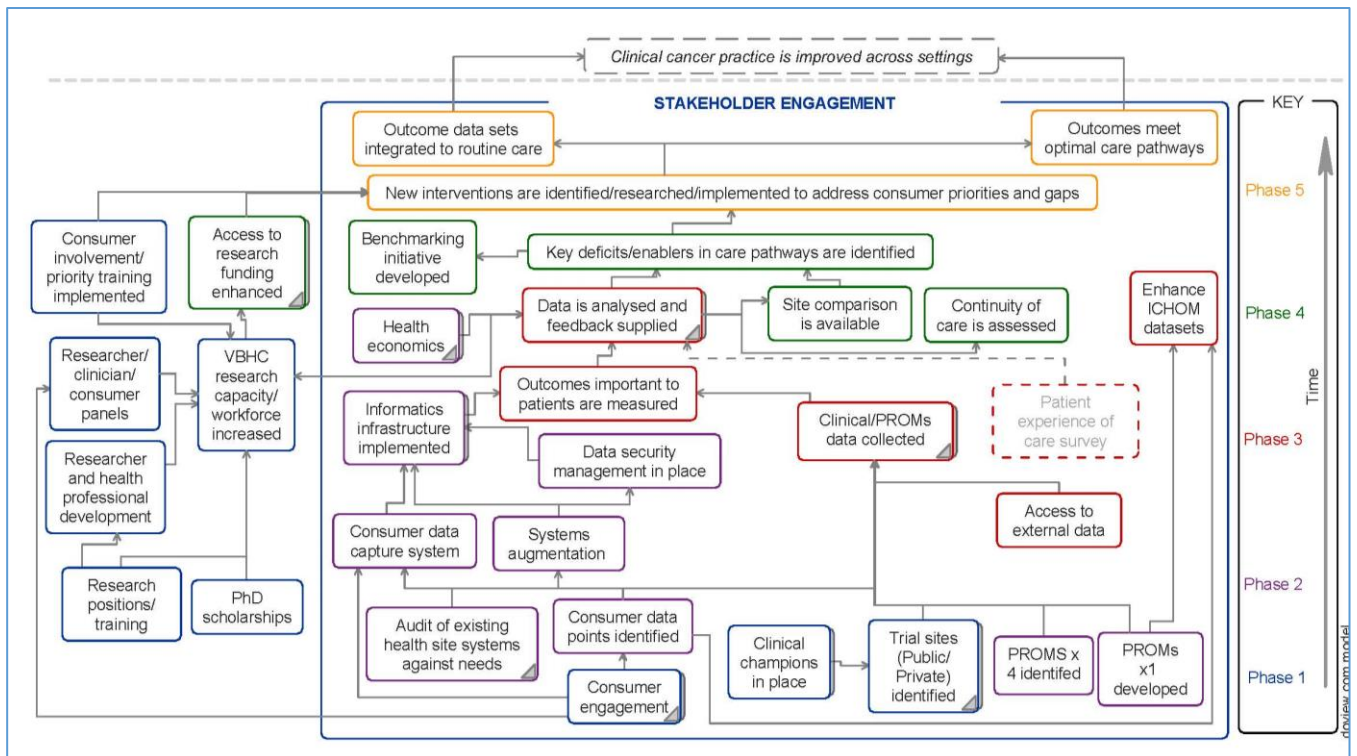


Figure 1: CIC Cancer Logic Model

### 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 (Phase 1)

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

All five hospital sites remain 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). Data collection is underway at SJoG Midland, SJoG Subiaco, and Royal Perth Hospital (see Section 2.2.7). Data collection work has not yet commenced at Fiona Stanley or King Edward Memorial Hospitals as we are still awaiting implementation of the IT Platform into the public sector and the prostate cancer and ovarian cancer datasets are still under development.

Further work with additional sites will be considered once the project is well embedded in all current sites with focus placed on possible involvement by Sir Charles Gairdner Hospital (SCGH). We did not involve this site initially as we had already been approached by, and confirmed, clinical champions at Royal Perth and Fiona Stanley Hospitals (RPH and FSH). Initial reasoning was that it would be better to wait until the systems are fully implemented and trialled at RPH, then phased into FSH, before approaching SCGH. This approach meant that only one hospital would be waiting significant periods for implementation – rather than three – and any major issues could be resolved before further implementation. CIC Cancer work was successfully presented at SCGH and they are interested in being involved in the future.

All five nominated tumour streams also remain engaged, however the lung cancer stream at SJoG Midland has not yet taken up the IT platform and has instead opted to collect clinical data using a different database. Focus is now on other opportunities to capture lung cancer patients, with discussions underway at SJoG Subiaco. The hope is that once the value of collecting patient-reported outcomes can be demonstrated, the original team will re-engage.

### **1.1.2 Consumer engagement**

#### Consumer Reference Group

The need for a consumer voice is vital in a project such as this and consumer engagement activities over the period have continued to incorporate the Consumer Reference Group and 'research buddies' model. Three new consumers joined the group in 2020, providing valuable input in the areas of colorectal and lung cancer.

The key inputs from the group this reporting period have included:

- contribution to the Consumer Review Panel application form for the Cancer Council NSW Project Grant application;
- feedback on usability and appropriateness of a survey tool and assistance with distribution via their networks; and
- planning for the Community Conversation event to be held as part of the VBHC Conference activities.

#### Ovarian dataset development

Consumers have been heavily involved in the development of the PROMs dataset for ovarian cancer. The work being undertaken utilises a sequential mixed methods approach to collect, analyse and interpret data in patients with ovarian cancer. Specifically, the study consists of an integrative literature review, qualitative data collection via community conversation, semi-structured interviews and focus groups, cognitive interviews (using 'think aloud' technique), a modified Delphi technique and Nominal group technique to reach consensus on the patient-reported outcome (PRO) items for ovarian cancer. The developed PRO instrument will be utilised within CIC Cancer as a pilot standard dataset and later analysed using Rasch analysis. It is anticipated that this research will provide national and international groups of consumers and clinicians with a validated and reliable standard set of outcomes for ovarian cancer that will inform clinical practice.

### 1.1.3 Other engagement activities

A further 32 engagement and collaborative activities have been undertaken over the period to enhance engagement with all stakeholders. This is a reduction on previous reporting periods because of the impact of COVID-19 and associated shutdown issues.

#### CIC Cancer Steering Committee

With project maturity, the CIC Cancer Steering Committee has moved to a schedule of meetings every six months with regular monthly communication via the CIC Cancer Newsletter (aka Clinical Champions Update). There have been several changes to the committee over the reporting period.

- Doug Robb, eResearch Senior Project Manager has been replaced by Professor Elaine Holmes, Director of the Centre for Computational and Systems Medicine, as the Murdoch University representative.
- Dr Lisa Millar has replaced Assoc. Professor Violet Platt as the WA Cancer and Palliative Care Network representative.
- Assoc. Professor Violet Platt has also withdrawn from her role as an Associate Investigator.

#### Promotional and Marketing collateral

The CIC Cancer website ([www.ciccancer.com](http://www.ciccancer.com)) continues to be the main portal for information associated with the CIC Cancer project. From 2020, this has also incorporated pages dedicated to the VBHC conference and associated activities.

Access to information via the website has increased significantly this year (1300% increase) with almost 16,000 visits (Figure 2). The majority of which (n=11,088) originated from the US (Figure 3). Much of this activity was generated from social media announcements about the conference.

Figure 2: No. of visits to CIC Cancer Website from Jan 1 – Oct 28 2020

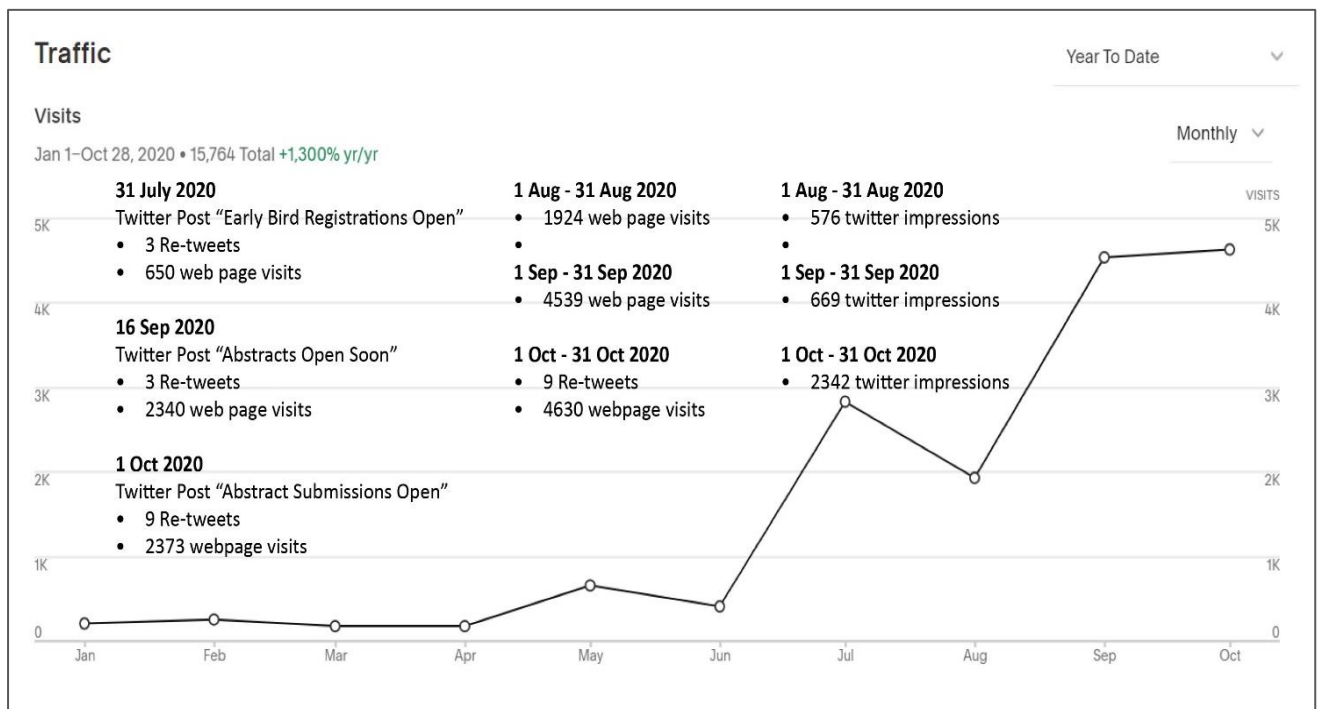


Figure 3: Visits by Country from Jan 1 to 28 October 2020



## 1.2 ICT system development (Phase 2)

### **St John of God**

The CIC Cancer informatics system (Figure 4) is now in routine use at St John of God (SJoG) Midland for colorectal cancer and the lung cancer dataset has been in place at SJOG Midland since February 2020, awaiting uptake and data collection by clinicians. The installation processes for the breast cancer container for SJoG Subiaco are also complete.

Delays to integration at SJoG were caused by:

- 1) corporate restructures within the SJoG IT department;
- 2) introduction of a container management system just as the CIC Cancer informatics platform was to be deployed – necessitating a change to the architecture of the system; and
- 3) a further change to the SJoG container management system in 2020 requiring the already deployed and functioning colorectal and lung cancer containers to be amended. Fortunately, this was able to be undertaken in a way that, whilst directing developer resources away from progressing forward, minimised any disruption to data collection for the teams already using the system.

Feedback from users within SJoG Midland Hospital has indicated that the system is easy to use. They have found the use of tablets to collect patient-reported outcomes from patients within waiting rooms is effective and have not experienced any issues. Users anticipate that the collection of clinical data will be the hardest to achieve, as this will be the most time consuming aspect. Planned work to link to other enterprise systems within the hospitals will assist in reducing this burden.

## Public health system

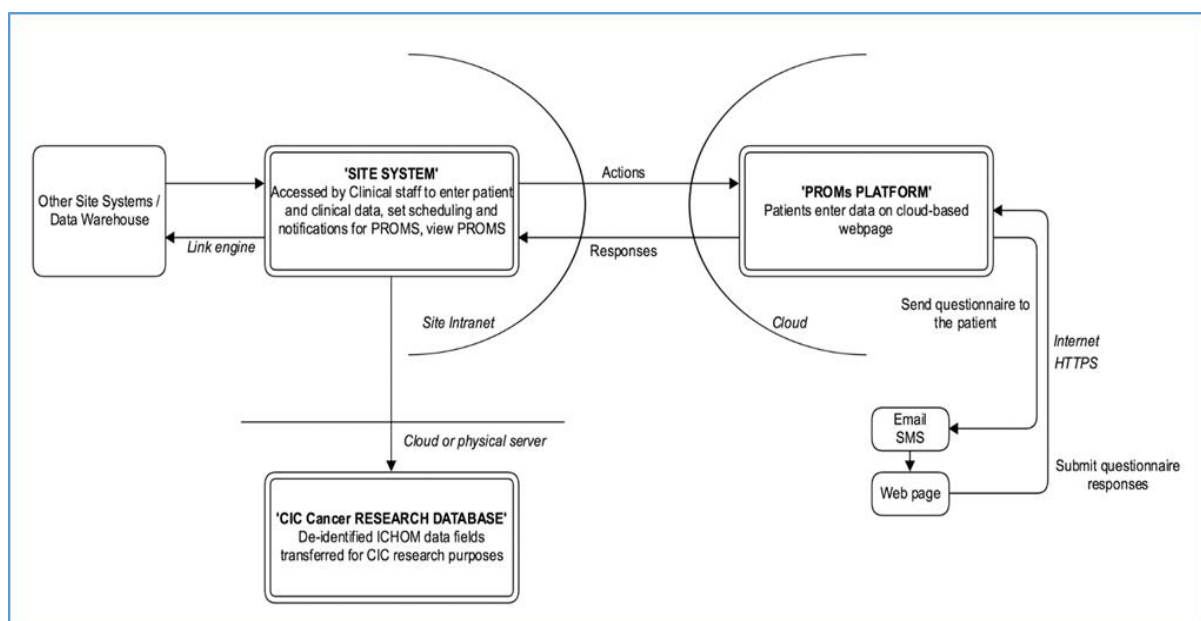
Final approval and sign-off of the Concept Approval Request (CAR) for integration into the public health system was achieved in February 2020. The CAR process was a major undertaking over almost 18 months with multiple iterations to accommodate the changing IT landscape with WA Health. System architecture is now being set up in readiness for the newly created Zone A (High Security) *HealthNext* cloud that will be the new site for major enterprise systems such as CIC Cancer, providing access to the public hospital sites. We have been advised that CIC Cancer will be the first system to go into the very recently approved Amazon Web Services public cloud component of *HealthNext* and so are reliant on the approval and implementation timeframes (and any potential delays) of Health Support Services (HSS). Initial indications were that this would occur by September 2020 but, as of the time of writing, the system architecture necessary for upload of the CIC platform had not yet been put in place by HSS.

Royal Perth Hospital will be the first public site to commence using the informatics system for lung, colorectal, and breast cancer. Data is currently being collected at Royal Perth via paper forms and manual systems. Arrangements will be put in place for this data to be uploaded to the informatics platform as soon as it is in place and tested.

Whilst awaiting this HSS integration we have taken the opportunity to:

- upload the breast cancer dataset to the staging system and undertaken testing;
- set up the newly developed ovarian dataset for testing;
- developed enhancements to provide custom reporting for the colorectal system at SJoG that will be easily transferrable to other tumour types;
- build reporting capabilities for the IT system to allow users to pull off information they require;
- set up processes to forward de-identified data to the research team so that data analysis can be undertaken once the HSS system is in place;
- developed a pdf assessment report function for lung cancer; and
- set up down-time status monitoring systems.

Figure 4: CIC Cancer Informatics System components



## Findings

Work to date has identified that the time and resources required for the due processes necessary to introduce new ICT systems to healthcare settings is significant. Differing ICT governance requirements between the public and private health sectors have also resulted in significant duplication of effort to introduce the CIC Cancer informatics platform as an enterprise system and integrate this to other

enterprise systems, many of which are unique to the specific environment – public hospital, private hospital, and clinician’s private rooms.

The best way of identifying patients who move between public and private settings during their treatment has not yet been identified. The required separation of the informatics platforms between health systems will likely exacerbate difficulties in identifying shared care and fully understanding outcomes resulting from these arrangements.

### **1.3 Additional Research Projects/Funding (all phases)**

#### **1.3.1 Sub Projects**

A further four sub-projects commenced during 2020. This was in addition to the overarching project and the five sub-projects in place in 2018 and two sub-projects commenced during 2019.

- Coordinated Care Model for Bundled Healthcare – Breast Pilot (see Section 2.1.6)  
The Bundled Care sub-project seeks to develop bundled care pathways for privately insured early breast cancer patients from diagnosis through to treatment for no, or a known, out of pocket cost and test these pathways in early-stage breast cancer patients with assessment of resultant patient outcomes and experience
- Advanced Analytics and Visualisation of Data (see Section 2.2.1)  
This project will consider design and implementation of visual data displays that enable effective use of the outcomes information collected. The project will identify user-friendly, interactive interfaces to compare and visually display these results. This will enhance quality of care through discussions of patient reported outcomes during patient-clinician interactions. Without easy to use simple visual depictions, PROs will not be fully integrated into care delivery.
- Introduction of VBHC into the Health Specialisation Stream of the UWA MBA program in Semester 2 2020 (see Section 2.1.18).
- COVID-19 related patient experiences  
Implementation of a short-term sub-project to allow capture COVID-19 specific patient experience measures (see Section 2.2.12).

#### **1.3.2 Grant Funding**

No additional external grant funding was awarded to CIC Cancer in 2020, despite submission of two applications.

An application (submitted in 2019, for 2020 commencement), from the Royal Perth Research Foundation Impact and Innovation Grants 2020 program for an Advanced Analytics and Data Visualisation Project was unsuccessful.

An application submitted for a Policy Grant initiative from MSD in July 2020 was also unsuccessful. This application sought to undertake a study to determine the value of intraoperative radiation therapy, hypofractionated radiotherapy, and conventionally fractionated whole breast external beam radiotherapy to the patients by comparing patient-reported outcome measures, patient-reported experience measures, and patient-reported out-of-pocket costs. The aim was for this information to add value to the existing body of knowledge and help create value-based guidelines and support policies to improve cancer care.

### Applications in Progress:

1. A grant application for interstate collaboration in an Advanced Analytics and Data Visualisation Project was submitted for a Cancer Council NSW Project Grant. The results of this further application will not be known until early 2021 (see section 2.1). Work has already commenced on early phases of this project in case the grant application is not successful.
2. A Request for Quote was submitted in October 2020 to the WA Cancer and Palliative Care Network Clinical Implementation Unit (WACPCN CIU) to undertake a patient experience survey to 10,000 Western Australian's across the whole state (inclusive of metropolitan and rural areas) who were diagnosed with cancer in 2017. The proposal is that the survey be undertaken via the use of a tool developed by All.Can.

A further three grant opportunities were carefully considered before deciding not to apply because of a limited chance of success.

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

An additional 30% of funding has been secured over and above the funding provided by the Cancer Research Trust (CRT).

## **1.4 Defined datasets (Phase 2)**

Work in this reporting period has focussed on finalisation of the breast cancer dataset and preparation for trialling of the ovarian dataset. Work to implement the prostate dataset is awaiting finalisation of the collaboration with the Prostate Cancer Outcomes Register.

### **Breast**

Changes were made to the clinician's view of the breast cancer PROMs to assist in easy identification and discussion of issues. This was completed because several of the validated tools used within the dataset include questions pertaining to similar issues and differences between the responses are not easy to discern when several questions about an issue are separated. In order to provide a better overall picture of responses, work was undertaken to group these responses in categories. The patients will see the questions in the order that they have been developed but the clinician will identify and consider differences from a more usable viewpoint.

### **Ovarian**

Collaboration with an external project – Getting the MOST out of Ovarian Cancer Follow-Up – is underway through use of the CIC Cancer Informatics system to capture the patient-reported outcomes for this additional research. This will pilot the use of the ovarian dataset, trial the IT platform for this cancer type, and extend the use of CIC Cancer beyond newly diagnosed women with ovarian cancer. This external pilot study will investigate the feasibility of a novel approach to the follow-up of women with ovarian cancer after completion of primary treatment.

### **Prostate**

The data collection system for CIC Prostate has been constructed based on the PCOR-WA fields. We continue to work with PCOR-ANZ so that PCOR-WA is part of CIC Cancer project; including how best to combine the two. Instead of opt out consent – which is necessary for the PCOR-WA – a new approach is being used 'opt out approach with informed consent'; an HREC amendment is being drafted. Also, PCOR-ANZ are moving from a Monash University hosted system to another cloud-based system based in Australia. Currently, we have not signed agreements with either PCOR-ANZ or Movember to undertake PCOR-WA data collection but with the new system different agreement

arrangements will be necessary in the next few months for all jurisdictions who provide data to PCOR-ANZ. Negotiations with Movember are underway to identify the best and quickest way forward.

### Findings

Early results of the use of the datasets have indicated that discussions between patients and clinicians are enhanced through the understanding gained by completion of the PROMs. Patient concerns that may not have previously been identified are now being discussed when PROMs are completed on arrival at the clinic.

The opportunity for CIC Cancer clinical champions to incorporate additional fields, including items particular to their clinical practice, processes, or clinical research interests has ensured data and outcomes relevant to WA patients are captured. Inclusion of this customised information also allows clinicians to take the lead on identification of areas of difference between procedures, clinicians, processes, and sites. The dataset customisation undertaken, however, has potential to increase the number of outcome measures. The resultant increase in data capture risks creation of large and cumbersome surveys and may affect completion rates. An important component of CIC Cancer program evaluation will be to gain an understanding of the minimum number of variables required for adequate measurement of clinical and patient outcomes.

## 1.5 Ethics Approval (all phases)

All ethical approval is in place. In this reporting period, additional ethical approval was obtained for the following amendments to the research protocol.

- Provision of de-identified data collected via CIC Cancer to clinical audit registries (e.g. Bi-National Colorectal Cancer Audit).
- Inclusion of students, junior medical staff, and a volunteer undertaking or assisting with research as team members.
- Inclusion of Health Economics project team members.
- Inclusion of the WA Health data custodian.
- Notation of possible use of marketing collateral at any site following specific permission for poster/flyer at RPH.
- Activities and processes for capture and storage of data whilst informatics system not in place.
- Notation of the Bundled Care project to be held at SJoG Subiaco and inclusion of this as an initiative within the protocol.
- Use of analytics and visualisation tools as feedback mechanisms.
- Additional clinical data fields requested by clinical champions and amended fields in datasets to reflect updates to the American Joint Committee on Cancer (AJCC) staging system.
- Evaluation survey to be undertaken at RPH initially but with possible roll out to patients at other sites necessitated a change to the protocol and PICF. The survey seeks to understand patients experience with completing patient-reported outcomes.
- Evaluation of students' experiences and potential impact of their participation in CIC Cancer in order to better understand a student/volunteer's experience.
- Adaptations to work practices as a result of changes to work practices and health care provision resulting from the COVID-19 pandemic. Permission for these changes is requested for the period that these changes are in force. This covered adaptations relating to:
  - Use of telehealth and telephone assessment
  - Research personnel working from home
  - Capture of verbal patient consent with follow up for written consent at earliest opportunity Capture of Covid-19 specific PROMs and patient experience measures
  - Short-term additions to research personnel.



## 1.6 Collaborations locally, nationally and internationally (all phases)

Twenty key activities have been undertaken to enhance opportunities for in-depth collaboration. These have included areas such as:

- liaison with academic/research/health policy groups with areas of expertise that can inform the project (e.g. Queensland University of Technology, QIMR Berghofer Medical Research Institute);
- advanced discussions with GenesisCare and private health insurers about collaboration on the bundled care project;
- liaison with experts in implementation of value-based healthcare in their role as keynote for the VBHC conference (e.g. Staten Island Provider Group, MD Anderson, Ministry of Health Singapore);
- involvement in governance or working groups of national groups including the Australian Centre for Value Based HealthCare Advisory Group and the Australian Health Review Editorial Advisory Board;
- inclusion in a new European-based project to determine how to bring together the fields of Person-Centred Health Care (PCHC) and Value-Based Health Care (VBHC) (which includes Shared Decision Making (SDM)), while ensuring population equity and health care system sustainability; and
- involvement in governance or working groups of international groups such as All.Can, ICHOM Breast Cancer Steering Committee, and OECD Working Group on Breast Cancer PROMs Data Collection.

Outcomes from these discussions have been incorporated into various sections of this report.

## 1.7 Publications, presentations, both scientific, policy and consumer (all phases)

The team has engaged with the health services, research, and consumer communities to raise awareness of both the project and value-based healthcare.

### **Publications**

*Table 2: Publications for reporting period*

<b>Title</b>	<b>Submission to</b>	<b>Date</b>	<b>Type</b>
Measuring the cost of continuous improvement in care in cancer	The Health Advocate ( <a href="https://issuu.com/aushealthcare/docs/the_20health_20advocate_20-20november_202020/34">https://issuu.com/aushealthcare/docs/the_20health_20advocate_20-20november_202020/34</a> )	November 20	Article
Moving towards value-based, patient-centred telehealth to support cancer care	Deeble Institute Perspectives Brief #11 ( <a href="https://ahha.asn.au/sites/default/files/docs/policy-issue/perspectives_brief_no.11_moving_towards_value-based_patient_centred_telehealth_to_support_cancer_care9197_1.pdf">https://ahha.asn.au/sites/default/files/docs/policy-issue/perspectives_brief_no.11_moving_towards_value-based_patient_centred_telehealth_to_support_cancer_care9197_1.pdf</a> )	20/8/20	Briefing paper
Women diagnosed with ovarian cancer: Patient and carer experiences and perspectives	Patient Related Outcome Measures	Submitted July 20 awaiting acceptance	Article
"Nothing beats the doctor's face to impart trust in their judgement" – the role of telehealth in cancer care	The Medical Journal of Australia  Australian Health Review	Submitted September 20 – rejected Submitted Nov 20 – awaiting acceptance	Letter to the Editor

During the reporting period, advice was received that MD Anderson Cancer Centre had circulated one of the early publications– Value-Based Care in the Worldwide Battle Against Cancer (Johansen and Saunders 2017) – as part of The Enhanced Recovery at the University of Texas (ERUT) quality improvement project. This paper was put forward as the “ERUT Paper of the Week.” The goal of the weekly paper is to build knowledge base and to help share expertise and best practices with enhanced recovery. The paper was selected because it provides detailed actionable guidelines that could be considered when transitioning current cancer care practices to a value-based system.

### **Posters/Presentations**

In addition to the publications listed above, several abstracts were submitted to conferences, most of which have been affected by cancellations or postponements due to COVID-19.

*Table 3: Posters and presentations provided during reporting period*

<b>Title</b>	<b>Submission to</b>	<b>Date</b>	<b>Type</b>
What is Value Based Health Care and why measure patient-reported outcomes?	HBF Grand Rounds	August 2020	Seminar presentation
First steps in patient-reported outcomes data visualisation for breast cancer	Science on the Swan	Postponed from May 2020	Abstract for poster
First steps towards value-based care for lung cancer	PC4 Symposium - Shaping Optimal Care Pathways around Australia	Postponed from May 2020	Abstract for poster
Reducing out-of-pocket expenses and optimising cancer care through bundled packages	GAP2020	Postponed from May 2020	Abstract for poster
Digital collection of outcome data in lung cancer: First steps	GAP2020	Postponed from May 2020	Abstract for poster
Patient involvement in the development of a patient-reported outcome measure for ovarian cancer	22nd World Congress of Psycho-Oncology & Psychosocial Academy (Japan)	Postponed from March 2020 to May 2021	Oral presentation
Patient Reported Outcome Measures in a Western Australian Pilot Group of Lung Cancer Patients: Implementation of the Continuous Improvement in Care - Cancer (CIC Cancer) Project	Australian Lung Cancer Conference	Feb 2020	Poster
Patient involvement in the development of a patient-reported outcome measure for ovarian cancer	ANZCOG 2020	Postponed to a virtual meeting in Feb 2021	Oral presentation
'Proof of Concept': Implementation of a patient outcomes data capture and analytics system	8th Annual NHMRC Symposium on Research Translation	Nov 19	Poster

### **Media**

*Table 4: Media releases and stories*

<b>Distributed by</b>	<b>Media Title</b>	<b>In relation to</b>	<b>Date</b>
AHHA's Deeble Institute for Health Policy Research	<i>COVID-19 priorities are delaying cancer care— but telehealth could help</i>	Release of our Perspectives Brief, <i>Moving towards value-based, patient-centred telehealth to support cancer care</i>	20 August 2020
UWA	<i>COVID-19 priorities are delaying cancer care but telehealth could help</i>	Release of our Perspectives Brief, <i>Moving towards value-based, patient-centred telehealth to support cancer care</i>	24 August 2020

## 1.8 Students trained (all phases)

The CIC Cancer Project is a program of work that aims to build capacity for emerging/future clinicians and researchers. As such, medical students and pre-med students who are keen to undertake health services research within their scholarly activities are involved in assisting with activities such as data collection, data entry, literature reviews, and simple data analysis.

### Activities

In 2020, students have worked on a number of sub-projects.

- Literature review on the effects of COVID-19 on the health of cancer patients.
- Review of the literature related to use of data visualisation tools for clinical and patient reported outcomes (across all health conditions and in cancer), prior to identification of
  1. examples of how to translate PROs and clinical data into meaningful visual summaries for use in clinician-patient discussions and informing continuous improvement initiatives;
  2. important questions around understanding of how to translate PROs and clinical data into meaningful visual summaries, to be included in the surveys and interviews for patients, their health care providers, and other key stakeholders.
- Review of the literature comparing patient reported quality of life outcome measures (PROMs) in early stage non-small cell lung cancer patients receiving radiotherapy and surgery with curative intent
- Data collection of clinical and patient reported outcomes in stage one non-small cell lung cancer patients undergoing curative surgical therapy and stereotactic radiation therapy and, if sufficient sample size, possible analysis and comparison
- Evaluation of participants' experience with involvement in CIC Cancer and PROMs collection
- Patient perceptions of cost of cancer treatment in the private sector

At the commencement of 2020, a PhD student was working on the ovarian cancer PROMs development work but due to unforeseen circumstances, this has since been reduced to a Masters by research level.

In addition to students within the CIC Cancer partner organisations, assistance with VBHC understanding was provided to undergraduate students studying Health Science at the Australian National University undertaking a research project in Value-Based Healthcare: Success Factors to Implementation as part of a vacation scholarship program with ACT Health.

### Quality improvement

The six students who commenced involvement with the team this year, have brought the total number of undergrad/postgrad or junior RMOs and volunteers involved to date to 12. Given this increasing level of involvement, it was important to review the success, or otherwise of these placements and implement an experience survey to evaluate the additional student research projects incorporated within CIC Cancer. As part of these evaluation processes, the project team has distributed a questionnaire to students to better understand:

- suitability and acceptability of student research activities;
- the 'value add' resulting from student projects and volunteer assistance;
- enablers and barriers of successful student research; and
- students' perception of how their involvement has impacted on their overall learning outcomes.

It is hoped that this information, combined with review of ways in which student research has enriched the overall program and how student research has contributed to research outcomes, will assist in 1) improving the student research activities and 2) measuring the overall success of the wider CIC Cancer program.

Results will be used to inform future student involvement in CIC Cancer Research projects and report to funding and governance bodies about the impact of student involvement on the CIC Cancer program of

research. Relevant academic and placement staff within UWA will also be provided with aggregated results and informed of any identified issues. This will assist in improving future research placements.

### **Awards and Scholarships**

One of the UWA Doctor of Medicine (MD) students undertaking research as part of her Scholarly activity was awarded one of eight Cancer Council WA Student Vacation Scholarships offered to students for cancer related research projects over the long summer vacation period. Emma Gardiner will receive a scholarship to explore patient views about importance of patient-reported outcome measures (PROMs) in management of lung cancer patients and their preferred way for completing the questionnaires. This study asks patients if they think the surveys they completed capture their main symptoms and health concerns well. Participants will also be asked about prefer to complete the survey: phone, mail, email or whilst waiting for an appointment. Participants will take part in a recorded interview and feedback will be analysed to find out what is important to them. This research will identify patient views of PROMs and how these could be used effectively in routine clinical practice.

Another MD student – Maddison Muller – was awarded an Ohman Suraski Sparrow Scholarly Plus Award in Cancer Research. This scholarship provides funding over 3 years to encourage and assist a high-achieving medical student to undertake a research project in the area of cancer. As part of the Bundled Care Package project, Maddison will undertake research to better understand the financial decision-making process in women with breast cancer across the private and public health sectors. This is a descriptive study using qualitative data collection. Data will be collected using semi structured interviews, transcribed verbatim and analysed using thematic analysis. The clinical pathway a patient goes through will be mapped, with the financial pathway and decision points overlaid on these maps to determine the best points to provide patients with more information regarding the financial aspects of their care. Three cohorts will be included of approximately 20 patients from two hospital sites:

1. SJOG Subiaco Hospital - Privately insured patients undergoing entirely private treatment at SJOG Subiaco as part of a bundled care package offered by their private health insurer (see Section 2.15)
2. SJOG Subiaco Hospital - Privately insured patients undergoing private surgery at SJOG Subiaco and either public or private chemotherapy and/or radiation therapy
3. Royal Perth Hospital - Patients (with or without private insurance) undergoing treatment in the public sector as public or private patients

### **Impact of COVID-19**

Adjustments were made to student's research projects, where necessary, to accommodate the restrictions imposed as a result of COVID-19. Students working on literature reviews or with existing datasets experienced minimal disruption to their research but significant impact was felt by those working directly with patients.

Options were explored to adapt these projects to ensure that students could meet their key deliverables. This included implementing processes and seeking permissions for:

- practices to be undertaken from home;
- capture of verbal patient consent with follow up for written consent at earliest opportunity;
- capture of data via phone for those patients who would normally attend clinics where paper PROMs are still being collected; and
- safe data management practices for capture of data offsite.

### **Implementation of VBHC in academic programs**

Discussion with the UWA Business School in relation to ways in which value-based healthcare methods might be incorporated into health-related academic programs have led to introduction of VBHC in the new MBA Health Specialisation. A course unit taught in Semester 2 2020 (Strategic Management and Innovation in Health) covered:

- value in health care;
- value- based healthcare delivery;

- care delivery value chains;
- patient-centred care and integrated practice units; and
- outcome measurements.

### **Volunteers**

An overseas trained doctor who is seeking Australian authority to practice is providing volunteer-based assistance with the breast cancer data collection at RPH for the health economics sub-project.

## **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 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)
- Understanding of value-based health care is increased. (Milestone/KPI Phases 1 and 4)
- The ICHOM standard datasets are enhanced and improved through the results of WA trials. (Milestone/KPI Phase 3)

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 (Phase 3)

The measurement of outcomes important to patients has commenced but very limited data is available to date. Once sufficient data has been collected and analysed, the information will be used to benchmark and inform care provision across sites and the disease trajectory.

### **Breast cancer pilot**

Early results for 11 women with breast cancer at SJoG Subiaco who completed both baseline and follow-up PROMs in the pilot study shows an overall trend for the quality-of-life to be marginally reduced at 6 months post-diagnosis, presumably when active treatment has commenced (e.g. surgery). There is a tendency for the functional scores to be reduced and symptomatic scores to be higher in the EORTC QLQ C30 and BR23 components.

### **Lung Cancer**

Early results for 36 newly diagnosed lung cancer patients who provided PROMs at Royal Perth Hospital and St John of God Midland identified that lung cancer patients experience a poorer quality of life than other Australians and are particularly burdened by cough, dyspnoea, and insomnia. The key learning of this pilot is that ongoing collection of PROMs will allow targeted interventions to be integrated into cancer service provision but the feasibility and formal utility needs further assessment. Next steps are to compare outcomes across sites and identify variations and areas of potential improvement.

Table 5: CIC lung cancer pilot EORTC Domain scores compared to the Australian general population

EORTC QOL Domains	CIC-Cancer Cohort Mean (SD), n=36	Aust. Reference Mercieca-Bebber <i>et al</i> Mean (SD), n=1821	Univariate T-Test Comparison
Global QOL	61 (27)	68.5 (21.5)	<b>0.04</b>
Physical Functioning	74 (19)	89.2 (19.0)	<b>&lt;0.0001</b>
Role Functioning	68 (33)	88.8 (23.4)	<b>&lt;0.0001</b>
Emotional Functioning	76 (21)	80.9 (24.1)	0.2
Cognitive Functioning	80 (17)	88.0 (21.9)	<b>0.03</b>
Social Functioning	77 (28)	90.7 (23.9)	<b>&lt;0.001</b>
Fatigue	37 (26)	23.9 (22.0)	<b>&lt;0.001</b>
Nausea/Vomiting	9 (15)	4.6 (17.0)	0.1
Pain	20 (22)	21.8(26.0)	0.7
Dyspnoea	34 (29)	11.7 (23.0)	<b>&lt;0.0001</b>
Insomnia	34 (34)	24.4 (30.0)	0.06
Appetite Loss	25 (30)	8.6 (21.9)	<b>&lt;0.0001</b>
Constipation	13 (21)	9.4 (22.6)	0.3
Diarrhoea	12 (24)	5.9 (20.1)	<b>0.07</b>
Financial Difficulties	17 (28)	6.2 (23.9)	<b>0.008</b>

EORTC: European Organization for Research and Treatment of Cancer. QOL: Quality of Life

### **Data evaluation**

Full data evaluation has not yet occurred, however data analysis planning is complete.

Raw, re-identifiable data will be transferred from the Site System and PROMs Platform to the CIC Cancer research team. Initial plans for how this data will be analysed have been identified. These plans will be subject to change and adaptation, however, as data will likely be explored in greater depth as understanding is gained of the data obtained and the potential for more complex evaluation.

Descriptive analysis will be undertaken on the clinical and patient-reported outcomes data collected via the Site System and PROMs platform. This will include, but is not limited to frequencies; medians and means; and cross tabulation. Based on the findings of the descriptive analysis, additional analysis may also be undertaken such as correlations; univariate analysis; and multivariate analysis such as Cox's proportional hazard models and/or time dependent variables. A biostatistician at the University of Notre

Dame will be consulted to assist with data analysis. Any deviations from this plan will be recorded, including justification.

Table 6: Data analysis to be undertaken on CIC Cancer clinical and PROMs data

Data type	Data source	Analysis type
<b>Overall</b>		
Response rates overall, per site, per cancer type	Site system, PROMs	Descriptive
Time point completion	Site system, PROMS	Descriptive
Eligibility/uptake	Site personnel	Descriptive
Custom fields e.g. <ul style="list-style-type: none"> <li>• Education</li> <li>• Marital status</li> <li>• Job status</li> <li>• Who live with</li> </ul>	Site system	Descriptive
Age	Calculated from site system dates	Descriptive
Sex	Site system	Descriptive
Post code/region	Site system	Descriptive
<b>Clinical *</b>		
Tumour type	Site system	Descriptive
Tumour site	Site system	Descriptive
Stage	Site system	Descriptive
Treatment types <ul style="list-style-type: none"> <li>- Type of surgery</li> <li>- Type of therapy</li> </ul>	Site system	Descriptive
Co-morbidities	Site system	Descriptive
Performance status	Site system	Descriptive
Cognitive status	Site system	Descriptive
Risk factors	Site system	Descriptive
Mutations	Site system	Descriptive
Tumour grade	Site system	Descriptive
Recurrence	Site system	Descriptive
Progression	Site system	Descriptive
Mortality status	Site system	Descriptive
Complications	Site system	Descriptive
Time periods	Calculated from site system dates	Descriptive
<b>PROMs</b>		
Changes over time	PROMs system	Descriptive
Differences between cancer types	PROMs system	Descriptive
Differences between sites	PROMs system	Descriptive
EORTC-30 vs EQ5D	PROMs system	Descriptive

\* As per the relevant dataset – not all fields are in all datasets

### **Program Evaluation**

The overarching CIC Cancer program evaluation focuses on attainment, or otherwise, of the outcomes and deliverables of the larger program of work and the program logic model. An evaluation plan has been developed that incorporates evaluation questions, potential data sources, and the data capture required. This is a dynamic plan that may be amended as further information comes to hand, particularly as the number of sub-projects increases. Data evaluation activities have been incorporated into this plan.

### **Analytics and visualisation of data**

Pivotal to the successful collection and use of patient-reported outcomes is advanced analytics combined with enhanced visualisation tools to ensure rapid adoption by clinicians and movement to evidence-based, patient-focused models of care.

The ICHOM standard dataset for each disease type captures approximately 65-80 demographic/clinical and 60-80 patient-reported outcome (PRO) elements. Thus, there are 125-160 indicators for clinicians to review. To handle this increase in workload, the CIC Cancer team seek to incorporate new advanced analytics and visualisation tools within the CIC informatics platform to help clinicians promptly identify patients whose scores fall outside the normal parameters and, in collaboration with the patient, plan appropriate interventions that best suit their personal needs. In addition to improving health outcomes for individual patients, this approach will allow interrogation of variation in outcomes between practitioners, units and services, and help rationalise health system costs to where benefits are most likely to accrue. The NHS Wales, and others, have successfully developed visualisation tools that make it easier to highlight deficits in care and outcomes within their health services.

In order to meet this identified need, a funding application was submitted to Royal Perth Research Foundation, in late September 2019, for a 2020 Innovation and Impact Grant. Unfortunately, this was unsuccessful. As a result, discussions were held with NHS Wales, the Digital Health CRC team, and others about other ways of achieving this. In early 2020, CIC Cancer partnered with a team from the South-Western Sydney Local Health District, University of Sydney and University of NSW to apply for Cancer Council NSW (CCNSW) grant to identify an effective method of developing, testing, and refining the data analytics reporting and visualisation of selected CIC Cancer sites within WA and PROMPT-Care sites within NSW. The potential benefits to interstate collaboration being a national understanding of potential needs and increased utility of the project. The longer-term vision is that this model will be suitable for uptake nationally, utilised routinely in clinical practice, and easily adopted across all health settings.

The objectives of the proposed project are to:

- identify requirements for clinical and PRO data reporting to clinicians, patients and carers, hospital management, and health service management across sites in WA and NSW;
- design and implement an advanced analytics and data visualisation tool ('dashboards') as an overlay for the CIC Cancer and PROMPT-Care informatics platforms; and
- to assess the feasibility and utility of integrating 'dashboards' that visually represent outcomes and changes in clinical and PROs of colorectal, lung, and breast cancer care into the CIC Cancer and PROMPT-Care informatics platforms and understand potential wider health service use.

The CIC Cancer Consumer Reference Group were also involved in the preparation of the CCNSW Consumer review process documentation, providing a consumer voice to the proposed work. If successful, we hope to commence the project in early 2021. As at the time of writing this report there had been no advise as to the success (or otherwise) of the grant application. Advice has been received, however, to indicate that CCNSW will be reducing the number of grants available because of a reduction in fund raising activities due to COVID-19.

Regardless of the success of the grant, work will be undertaken to implement dashboards. As such, early work has commenced and will be built on as appropriate.

## 2.2 Consumer Priority setting (Phase 1)

Nil to report at this time as sufficient data is not yet available to require consumer input to inform priorities for research into improvements in care provision.



A Community Conversation event will be held as part of the VBHC Conference on Wednesday 26th May 2021 in Perth. This opportunity will give consumers an opportunity to discuss a range of questions or key factors related to value-based healthcare and the potential impact on health consumers. The Community Conversation is the starting event of a series of three discussion forums and will allow consumers to provide valuable input to the concept of value-based healthcare implementation and discuss practical strategies within a WA health services context. The recommendations arising from this session will feed into two health-professional focussed sessions focussed on VBHC in primary care and the wider health care sector.

### 2.3 Identification and implementation of new interventions (Phase 4)

Nil to report at this time as deficits/gaps and areas of unmet need in care pathways have not yet been identified.

### 2.4 Enhanced understanding of VBHC/International conference (Phases 4 and 5)

#### **International VBHC Conference**

Planning is well underway for the international value-based healthcare (VBHC) conference. This aims to showcase the research project findings and cement WA as a key player in this research area. The desired outcomes of the conference are to:

- enhance understanding of VBHC principles;
- build an understanding of the importance of measuring patient reported outcomes in identifying improvements in care provision and encourage participation;
- provide an opportunity to hear of similar work underway, national and internationally, and learn from their findings; and
- encourage opportunities for further research and build capacity amongst post graduate research students.

Other than implementation of preparatory/set-up functions for the event ([www.ciccancer.com/vbhconf](http://www.ciccancer.com/vbhconf)), activities during 2020 have focussed on adaptations required to address any potential impact of border closures resulting from COVID-19.

In June, the Conference Working Group decided to move the date of the event to 25-28th of May 2021, rather than the previously advertised dates in March 2021. This decision took into account the need to maintain momentum and the significant interest seen so far against the possibility that the restrictions with incoming international travellers may still be in place. If the wider international borders are not yet open, the aim is to have an Australia-focused face-to-face meeting and seek to beam international keynote presentations in via video link. It is hoped that, by this new date, restrictions would have eased and the event will be more accessible. As such, work is underway to hold a hybrid event with locals attending face-to-face and a virtual modality available for interstate and international delegates. This will be an expensive option as full costs will be required for the two modalities, particularly as the costs for a virtual conference are significant. Having a virtual mode will allow marketing of the conference to New Zealand and South East Asia.

The 2-day pre-conference workshop will now be held online, over four sessions in May 2021. This workshop will build on the Health Care Transformation Leadership Program launched by the Australian Centre for Value-Based Health Care in July 2020; a collaboration between the Australian Centre for Value-Based Healthcare, the Australian National University and the Value Institute for Health & Care at the University of Texas in Austin. Content of the pre-conference workshop will include sessions on:

- designing care differently;
- which outcomes to measure;
- knowing when outcomes have improved; and
- when to redefine outcomes.

A block of pre-purchased registrations was sold to WA Health in May for the combined workshop/conference and a significant level of interest has been expressed. With minimal advertising, 80 expressions of interest have been received from people wishing to be kept informed or indicating that they wish to take part. Early Bird registration, abstracts, and VBHC Award nominations are now open but until certainty of travel is available it is possible that registration numbers will be low.

Sponsorship uptake has also been high with sponsorship 'sold' to groups as diverse as state health departments and primary care agencies, university and research funding sector, corporate sector, health insurance sector, and private hospital sector. Opportunities for additional sponsorship to assist with funding the virtual platform are being sought.

Six keynote speakers have been identified from Australia and overseas:

- Julie McCrossin, consumer, advocate and journalist
- Dr Joe Conte, Executive Director, Staten Island Performing Provider System
- Professor Elizabeth Teisberg, Executive Director Value Institute for Health & Care, Dell Medical School
- Elizabeth Koff, Secretary NSW Health
- Dr Daphne Khoo, Deputy Director Medical Services (Healthcare Performance Group) Executive Director Agency for Care Effectiveness, Singapore Ministry of Health
- Professor Ross Crawford, Professor of Orthopaedic Research, Queensland University of Technology

Opportunities will be provided at the conference for stakeholder input and discussion via a Community Conversation, World Café, and Think Tank. Work is underway to provide links and a thought thread through these through utilisation of the one facilitator for all events. This aims to ensure a flow of information between each and maximise input, findings, and useability of information.

A draft program has been developed but this will be require review now that a virtual mode is to be incorporated and once the abstracts close in December 2020.

### **Introduction of VBHC to other areas**

Early work is underway to understand ways in which public pathology services can operate within a Value Based Framework. A draft discussion paper has been developed for discussion and consideration by the executive and board of PathWest.

### **Value of CIC Cancer to government priorities**

A review of the linkages between CIC Cancer and major national and WA based initiatives resulted in identification of the benefits of the research in meeting strategic government priorities. This found important links between the project and the:

- Addendum to National Health Reform agreement 2020-2025;
- WA Sustainable Health Review (SHR); and
- WA Cancer Plan 2020-2025.

These links to the cancer care environment within WA demonstrate the value that the project can bring to strategic decisions through ensuring that patient's perspectives and experiences are embedded in the planning and delivery of cancer services and outcomes.

The CIC Cancer project was incorporated into the WA Cancer Plan and collaboration initiatives are being integrated into implementation plans. The ways in which CIC Cancer can be integrated into the evaluation of the WA Cancer Plan are also currently being considered with information provided to the contractors undertaking the independent evaluation of the plan.

## **2.5 Enhancement of ICHOM datasets (Phase 3)**

Work to assist ICHOM to update and harmonise the breast cancer standard dataset continued in the early months of 2020. The information provided drew on the learnings from the CIC Cancer breast

cancer pilot and issues experienced with fully and correctly interpreting the data fields and ensuring consistent data capture across all users. Transfer of the ICHOM dataset into the CIC Cancer informatics platform also identified inconsistencies between the ICHOM Reference Guide and the list of fields. The types of changes suggested included:

- increase in number of co-morbidities included;
- update to version 8 of the American Joint Committee on Cancer staging system;
- maintaining the use of previous version of HER2 measures as some countries still use immunohistological chemistry;
- inclusion of more details about the types of reconstruction and axillary surgery;
- additional details about radiotherapy, targeted therapy and chemotherapy;
- inclusion of complications; and
- improved definitions relating to data capture timing.

Having themselves identified the need to update the datasets to address the American Joint Committee for Cancer (AJCC) staging updates, ICHOM have yet to complete this process.

## 2.6 ICT systems and personnel operating at each hospital (Phase 3)

As previously reported, the informatics platform is in place within the centralised SJoG IT department and operating at SJoG Midland and Subiaco Hospitals.

## 2.7 Capture of PROMs at each site (Phase 3)

Recruitment of patients and capture of relevant PROMs for each nominated tumour type is underway at several hospitals and across a limited number of tumour types. An additional number of patients have had clinical data captured against the dataset at SJoG Midland for lung cancer (see Section 2.1) but these have not been included in the numbers below as PROMs have not been collected.

Table 7: PROMs data capture per site and tumour type

Site	Cancer type	# recruited to date	Declined	% decline	Withdrawal/failed to respond to f/up	% Withdrawal
SJoG Midland	Colorectal	37	2	5%	0	0%
SJoG Midland	Lung	-	-		-	
SJoG Subiaco	Breast	35	3	8%	0	0%
SJoG Subiaco	Colorectal	-	-		-	
SJoG Subiaco	Ovarian	-	-		-	
SJoG Subiaco	Prostate	-	-		-	
RPH	Colorectal	28 ^	1	3%	3	11%
RPH	Lung	67	4	6%	13*	19%
RPH	Breast	59	6	9%	40*	68%
KEMH	Ovarian	-	-		-	
FSH	Prostate	-	-		-	
<b>TOTAL</b>		<b>226</b>	<b>16</b>	<b>7%</b>	<b>56</b>	<b>25%</b>

^ clinic most significantly affected by COVID-19 as some consultants relocated to SJoG Midland

\* clashing clinic timetables has resulted in difficulties in capturing all eligible patients as consenting and follow-up has had to be undertaken by mail once the patient has left the clinic – this has recently been addressed through additional resources and introduction of changes to processes through COVID period

Data collection at RPH is on hold temporarily. The project officer seconded to the project team in 2019 to collect data was recalled to her substantive position in September 2020. Unfortunately, her

replacement had commenced work for 1 week prior to having to resign, effective immediately due to unexpected and severe ill health. Arrangements are underway to recruit into the position again.

Conflicting clinic timetables have affected data capture at Royal Perth Hospital. Several clinics are on at similar times and the project officer has had to alternate between them to recruit patients. This has required some patients to be recruited via mail with limited success. Additional resources were identified in August 2020 through sharing a research nurse with another project. Recruitment levels have since improved.

One issue affecting recruitment rates within the public hospitals is the 'opt-in' nature of consent required in these sites. This is fairly time consuming and, in situations whereby the patient has only just learnt of their diagnosis, it can be difficult to find an appropriate opportunity. The temporary use of phone and verbal consent taking and data collection – enacted as part of the COVID-19 response measures – has assisted in capturing a greater number of eligible patients and maintaining follow-up.

### 2.8 Treatment data capture at each site (Phase 3)

Nil to report at this time as sufficient data is not yet available to allow for identification of treatments per patient group.

### 2.9 Numbers of patients across each site (Phase 3)

Very limited data is available about the numbers of patients with the nominated tumour types involved in the study across participating hospitals. See Section 2.7 for detailed breakdown per site and tumour type.

### 2.10 Documentation of clinical tumour stage (Phase 3)

Nil to report at this time as sufficient data is not yet available to allow for identification of clinical tumour stage.

### 2.11 Comparison with optimal care pathways (Phase 4)

Nil to report at this time as sufficient data is not yet available to allow for evidence of treatment based on the relevant optimal care pathway.

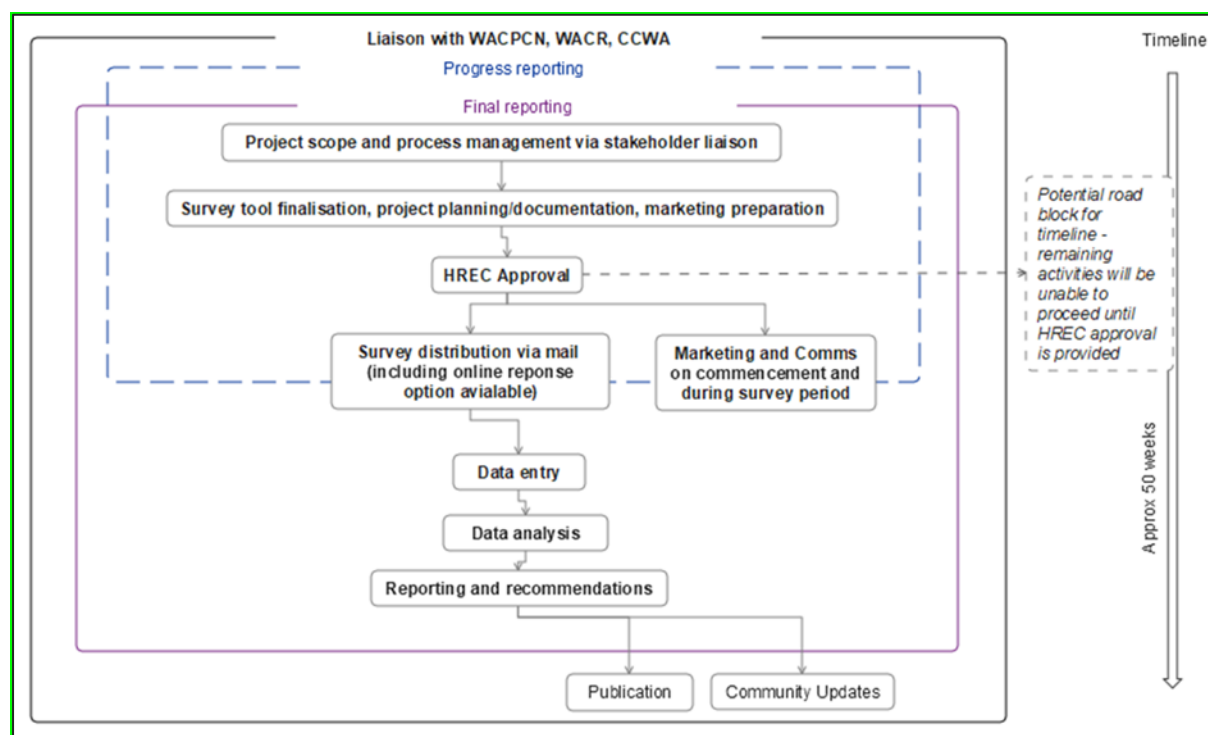
### 2.12 Patient Assessment of Care (Phase 4)

#### **Statewide patient-reported experience survey**

The CIC Cancer team has put forward a tender submission to WA Health to undertake a patient experience survey with 10,000 Western Australian's across the whole state (inclusive of metropolitan and rural areas) who were diagnosed with cancer in 2017. The proposal will include use of the survey tool developed by All.Can with some modifications.

This proposed project methodology has been kept deliberately simple to allow for easy repetition of the survey longitudinally. Maximisation of patient involvement will rely on promotional and marketing activities rather than complex follow-up strategies that risk compromising participant anonymity and confidentiality. Liaison with stakeholders will be a key focus of this project with high levels of collaboration incorporated to ensure sustainability and ongoing usefulness of information collected and analysed.

Figure 5: Proposed summarised Patient Assessment of Care project activities



### **COVID-19 related patient experiences**

The research team also identified an opportunity to implement a short-term sub-project to allow capture COVID-19 specific patient experience measures. This survey asked if, and how, COVID-19 had an impact on their cancer care and if telephone and video telehealth appointments met their needs and/or lessened their concerns.

Using the key themes arising from the All.Can Patient Survey, questions sought to identify:

- the extent to which diagnosis and treatment were delayed, altered, or halted and patient concerns about these changes;
- the impact of COVID-19 on attendance at clinics and hospitals and the acceptability of telehealth options to patients; and
- any impact of COVID-19 on patients' out-of-pocket expenses.

Because the experiences of patients at this time had the potential to mirror the issues raised within the international All.Can patient survey (<https://www.all-can.org/what-we-do/research/patient-survey/findings-from-the-international-all-can-patient-survey/>), implementation of this data collection was thought important enough for distribution to other groups such as Cancer Australia, WA Health Networks, and WA Cancer and Palliative Care Network (WACPCN). Professor Fiona Woods also indicated that she was keen to adapt the questionnaire for use with burns patients.

The CIC Cancer project was in a unique position to add questions to the patient-reported outcomes already being asked, with little or no inconvenience to health services or patients. As such, a questionnaire was developed to understand any potential impact, as perceived by the patient, of possible changes to treatment. This information was collected as part of the PROMs already collected within CIC Cancer for the period of changes to surgery and treatment priorities because of the pandemic. Once they were no longer applicable in WA, this specific data capture ceased. A total of 52 responses were received from CIC Cancer participants.

The WA Cancer and Palliative Care Network – Clinical Implementation Unit decided to include the survey in their Community Consultation Hub (an online consumer portal hosted by WA Health (<https://consultation.health.wa.gov.au/>)), seeking community responses for one month from mid-May 2020. The aim of this was to increase understanding of any variations in the Western Australian experience of cancer care during the COVID-19 pandemic and inform implementation of the WA Cancer Plan 2020-2025. WA Health staff have indicated that results will be used to identify areas across the cancer care pathway that potentially need to be addressed during or following the COVID-19 pandemic with the intention of improving the care of people diagnosed with cancer. This Community Consultation medium resulted in 97 responses with high-level results presented as an infographic. The raw data was added to the 52 surveys collected via CIC Cancer and analysed by the CIC research team prior to joint publication via a submission to the Medical Journal of Australia/Australian Health Review.

Initial analysis of the results showed that telehealth lessened the worries of 72% (51/71) of participants concerned about attending clinics/hospital because of COVID-19. Telehealth met some of the needs of all 33 participants attending video appointments (Somewhat=49%; Quite a lot=24%; Significantly=27%) and of 84% (84/101) of participants attending telephone appointments (Somewhat=35%; Quite a lot=22%; Significantly=27%). Respondents indicated that appointment preferences of online participants were in-person appointments (56%), telehealth (17%), and telehealth in combination with in-person appointments (16%).

Multiple participants commented that they “prefer to speak face-to-face with medical practitioners”. In-person visits were perceived as “more personal and less rushed”, reduced patient anxiety, allowed participants “to connect emotionally” and were favoured for test results, prognosis discussions, treatment decisions, or clinical examinations. Telehealth was convenient for follow-up appointments, reduced patient anxiety about COVID-19, and saved time, travel and parking expenses. Telephone calls posed communication difficulties for people with hearing impairments, were seen as “cold and impersonal”, and not appropriate for discussing important issues. Video telehealth – whilst recognised as a better option – did however, require skills and technology.

WA has low COVID-19 case numbers and limited community transmission. Findings, however, are consistent with a German study (Rodler S, Apfelbeck M et al 2020) reporting that 63% of uro-oncology patients preferred in-person appointments but accepted remote care during the pandemic. Maintaining telehealth after the pandemic had low preference.

The potential impact of COVID-19 on the experiences of cancer patients also led the team to undertake a literature review about the use and benefits of value-based and patient-centred telehealth in cancer care with subsequent submission of a Deeble Institute Policy Perspectives Brief (#11, 20/08/2020). This found that telehealth has an important and increasing role in the future of cancer care. For it to be of benefit to patients and clinicians, however, a well-funded and technologically supported model of telehealth is needed. Patients greatly value personal interactions with their health providers, and it is important to choose the right type of visit to meet the specific needs of each individual patient.

### **Experiences with participation in CIC Cancer**

To better understand a patient’s experience with their participation in CIC Cancer, evaluation of individual participants’ experiences was commenced through use of a short, qualitative evaluation survey. Using a script, participants are asked open-ended questions related to:

1. how well they think the questionnaires assess their concerns;
2. their preferred method for completing the questionnaires (paper version sent via mail, electronic form emailed to them, over the phone, while waiting for their appointment in the hospital, and automatically generated reminder from the informatics platform when operational at the site);
3. treatment they received and where this occurred; and
4. any difficulties, if any, they may have experienced navigating their care.

This began in May 2020 with lung cancer patients attending Royal Perth Hospital. Once data has been analysed, this may be extended to other CIC Cancer patient groups and sites if successful in providing insight into how the activities of the project can be improved. The information gained will also contribute to understanding of how cancer patients prefer to convey their concerns in the future.

### 2.13 New interventions and clinical translation (Phase 4)

Nil to report at this time. Data is not yet available to allow for demonstration of novel interventions, positive results, and translations into clinical care in each tumour type at each hospital.

### 2.14 Improvements in care (Phase 5)

Nil to report at this time as required improvements in care – including disease-free survival after primary treatment and decreased rate of in-hospital death from surgical complications – have not yet been identified.

### 2.15 Cost effectiveness (Phase 5)

#### **Health Economics Proof of Concept sub-project at RPH**

A health economics based 'proof-of-concept' project within Royal Perth Hospital (RPH) will provide an understanding of the economic impact on the health system resulting from any practice, process, or resource changes initiated through the CIC Cancer Project. The analysis of key drivers of cost and patient outcomes over time is important so that certain categories of patients receiving particular interventions who experience a better or worse health trajectory (or increased costs) can be identified. The outcomes of this work will provide valuable insights into appropriate methods for analysing patient outcomes and cost data, which will inform other projects looking to use longitudinal data to identify drivers of health system value (success or failure) and sustainability. The longer-term aim is that this model will be utilised routinely in clinical practice, easily used across other health settings; and as a gold standard for follow-on projects and service evaluations. A proven economic evaluation will also provide opportunities for modelling to compare cost-effectiveness.

The CIC Cancer project is implementing the ICHOM standard dataset where available. As such, the PROMs survey incorporates the EORTC generic quality of life (QoL) measure together with tumour specific outcome measures. In order to implement a health economics evaluation, the CIC Cancer PROMs tool has also included the EQ-5D-5L instrument. To better understand the effectiveness of these instruments, a comparison of the effectiveness will be undertaken to inform ongoing practice and, possibly, reduce the number of data points to be collected on a long-term basis.

Use of Activity Based Funding cost data has identified individual patient pathways and associated costs throughout diagnosis and treatment. A trial analysis of the cost data, using QoL and costing information from a sample of 30 patients, has been completed and this has indicated the scope of available data is suitable for larger exploration once the full number of participants has been attained. In the next steps of the analysis – once more patient data is available – the health economists plan to:

- integrate QoL data to cost data;
- explore associations between costs and quality of life data; and
- compare the distribution of costs by categories of quality of life (i.e. low vs high quality of life etc.).

An article discussing this project has been published in the Australian Healthcare and Hospitals Association's magazine, The Health Advocate as part of an annual update program we hope to have on CIC Cancer activities (see Appendices).

### **Bundled Care sub-project**

An issue highlighted within the international All.Can patient survey and other research is the escalating and varied out of pocket (OOP) expenses for cancer patients – with no or limited transparency – that cause distress amongst patients and the community. This is further supported by 1) a commitment from both sides of government to improve awareness of clinician fees, and 2) OOPs and an identified increase in patients moving to public health care and no longer seeing value in their private health care membership because of escalating OOPs.

Discussions to address this issue resulted in commencement of a 'Bundles of Care' sub-project within the CIC Cancer program, in partnership with GenesisCare. Working initially with Bupa, the project has developed bundled care pathways for women diagnosed with early breast cancer from first surgeon's appointment for 12 months for no, or a known, out-of-pocket cost. Discussions are now underway with two large private insurers (HBF and Medibank) to pilot these pathways in WA. The aim is to improve patient outcomes and decrease patient distress during treatment through provision of a pathway – including allied health and survivorship support – that provides patients with financial transparency and choice. The trial will include an evaluation of resultant patient outcomes and experience.

Activities to date have included:

- identification of desired outcomes and measures for the pilot study;
- engagement of stakeholders – hospital services, clinical services, imaging and pathology services, allied health/survivorship providers;
- identification of patient pathways and bundled care options;
- identification of cost models and finalisation of costs for each pathway;
- identification of touchpoints, operational flow, health economic requirements, and data collection points;
- beginning development of a patient experience questionnaire, based on the All.Can survey;
- beginning development of an evaluation framework;
- beginning development of information and marketing collateral; and
- contractual and governance activities.

Cost data has also been mapped and will be used when analysing and comparing the patient outcomes and experience for patients with known OOP costs compared to standard care for those with private insurance cover.

One of the medical students involved in CIC Cancer will be undertaking an associated sub-project looking at patient perceptions of cost of cancer treatment in the private sector. The study will survey privately insured patients going through cancer treatments, using semi-structured interviews that are then transcribed and analysed using thematic analysis. This will be undertaken with three cohorts of patients:

- privately insured patients undergoing entirely private treatment
- privately insured patients undergoing private surgery and either public or private chemotherapy and/or radiation therapy
- patients undergoing treatment in the public sector (with or without private insurance) and privately insured patients undergoing private treatment in a public hospital.

The results will then be mapped against the clinical pathway of the patient through overlaying the financial pathway and decision points to identify the best opportunities to provide patients with information regarding the financial aspects of their care.



### 3 Long-term outcomes/outputs (5+ years)

#### 3.1 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)

#### 3.2 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.