Continuous
Improvement in
Care *cancer*

Annual Outcomes Report

December 2019

Contents

Table of Figures

Table of Tables

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

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Summary of progress

The Continuous improvement in Care – Cancer (CIC Cancer) Project is progressing well (Table 1). 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 progress to date against both the desired outcomes and the milestones/KPIs.

Major activities, findings and achievements

The key objectives for 2019 were:

- data collection across all cancer types following the lessons learnt from the colorectal trial;
- refinement of the informatics system and link into currently available site-based systems;
- implementation of a sub-project for health economics; and
- finalisation and testing of the ovarian dataset.

Data collection

Formal data collection has commenced for colorectal cancer, lung cancer, and breast cancer with data collected for patients across these three tumour streams and three sites (see Section 2.7). Much of this has been collected using paper forms, however, given unavoidable delays in installing the CIC Cancer informatics system within the hospital settings. Benefits have been found in these delays, however, with opportunities to fully test and refine the datasets and implement processes in a measured way. Opportunities to test different workflows across tumour types and clinics have also been possible.

Lung cancer data collection is hampered by processes required to ensure that a patient has been properly informed of their diagnosis prior to being asked to take part in the study. Furthermore, requirements for referral to off-site treatment means that patients are often lost to follow-up. Several options for consenting patients in a busy outpatient clinic and for capturing paper-based PROMs have been trialled within RPH in an attempt to identify the best methodology. These have involved 1) obtaining consent and capture of PROMs from eligible patients during their consultation; 2) eligible patients being informed about the project during consultation, provided with the consent and PROMs form and asked to complete at home and post back; and 3) all patients attending the lung clinic asked to complete PROMs in the waiting room to ensure that people with suspected cancer are not singled out within a busy waiting room and consent is then obtained during consultation post-delivery of the diagnosis. The latter option allowing commencement of discussion, by some clinicians, about issues identified by any patient attending the clinic rather than just those enrolled in CIC Cancer.

Work continues to identify the best way to capture prostate cancer data and we have been working with the Prostate Cancer Outcomes Registry (PCOR) to combine the two projects. Engagement with prostate cancer specialists has identified that they are very keen for the PCOR WA data to be collected and analysed within WA and that the CIC Cancer informatics system should collect all prostate cancer data requirements and maintain these at UWA prior to transfer to the national registry.

Informatics system

As of 23/10/2019 the informatics system is in operation at St John of God (SJoG) Midland for colorectal cancer and is scheduled to become operational for lung cancer at SJoG Midland before the end of the year. Further sites are scheduled to ‘go live’ in early 2020 (see Section 1.2).

Whilst awaiting on-site implementation, work continued on refining the informatics system. Upgrades in 2019 included:

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

- inclusion of a new feature to highlight abnormality conditions, allowing clinicians to easily identify PROMs responses that require further review;
- updating the clinical component of the lung data capture module to allow for multiple investigations;
- improved usability of PROMS by removing ‘swiping’ and including back arrow buttons ("glyphs");
- data dictionary and user guide development;
- bug fixes relating to the definition import routines; and
- consumer testing of the electronic PROMs notification and completion processes.

St John of God

Initial plans were to implement the IT system at SJoG by the end of 2018. Delays with preparation of the necessary legal agreements by SJoG, however, delayed this significantly as SJoG IT personnel were unable to begin preparatory work until legal approval was in place. Following finalisation of the legal documentation in mid-2019 and subsequent final approval by the Human Ethics Committee, we worked towards a ‘go live’ date for colorectal cancer data collection at SJoG Midland of 3/7/19 but further issues within SJoG IT service delayed this again. These issues included time required to complete an upgrade to the hospital’s patient administration system (WebPAS) and a requirement to address cybersecurity issues before proceeding with the CIC Cancer upload. Once these items were addressed, an unexpected decision was made to pursue a change to the management of external ‘container-based’ systems, requiring alterations to the CIC Cancer software to meet this change. The cumulative effect of these changes meant a further delay of three and half months with the system finally becoming operational on 23/10/19.

WA Health

Work to implement the CIC Cancer informatics platform within WA Health has continued over the entire period. This has involved many iterations to the Concept Approval Request (CAR) first submitted in 2018. The CAR is the key documentation required to gain permission to place the CIC Cancer platform within WA Health facilities and gain status as an enterprise system capable of interoperability with other enterprise systems. These iterations have resulted from the need to meet the changing landscape within Health Support Services (HSS) as decisions are made about the best way to implement this innovative concept and the best way to access relevant data within a number of current and planned HSS data systems in order to limit duplication of data entry. The HSS processes to review and progress the CAR to the next stage – review by the ICT Governance Committee – have been complex and a likely completion date is not yet known.

As part of the processes to submit the CAR, permission was sought from all data custodians of the enterprise systems that we are seeking to access. This was also a lengthy process with, in some instances, a requirement for permission to be gained from a committee responsible for the overall management of the particular enterprise system. We now have written in-principle agreement to access information from all but one of the key enterprise systems.

- WebPAS for patient demographics, identifiers (e.g. MRN, Medicare #), death notification
- iSoft/iCM for pathology and imaging results
- MOSAIQ for treatment details
- WA Cancer Registry for recurrence and prostate cancer patient identification
- CoCA for receipt of ICD and surgical process data and provision of patient reported outcomes (PROMs) data
- WA QOOL or similar MDT software (once available) for receipt of staging, treatment decisions, clinical characteristics and provision of clinical characteristics, +/- PROMs
- ULTRA/LIS for staging and diagnostic pathology details
- iPharmacy for pharmaceutical treatment details

The remaining system (IMPAX for staging and diagnostic imaging details) will require special committee-based decision-making and additional ethical approval.

In readiness for final permission, senior managers from WA Health have agreed to take on the roles of Data Custodian and Data Steward for CIC Cancer, once the platform achieves enterprise system status.

Findings

Attrition and staff changes in the ICT team late in 2018 posed a risk to timeframe adherence but internal management of these concerns resulted in a significant upskilling opportunity for one of the researchers who worked closely with the software developers to upload the dataset to the platform. An unexpected positive outcome of this change was the benefits derived from inclusion of a clinical viewpoint to the design of the data fields within the platform. This combination of both clinical and research knowledge allowed for greater applicability of the dataset and enhanced the ultimate usability of the system from the perspective of both clinical users and data analysis.

Measurement of Cost effectiveness

Following receipt of grant funding (see Sections 1.3.1 and 1.3.2), a new sub-project has been implemented that will build on, and extend the CIC Cancer project. This work will inform assessment of ongoing sustainability through identification of the most effective method of establishing, testing, and refining the health economics/cost component. Building on the implementation of patient-reported outcomes (PROs) in the care of cancer patients via the CIC Cancer project, this project will use a 'proof-of-concept' model within RPH by obtaining cost information to quantify quality of life and cost-effectiveness.

Health economics modelling 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. This is expected to lead to swift adoption of the model within other CIC Cancer sites. A proven economic evaluation will also provide opportunities for modelling to compare cost-effectiveness and act as a gold standard for future CIC Cancer and other continuous improvement projects.

Ovarian Cancer PROM development

Focus groups were held in February/March 2019 in Perth, Mandurah, and Bunbury to build on the information gained during an initial 'Community Conversation', held in 2018. Collaboration with Cancer Council WA and Ovarian Cancer Australia was implemented to maximise access to these groups. A number of 1-on-1 telephone interviews were also conducted to further explore what is important to this group of patients (see Section 1.1.2).

The qualitative component of the dataset development work has taken longer than expected due to difficulties recruiting to the focus groups, which were outside of the research team's control. Furthermore, the PhD student – who commenced April 2019 – required time to become familiar with the topic and the study methodology. A decision was also made to improve the PROMs development processes through inclusion of a validation step called Cognitive Interviewing. This qualitative method will provide an opportunity to invite 10-15 women to review the draft statements and comment on ease of understanding and provide feedback on their perception of the importance of each identified issue.

The cognitive interviewing process is scheduled for December 2019/January 2020 following presentation of the early results to Australia and New Zealand Gynaecological Oncology Group's (ANZGOG) *Survivors Teaching Students*. This is an ovarian cancer awareness program that brings ovarian cancer survivors and caregivers into the classrooms of health professional students to teach them about women's experiences with the disease. Following these discussions, the issues raised in the cognitive interviewing will be cross matched with an Australian tool (MOST) and other items used within similar tools to determine priorities of the women and clinicians.

This work will also inform a collaborative project that provides follow-up of women with ovarian cancer after completion of surgery and chemotherapy. This external pilot study plans to utilise our informatics platform to capture PROMs information from ovarian cancer patients in both WA and QLD in 2020 (see Section 2.1.3)

CIC Cancer data collection for ovarian cancer is now scheduled to commence in 2020.

Table 1: Results ladder

Activity theme	Achieved 2018	Achieved 2019	In progress
Stakeholder engagement	✓ 5 sites ✓ 5 tumour types ✓ 8 clinical champions ✓ Consumer Ref. Group ✓ Website ✓ Steering Committee	✓ Consumer testing of PROMs data capture system ✓ Ovarian cancer PROMs focus groups/ interviews/ feedback ✓ AHHA's Deeble Institute for Health Policy Research Perspectives Brief	• Cognitive Interviewing for ovarian PROMs development
IT system	✓ Agreement by senior informatics personnel in WA Health, Cancer Registry and SJoG ✓ Evaluation of commercially available PROMs systems	✓ IT integration at SJoG Midland ✓ Data custodian approval for system integration within WA Health and data custodian appointment ✓ Mapping against other registries ✓ Dataset refinement	• Interoperability with other SJoG systems • Concept approval for IT integration to WA Health
Research/ Funding/ Students	✓ 5 sub-projects commenced ✓ Additional $1.19 m secured ✓ 1 student; 1 fellowship	✓ Further 2 sub-projects ✓ Further $212k secured ✓ Further 5 students/junior doctors ✓ 1 volunteer ✓ Discussions about inclusion in MBA program	• Grant application for visualisation project • New project with Genesis/BUPA re bundles of care
Ethics	✓ HREC approval	✓ HREC amendments x 2	-
Collaborations	✓ COSA Think Tank ✓ ICHOM, All.Can, OECD	✓ All.Can International and Australia Steering Committees ✓ Aus. Centre for VBHC advisory group ✓ OECD Breast Cancer Working Group ✓ AHHA	• Access to CIC Cancer IT system by external ovarian cancer research • VBHC conference • Input to review of ICHOM datasets
Publications	✓ 2 publications ✓ 3 posters/ presentations ✓ 12 seminars	✓ 4 publications ✓ 11 presentations/posters/seminars ✓ 5 media releases/items	-
Outcomes measurement and analysis	✓ 4 cancer datasets in place ✓ Patient pathway mapping commenced	✓ Data collection commenced ✓ Baseline patient experience results (All.Can pilot in WA) ✓ Early breast cancer pilot data analysis	• Comparison data lung cancer RPH & Midland • Dataset for ovarian cancer
Economic analysis	✓ QALY Instrument identified	✓ Health economics project commenced	-
Implementation as best practice	-	-	-

Variation from aims

The organisational, legal, ethical, and changing site requirements led to substantial delays with the deployment of the IT system, which had an effect on data collection, clinician engagement and willingness to collect outcomes. In addition, the initially promised site support for data managers was not provided, exacerbating these issues further. Whilst working through these matters, we collaborated with clinicians and worked on process mapping to optimise both attainment of consent and PROMs collection. In the interim, we have commenced paper-based PROMs collection.

Efforts to address variation

An understanding that it is impossible for tech-based projects to be concurrently fast, good, and cheap has assisted in managing the inevitable delays associated with informatics system development. Use of an agile process methodology of building, testing, and learning has also assisted in managing changing needs and adaptations as the work evolves. Effective utilisation of the timeline deferments has also allowed opportunities for ongoing refinements to the usability of the dataset, in consultation with users. This improved the final product and will ultimately save on development costs.

Lessons learnt this year resulted in development of a perspectives brief for the AHHA's Deeble Institute for Health Policy Research – Policy Perspectives Brief #5: *Towards value-based healthcare: Lessons learnt from implementing outcomes measures* – reflecting lessons learnt from implementation of a value-based healthcare initiative.

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.

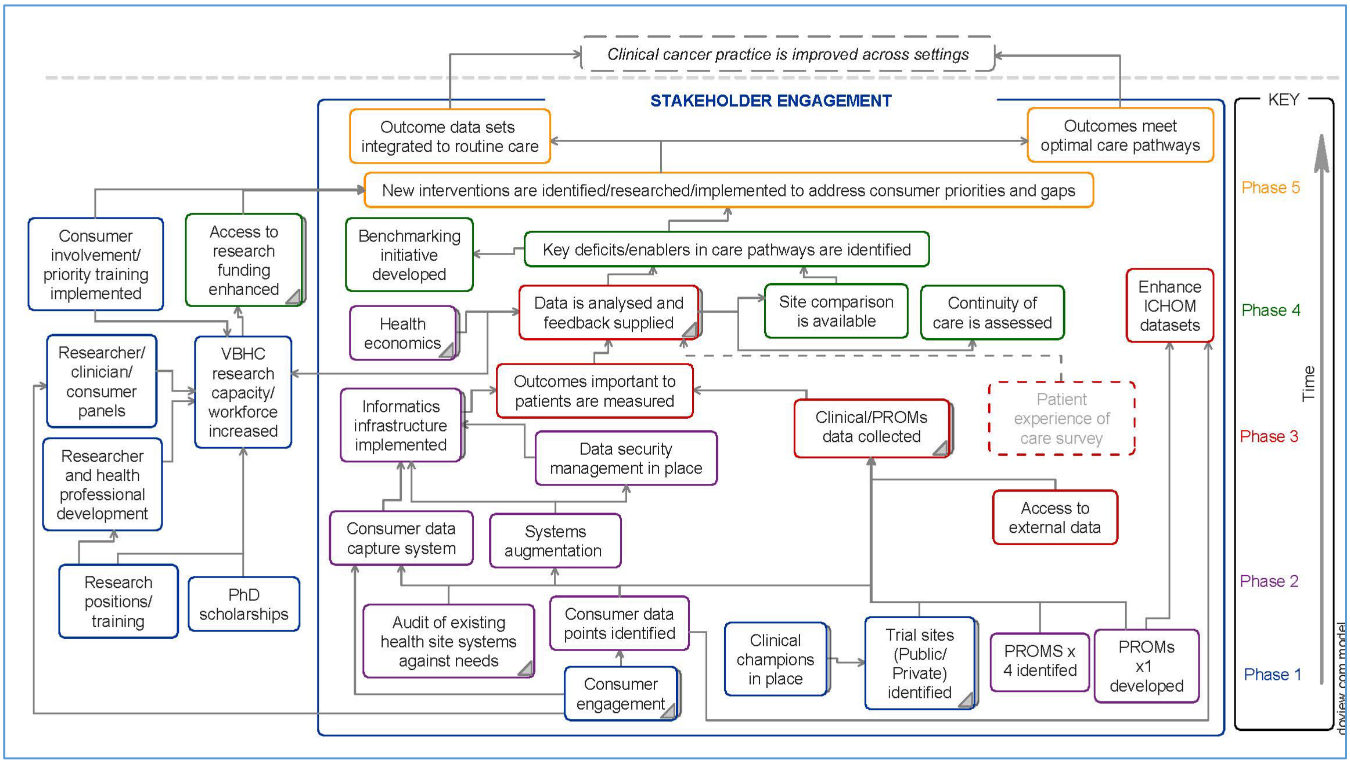


Figure 1: CIC Cancer Logic Model

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: SJoG Subiaco Hospital (private hospital), SJoG Midland Hospital (private/public partnership) and Royal Perth, Fiona Stanley, and King Edward Memorial Hospitals (tertiary public hospitals). All nominated tumour streams also remain engaged (Figure 2).

An unavoidable delay with project governance approval resulted in delays to commencement activities, risking a loss of engagement from stakeholders not fully familiar with these requirements. In addition, those working on the project for a specified timeframe (e.g. fellowship funding) were required to make adjustments to processes to fully complete planned work within their particular research component when specific ethics submissions for these sub-projects were held up until the overarching approval was available. Effective communication streams were vital to maintaining engagement during these delays.

Differing levels of interaction with each tumour stream have been required over the reporting period as efforts ramped up for electronic data collection, particularly with the implementation of the IT system in the first site – colorectal cancer at SJoG Midland. Focus over the period was mostly placed on liaison and interaction with the colorectal team at SJoG Midland, and the lung teams at RPH and Midland as we prepared for colorectal to be the 'test-bed' for online data collection and lung cancer at RPH to test effective patient recruitment processes (see section 1.4).

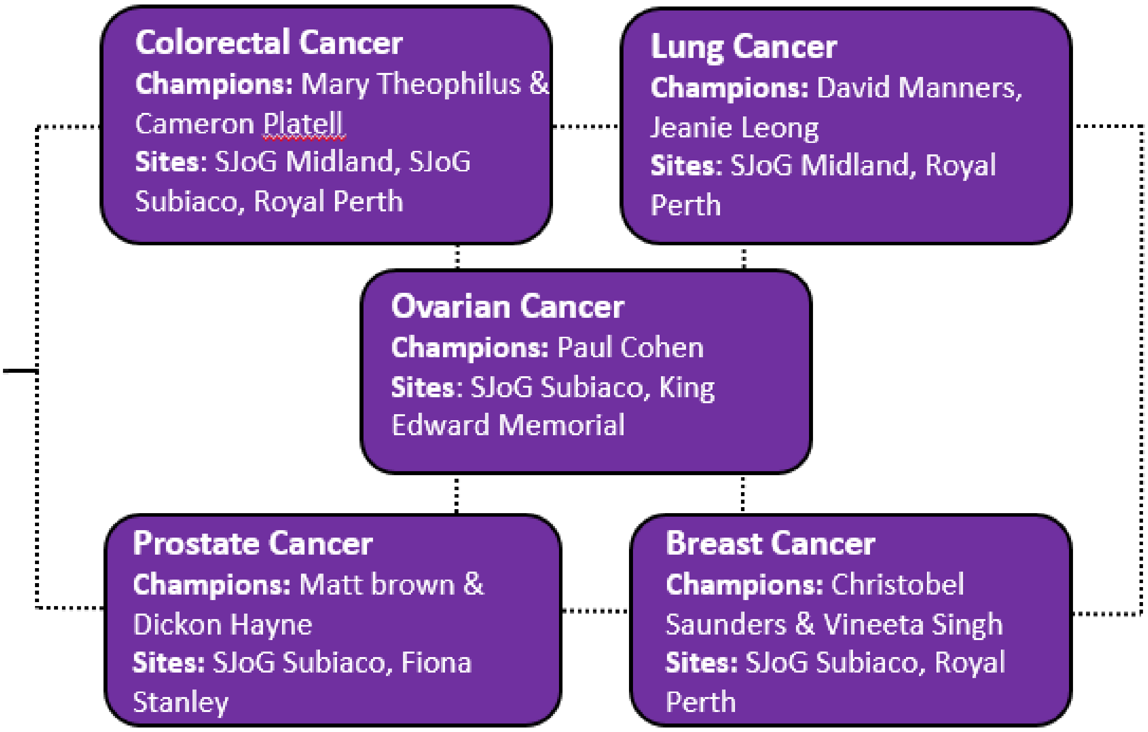


Figure 2: Sites, champions and tumour types

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 involved a Consumer Reference Group and 'research buddies' model with representation from the 5 tumour streams. The key inputs from the group have included feedback on:

- the consumer related key messages and communication pathways within the CIC Cancer Communications Plan;
- the usability, applicability, relevance, and 'look and feel' of the PROMs data capture platform components and associated messages; and
- consumer-related activities incorporated in grant applications submitted.

The nature of some of the cancers included within CIC Cancer has resulted in 20% attrition from the Consumer Reference Group because of disease progression. Member's busy lives, as they seek to recover from their cancer and/or treatment, has also led to challenges in scheduling and maintaining engagement whilst the group is rebuilt following resignations. In addition, work with the group has identified that it is important to ensure that all consumer types are well represented in a consumer reference group with sufficient diversity of social and cultural identities, particularly those people who may feel unable to take part in consumer engagement activities.

A key finding of the discussions to date is that only English language surveys will be used and significant additional work will be required to include other languages for long-term use in everyday clinical practice. This is a limitation of the project but unavoidable in the current 5-year funding timeframe.

Ovarian dataset development

Consumers have been heavily involved in the development of the PROMs dataset for ovarian cancer. This took the form of 1) a 2.5 hour long 'community conversation' held with participants from the WA Ovarian Cancer Support Group in 2018; 2) two focus groups held in early 2019 with 20 women; and 3) in-depth interviews with a further 14 women in mid-2019. Although often challenging, the qualitative nature of engaging consumers has resulted in a richness of information that would otherwise be unachievable. Those who participated to date have expressed a willingness to be further involved in the project depending on their health status.

Undertaking these activities to develop the ovarian cancer patient-reported outcome measures identified that engaging consumers in focus groups may bring about distress during discussions and it is important to ensure that psychosocial support mechanisms are in place to immediately address this distress – a key unexpected finding. Linking focus group meetings to cancer support groups would assist in managing this issue but can be seen as contrary to support group principles.

1.1.3 Other engagement activities

Approximately 70 engagement and collaborative activities have been undertaken in 2019 to enhance engagement with all stakeholders (see Sections 1.6 and 1.7).

Promotional and Marketing collateral

Updates and refinements have been made to the dedicated CIC Cancer website (www.ciccancer.com) and enhanced marketing (promotional banner), communication (clinic posters to aid in recruitment), summary reporting (Annual scorecard), and promotional collateral has been produced over the period.

CIC Cancer Steering Committee

The CIC Cancer Steering Committee continued to meet every three months. There have been several changes to the committee over the reporting period.

- Grahame Bowland of Murdoch University, who had taken the place previously held by Dr Kathryn Napier, following her resignation from Murdoch University, has also resigned. Doug Robb, eResearch Senior Project Manager, has joined the committee as the Murdoch University representative. CIC Cancer is also supported by Professor David Morrison, Deputy Vice Chancellor Research and Innovation.

- Dr Andrew Yeates, Director of Medical Services, has now taken up the SJoG representative position again following a restructure and the resignation of Dr Alexius Julian, Chief Medical Information Officer.
- Melissa Ledger is now representing Cancer Council WA.
- Dr Audrey Koay has joined the committee as the WA Health CIC Cancer data custodian.

1.2 ICT system development (Phase 2)

1.2.1 System design and creation

The CIC Cancer informatics platform (Figure 3) is now in production and f the system has been deployed in SJoGHC. The first site to be involved is SJoG Midland, with SJoG Subiaco to follow. This will allow any potential unexpected production and usability issues to be identified and resolved before multiple sites are involved. Integration with other enterprise systems – such as WebPAS, the patient administration system – will be the next focus of the integration into hospital settings.

Engagement by health service providers and policymakers has been high, with both private and public health services keen to accept and integrate CIC Cancer into existing systems and infrastructures. Data custodians of current enterprise systems are very willing to share data and work together to improve data collection and limit duplication of effort.

Work has also been undertaken to explore third-party opportunities for the provision of the required analytics and visualisation tools to be used during patient consultations and as an aid to decision-making. This review initially included commercially available products such as VisionTree and Cankado but it was determined that none of these products seem suitable for our setting. As such, we are now exploring the use of Microsoft's PowerBI or Tableau as both these products are used with the WA health sector.

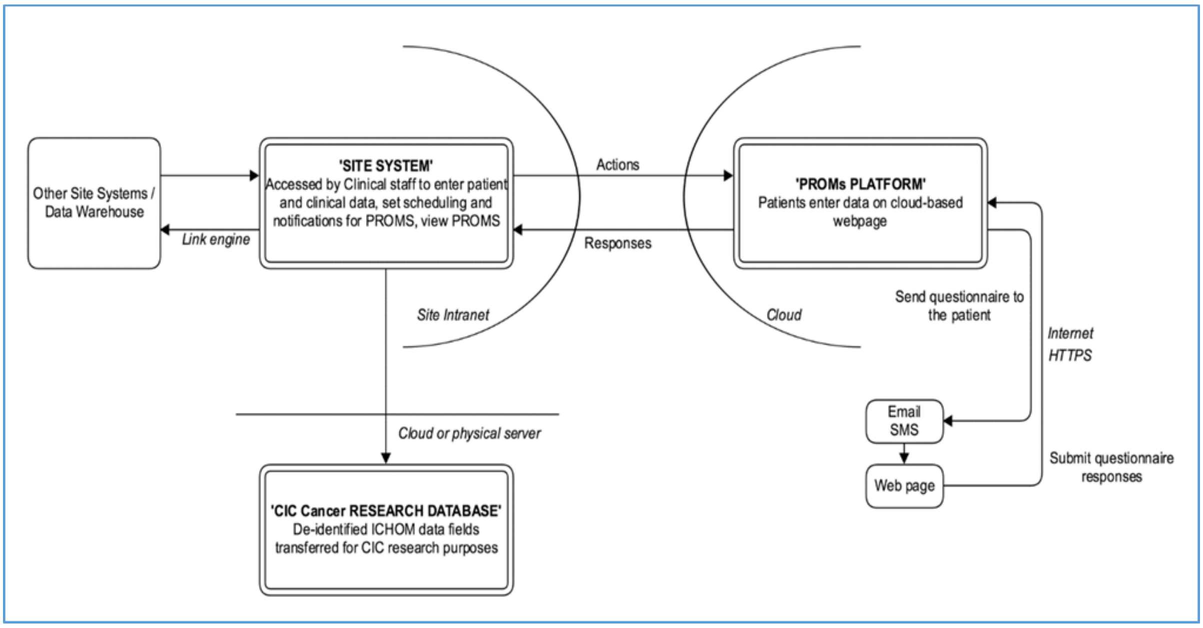


Figure 3: CIC Cancer Informatics System components

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

In addition to the overarching project and the five sub-projects in place in 2018, an additional two sub-projects commenced during 2019.

2019

- *Measuring the cost of continuous improvement in care-cancer at Royal Perth Hospital - a 'proof-of-concept'*
  This sub-project received additional funding from the Medical Research Future Fund Rapid Applied Research Translation Grants co-ordinated by WA Health Translation Network (WAHTN) and extends our collaboration to the team of Health Economists in the School of Public Health at Curtin University. Building on the implementation of patient-reported outcomes (PROs) into standard clinical practice in the care of cancer patients via the CIC Cancer project, this project will undertake health economic evaluation by obtaining associated cost information to quantify quality of life and cost-effectiveness to inform assessment of ongoing sustainability. This 'proof-of-concept' will also 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. (see Section 2.15)

- *Does timely care matter to lung cancer patients? A sub-study of the Continuous Improvement in Care – Cancer (CIC Cancer) Project*
  This project seeks to establish whether the provision of patient review and treatment within the Optimal Care Pathway (OCP) recommended timeframes improves patient satisfaction with cancer-related healthcare. All patients with confirmed primary lung cancer undergoing active cancer treatment will be offered inclusion in the project. The Patient Satisfaction with Cancer Care (PSCC) survey tool will be administered within one week of commencing treatment. Demographic and clinical data, such as age, gender, health insurance status, medical comorbidities and performance status will also be extracted from the CIC Cancer database to be analysed as possible confounding factors.

Planning has also commenced for further sub-projects:
- pilot of bundled care arrangements for women with early breast cancer (see Section 1.6.2);
- introduction to VBHC in UWA Masters program (see Section 1.8.1); and
- advanced analytics and visualisation of data (see Sections 1.2.1, 1.3.2, 1.6.3).

2018
- *Implementing ICHOM Breast Cancer Dataset - Feasibility Pilot Study*.
  Pilot testing of the uptake of patient-reported outcomes measurement (PROMs) by women with newly diagnosed breast cancer at Perth Specialist Breast Care clinic at St John of God (SJoG) Subiaco Hospital. (See section 2.1.1)
- *Continuous Improvement in Care - Cancer: moving towards the first Western Australian lung cancer Clinical Quality Registry*.

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.

- *Continuous Improvement in Care – Cancer: Identification of WA specific data variables for colorectal cancer*.
  Identification of 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.
- *Patient Reported outcome measures (PROMs) in Colorectal Cancer Surgery*
  Provision of laptop computer hardware and tablets for use by clinicians and patients for data entry into the web-based registry.
- *CIC Cancer - Ovarian Cancer PROM development*
  Building on feedback from patients diagnosed with ovarian cancer and their carers during a 'Community Conversation', further insights to the issues that are important to ovarian cancer patients have been more deeply explored by focus groups and one-on-one interviews. Statistical analysis to analysis of key themes has just been completed and will inform the next stages of this work which also forms part of a PhD research program. (See Sections 1.1.2 and 2.1.3)

1.3.2 Grant Funding

In 2019 additional $211,500 external grant funding was awarded for the health economics sub-project. This brings the total grant funds secured since commencement of the CIC Cancer project to almost $400,000.

Table 2: Grant funding obtained since commencement

Period	**Funder**	**Funding ($) excl GST**
2019	MRFF Rapid Applied Research Translation Grants (health economics proof of concept)	$211,500
2018	WA Cancer and Palliative Care Network (WA specific colorectal data variables)	$18,029.35
2018	WA Cancer and Palliative Care Network (PROMs collection in colorectal surgery)	$10,454.55
2018	WA Cancer and Palliative Care Network (lung cancer registry)	$150,000
TOTAL since commencement		**$389,983.90**

In addition:

1. An application seeking $575,585 has been submitted to the Royal Perth Research Foundation Impact and Innovation Grants 2020 program for a project that will identify the most effective method of establishing, testing, and refining the data analytics reporting and visualisation component of the CIC Cancer project at Royal Perth Hospital (RPH). The longer-term vision is that this model will be utilised routinely in clinical practice, easily adopted across all health settings and provide a gold standard for follow-on projects and outcomes reporting; not only in cancer but other conditions.

   The results of this application will not be known until early 2020.

2. An ARDC Transformative Data Collections Grant was applied for in May 2019 but not awarded. This application sought $47,638 to pilot the integration of the CIC Cancer informatics application onto the SJoGHC server as an enterprise system allowing for communication with other SJoGH enterprise systems such as the Patient Administration System.

3. A further 4 opportunities were carefully considered before deciding not to apply due to the limited chance of success at this current stage of the CIC project. These opportunities will be reconsidered next year.

1.3.3 Funding from sources other than CRT

Total cash contributions (other than CRT and excluding in-kind) include:
- $1,190,000 from all partner organisations; and
- $390,000 of grant funding.

This equates to 30% increase on CRT funding alone.

1.4 Defined datasets (Phase 2)

An iterative approach was undertaken to identify local needs and refine the ICHOM datasets for colorectal, lung, and breast cancer prior to building the CIC Cancer dataset. Researchers worked with stakeholders through a cyclical methodology whereby iterative amendments were made to better reflect local needs and address stakeholder feedback prior to further discussion and testing. This was implemented through:
- liaison with the CIC Cancer clinical champions to identify clinical data capture items relevant to their practice and settings and how these aligned to the ICHOM standard dataset;
- review of data items to identify how well data capture could be implemented in practice and meet current workflow practices within the public and private healthcare sites;
- liaison with the CIC Cancer Consumer Reference Group to obtain input and advice from consumers; and
- user-friendly input of the data variables to the bespoke CIC Cancer data capture system, system testing, and development of a data dictionary.

1.4.1 Adaptation

These activities also identified that in order to effectively include the ICHOM standard datasets in the CIC Cancer informatics system a level of adaptation was required to ensure practical application of the dataset. This resulted in changes to:
- include additional date fields so that time periods between episodes can be determined;
- include additional data fields relevant to the WA health system;
- the way in which the variables were presented, this included rearranging the variables so that they followed the patient journey or clinic workflows, thus making the dataset more intuitive to use;
- wording of some of the questions and responses to allow for better interpretation while retaining the meaning of the question;
- include fields necessary for College audit datasets; and
- combine or replace fields to work in with other data registry fields.

During all these processes it was identified that clinical knowledge is of significant benefit when preparing a dataset and working with clinicians to finalise data items.

In was also identified that the time frame between development of the ICHOM standard datasets and CIC Cancer implementation has resulted in some data items becoming out-of-date (e.g. tumour staging). The standard dataset currently captures data relating to the American Joint Committee on Cancer staging system 5th – 7th Edition. A new edition (8th edition), however, is now in use and these changes needed to be incorporated into the data capture system, particularly to ensure successful interoperability with other enterprise data collection systems.

1.4.2 Dataset mapping

Clinicians are keen to minimise duplicate data capture and try wherever possible to capture information that will satisfy both the ICHOM standard dataset and any clinical quality registers in place locally, nationally, or internationally. To this end, activities were also undertaken to integrate and map the clinical variables required for these different databases so that, where possible, data could be collected once and used for multiple purposes. A thorough review of the ICHOM standard dataset has been undertaken to ensure practical application by testing fields within a clinical context and ensure that care variables and timeframes suggested in the Cancer Council Optimal Care Pathway (OCP) for colorectal cancer can be measured.

Although the PROMS variables from the ICHOM set have been adopted as a whole, data mapping identified that the clinical variables across different data models employed different nomenclature for anatomical location categorisation, surgical techniques, and adjuvant treatment regimes. This required additional software coding to allow for cross population of databases. In some instances, this also necessitated additions to the ICHOM response options within the CIC Cancer dataset – the findings of which are being fed back to ICHOM (see Section 2.5).

Colorectal cancer
Amalgamation of the ICHOM standard dataset for colorectal cancer and the Bi-National Colorectal Cancer Audit (BCCA) has identified that neither dataset fully accounted for local process variations and adherence to national/international best practice guidelines. This has necessitated incorporation of even further variables.

The time and effort put into identifying local needs for colorectal cancer resulted in much easier achievement of a draft of lung cancer clinical variables and the breast cancer dataset.

Lung cancer
Review of the lung cancer datasets from ICHOM, the Victorian Lung Cancer Registry (VLCR) and the Queensland Cancer Analysis Control Team (QOOL) was undertaken with subsequent production of a local minimum dataset, which includes 160 data points. This dataset has been reviewed by several local respiratory physicians and a radiation oncologist.

A review of the processes necessary to implement data collection at RPH identified that use of a standardised proforma (completed by clinicians at the initial review of a patient with suspected or confirmed lung cancer) will minimise subsequent time requirements when adding information to the online data platform, when available.

Breast cancer
Findings from early preparation of the CIC Cancer dataset have been used to refine and amend the ICHOM standard set.

Prostate cancer
The ICHOM dataset and the Prostate Cancer Outcomes Registry (PCOR) dataset have been reviewed and decisions about the best way to capture data that meets the needs of CIC Cancer and PCOR will be finalised shortly.

1.4.3 User testing

Ongoing feedback and user testing was sought as each amendment to the dataset was made. The CIC Cancer Consumer Reference Group also provided a community perspective on the implementation of the patient-reported outcome measures (PROMs) within the colorectal dataset as part of the testing processes prior to the production phase of the platform.

Information obtained through user testing has been iteratively fed into the data capture platform and thoroughly tested by IT teams, researchers, and clinical teams to ensure the relevance of the data fields prior to commencement of data collection. A data dictionary – describing the contents, format, structure, and usage of the database and the relationship between data fields – was developed to ensure consistency and accuracy in data capture.

1.4.4 Findings

Early results 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. This resultant increase in data capture risks creation of large and cumbersome surveys and may impact on completion rates. An important component of CIC Cancer program evaluation will be to gain an understanding of the minimum number of variables required to adequately measure clinical and patient outcomes.

Many of the ICHOM datasets have included consumers in identification of appropriate and relevant patient reported outcome measures. It is recognised, however, that these standard sets are not capable of identifying what is important to all cultural groups. A limitation of the CIC Cancer project, as with many other research projects, is that only participants capable of reading and understanding English will be asked to take part, and so an understanding of culturally-specific outcomes will be reduced.

1.5 Ethics Approval (all phases)

All ethical approvals have now been received. Further approval has also been sought and gained for:

- 2 amendments to the protocol;
- reciprocal approval at all partner universities;
- ovarian cancer focus groups via Notre Dame University;
- ethical approval for associated sub-projects; and
- approval for closure of the pilot project to collect breast cancer data at SJoG Subiaco and approval to move the collected data to the wider CIC Cancer project (subject to additional patient consent).

1.6 Collaborations locally, nationally and internationally (all phases)

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

- local liaisons with academic/research/health policy groups with areas of expertise that can inform the project (e.g. Health Systems and Health Economics at Curtin University and UWA Business School);

- discussions and contribution to activities for national bodies such as Quality of Life Office, Sydney University and the Centre for Cancer Research and Centre for Health Policy at the University of Melbourne;
- advanced discussions with GenesisCare and BUPA about collaboration on a new pilot project;
- meetings with NHS Wales and NHS Grampians about their work in VBHC data visualisation;
- discussions about collaboration with international groups including the Value Institute for Health and Care – Dell Medical School, University of Texas and Harvard Business School;
- 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; 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.

1.6.1 All.Can

In 2019, CIC Cancer representation was incorporated into the Steering Committees for both All.Can Australia and All.Can International.

1.6.2 GenesisCare/BUPA

Discussions are underway for implementation of a pilot project involving Genesis Care, CIC Cancer and BUPA. The aim of the pilot is to test a new business model for women with early breast cancer that demonstrates good health outcomes and patient experience, as well as transparency and certainty of out of pocket costs, over a 12-month cycle of care. A bundle of care/payment model is being considered that will be available to women who hold BUPA Health Insurance and are treated within the Perth Specialist Breast Care service, providing a known (or no) out of pocket expenses for their care pathway with measurement of the impact of this approach on health outcomes and experience.

1.6.3 NHS Wales/NHS Grampians, Scotland

Liaison with key policy managers working on VBHC in Wales – Dr Sally Lewis, National Clinical Lead for Value-Based & Prudent Healthcare, NHS Wales and Prof. Alan Brace Director of Finance, Welsh Government – has resulted in access to, and understanding of, the way in which clinicians, health services, and policymakers can visualise outcomes data collected in NHS Wales.

Discussions with Katie Wilde, Manager of Grampian Data Safe Haven in Aberdeen also identified ways in which we can collaborate with groups who have already implemented advanced data analytics and visualisation platforms and how we might learn from their work.

Findings
An unexpected outcome of these discussions and forward sharing of the information made available to CIC Cancer was that seeing the example dashboards helped with conceptualisation of the Notre Dame PhD student’s trajectory in developing the PROMs for ovarian cancer.

1.6.4 Value Institute for Health and Care, Austin Texas

Discussions have been held with Elizabeth Teisberg, Scott Wallace, and Alice Andrews of the Value Institute for Health & Care at Dell Medical School University of Texas, Austin to identify appropriate ways of implementing VBHC education in Australia. As a result, one of the CIC Cancer team members attended a 2-day short course in Austin in March 2019 – Implementing High Value Health Care

Workshop – to better understand the program before discussing the potential for implementation within Australia (see also Section 1.8.1).

As a CIC Cancer partner for the VBHC Conference in 2021, the Australian Healthcare and Hospitals Association (AHHA) is also in discussion with this team to conduct a similar workshop as a component of the conference.

1.6.5 ICHOM

As discussed in more detail in Section 2.5, feedback is being provided to refine the ICHOM datasets.

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

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

1.7.1 Publications

Publications this period centred on early reflections of progress.

Table 3: Publications for reporting period

Publication	Article title	Format	Date
Blog for www.all-can.org	*Understanding what's important to patients so that improvements can be made*	Online blog	Nov 2019
Deeble Institute for Health Policy Research Perspectives Brief No: 5	*Towards value based healthcare: Lessons learnt from implementing outcomes measures*	Health Policy Perspectives Brief – a short, easy to read paper designed to provide health leaders, policymakers and health practitioners with personal and business insights on a particular area of health practice or health management https://ahha.asn.au/sites/default/files/docs/policy-issue/perspectives_brief_no._5_toward_value_based_care_outcome_measures_3.pdf	11 Oct 2019
The Health Advocate (Issue 54 of the official magazine of the Australian Healthcare and Hospitals Association)	*CIC Cancer - Evaluating outcomes that matter most to patients and improving care*	Online and hardcopy magazine article updating audiences in relation to the progress of the project https://ahha.asn.au/system/files/docs/publications/jun2019_tha_web.pdf	June 2019
Australian Health Review, 2019, 43, 121–122 (Journal of the Australian Healthcare and Hospitals Association)	*Towards Value Based Healthcare – modelling an answer for cancer care delivery*	Policy reflections editorial for the online and hardcopy AHHA journal https://doi.org/10.1071/AHv43n2_ED	March 2019

CIC Cancer was also mentioned in an online article about improving cancer outcomes through good communication arising from the University of Melbourne (https://pursuit.unimelb.edu.au/articles/improving-cancer-care-through-good-communication).

1.7.2 Posters/Presentations

11 podium presentations and poster presentations have occurred this reporting period (Table 4).

Table 4: Posters and presentations provided during reporting period

Event	Title	Format	Date
NHMRC Symposium 2019	*'Proof of Concept': Implementation of a patient outcomes data capture and analytics system*	Conference Poster	Nov 2019
UWA Medical School Research Day	*In Pursuit of Value-Based Health Care in Cancer: the CIC Cancer Project*	Conference oral presentation	Oct 2019
ACTA International Clinical Trials Symposium	*Should PROMs and PREMs be standard in clinical care*	Conference oral presentation	Oct 2019
2019 Gynaecologic Oncology Strategic Review meeting	*CIC Cancer Project and Value Based Health Care*	Presentation as part of a mix of speakers	Sept 2019
SJoG Research Week	*Improving patient outcomes to improve value*	3 hour seminar event with 7 integrated CIC presentations and a Q&A session	August 2019
SJoG Ethics seminar	*Understanding outcomes important to patients – benefits for quality improvement and challenges in implementation*	Sole presentation	June 2019
ICHOM International Conference - Rotterdam	*Buy or Build? Comparison of commercially available data capture systems for cancer against a specifically designed platform*	Conference Poster	May 2019
South Metro Health Service Breakfast Research Forum - 'Use of Patient Databases in Research and Clinical Decision Support'	*Implementing patient reported outcomes: measuring what really matters to patients and the healthcare system – Value Based Healthcare*	Presentation as part of a mix of speakers	May 2019
Royal Australian and NZ College of Radiologists Conference	*Implementing patient reported outcomes : measuring what really matters to patients and the healthcare system – Value Based Healthcare*	Conference oral presentation	April 2019
Department of Human Services - Victoria Health Innovations Conference	*Implementing patient reported outcomes : measuring what really matters to patients and the healthcare system – Value Based Healthcare*	Conference oral presentation	April 2019
SJoG Grand rounds	*How to implement patient reported outcomes in the real world: measuring what really matters to patients and the healthcare system*	Sole presentation	Feb 2019

Feedback received from the SJoG Research Week event included:

> *"Today I had spoken with two of my colleagues, separately, about the talks last night. We were blown away by the presenters and the overall content. We were, in*

particular, huge fans of the GP who didn't present but sat on the panel. He highlighted the issues of coordinated and ongoing care in the wider community. Alexius Julian's "Hawaii slide" was brilliant as was the music video. The passion for the void CIC Cancer fulfils was thoroughly evident from the health care professionals in the audience crying out for help in their respective fields. To have a young man attempt to question the current system also shows how widely reachable the content was. To the immediate organizers of this event, congratulations and I believe it would be worth repeating at some stage." Dr Niloufer Johansen

"We are pleased to communicate that we achieved a 250% increase in attendance across our full program of industry and public events compared to last year." St John of God Subiaco Hospital email announcement

1.7.3 Media

Five media releases and media items have been provided this period.

Table 5: Media releases and stories

Distributed by	Media Title	In relation to	Date
AHHA's Deeble Institute for Health Policy Research	*To implement value-based health care is to play the long game*	Release of our Perspectives Brief, *Towards value-based healthcare: Lessons learnt from implementing outcomes measures.*	11 October 2019
Subiaco Post	*Inside look at SJoG research*	Article to promote SJoG Research Week events, including seminar by CIC Cancer	10 August 2019
UWA	*Patient Survey Reveals Flaws In Cancer Treatment*	Involvement in All.Can patient satisfaction survey	9 August 2019
UWA	*Improved physician communication for cancer patients*	Discussion about CIC Cancer work in a release about associated work	26 July 2019
Sunday Times	*Cancer carers eye holistic path*	Article about ovarian cancer with inclusion about CIC Cancer project	17 February 2019

Results from the All.Can Patient Experience of Care survey were also discussed in an article called *Failings identified in cancer treatment* on 6/9/19 in a story by Sean Parnell, the national health writer for *The Australian* newspaper.

1.8 Students trained (all phases)

A number of students and junior medical officers are now involved in CIC Cancer (Table 6).

In addition, work is underway to involve further students during 2020 – one of who was awarded one of 6 inaugural medical student scholarships to undertake research.

Table 6: Student/junior medical practitioner involvement

Date	Name	Status	Site/activity
Feb-19 - current	Sharolin Boban	PhD student - Notre Dame	Ovarian cancer dataset development. The primary learning activities are use of QSR NVivo, cognitive interviewing techniques, and use of Rasch analysis for (PROM) scale development
Feb-19-current	Dr Phoebe Brownwell	Fellowship year - WA Health Cancer & Palliative Care Network Fellowship	Determination of WA lung cancer registry, measurement of patient experience, CIC data capture initiation for lung cancer at SJoG Midland and RPH
May-19 - current	Dr Hamidah Olaosebikan	Surgical registrar seeking urology specific research experience	Mapping patient pathways for prostate cancer at FSH and RPH
May-19 - Oct 19	Dr Laurence Liu Jian Liang	Intern seeking research experience	Assistance with initiation of colorectal cancer data at SJoG Midland
May-19 - current	Olivia Beetane	Masters Student - Notre Dame	Assistance with ovarian cancer dataset development
Aug-19 - current	Trong Nguyen	UWA undergrad - BPhil completing research project	Completion of a literature review to inform time-driven activity based costing (TD-ABC) component of health economics sub-project

1.8.1 Implementing VBHC in academic programs

Discussions have been held with the UWA Business School in relation to ways in which value-based health care methods could be incorporated into health-related academic programs. These have identified that a new Health Leadership and Management Graduate Certificate and MBA Health Specialisation have been approved by UWA for a Trimester 2, 2020 start. Several options are available to provide education about VBHC:

- inclusion of relevant case studies in existing UWA units – possibly under license from the Master's of Science in Health Care Transformation offered by the Value Institute for Health and Care, University of Texas, Austin;
- creation of a new value-based health approach unit in the UWA MBA Health Specialisation; or
- cross-credit of University of Texas, Austin units should UWA students wish to enrol in the US Masters for a specific unit; and
- guest lectures provided by University of Texas faculty staff who have agreed to be involved in the VBHC conference in Perth in March 2021.

1.8.2 Volunteers

An overseas trained doctor who is contemplating whether to seek Australian authority to practice or undertake further study/research is providing volunteer-based assistance with the breast cancer pilot sub-project at SJoG Subiaco Hospital and will transfer to RPH to assist with data collection 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 only just commenced. 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.

2.1.1 Breast cancer pilot

Very early results for 11 women with breast cancer at SJoG Subiaco who had completed both baseline and follow-up PROMs 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. It is however very early and insufficient data is available for any meaningful results.

Figure 4: EORTC QLQ C30 QOL scale at Baseline and 6 Month

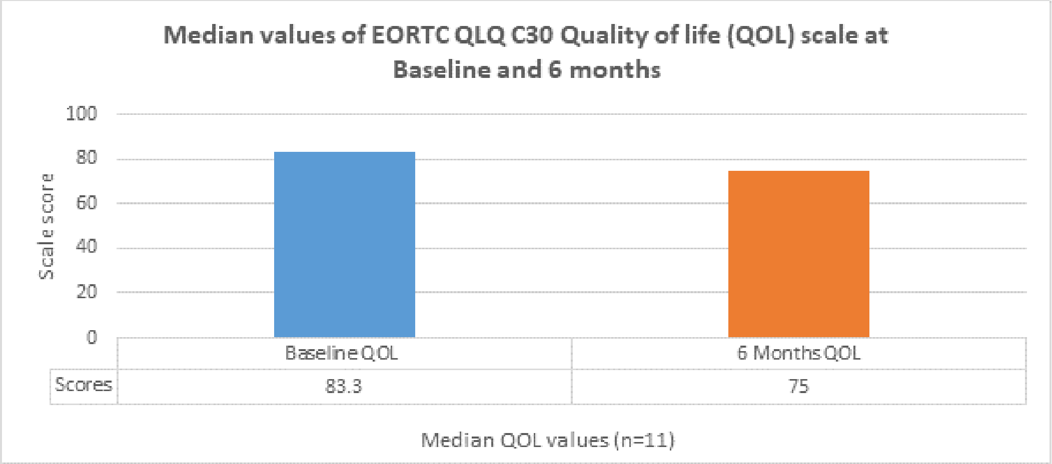


Figure 5: EORTC QLQ C30 Functional scales at Baseline and 6 Months

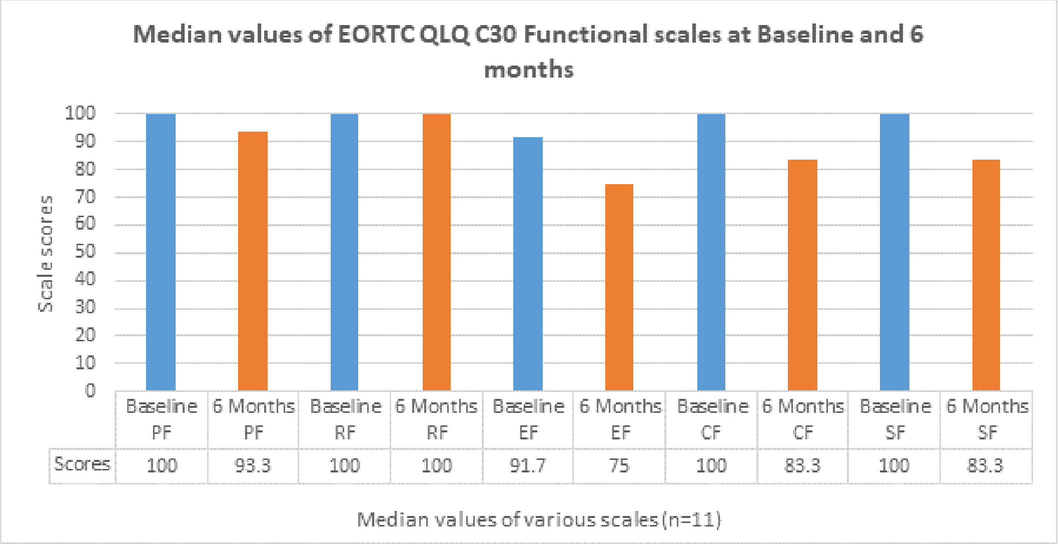


Figure 6: EORTC QLQ BR23 Functional scales at Baseline and 6 Months

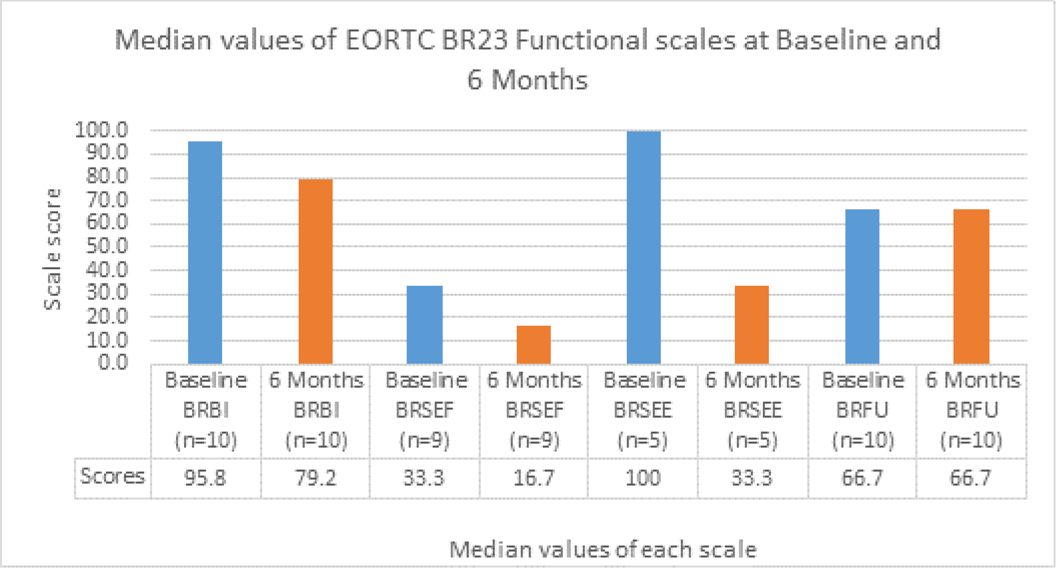
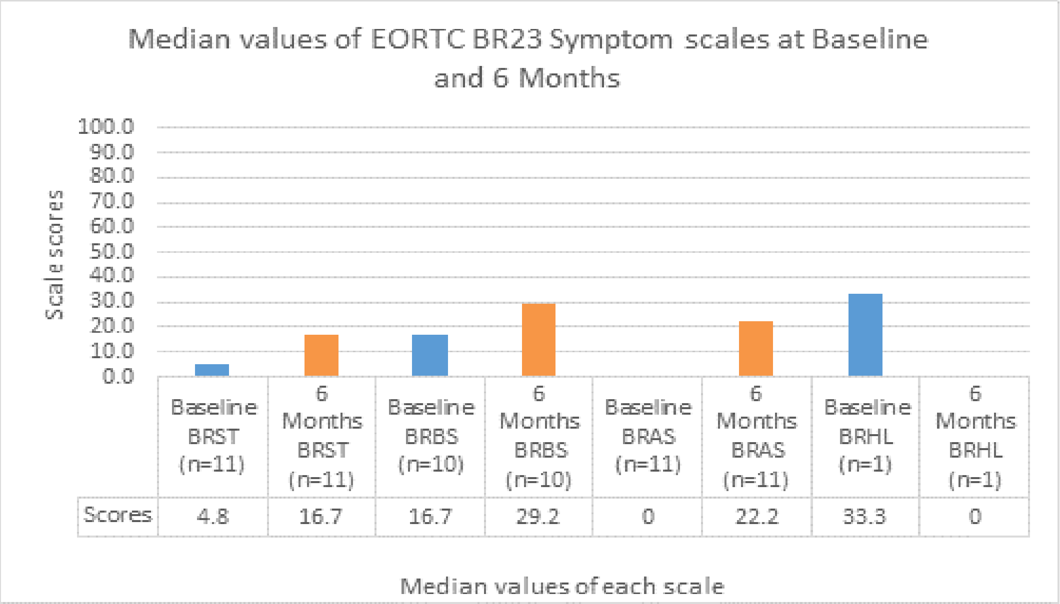


Figure 7: EORTC QLQ BR23 Symptom scales at Baseline and 6 Months



	Baseline BRST (n=11)	6 Months BRST (n=11)	Baseline BRBS (n=10)	6 Months BRBS (n=10)	Baseline BRAS (n=11)	6 Months BRAS (n=11)	Baseline BRHL (n=1)	6 Months BRHL (n=1)
Scores	4.8	16.7	16.7	29.2	0	22.2	33.3	0

Approval has been obtained for the data collected via this pilot to be transferred into the CIC Cancer project. This will allow for ongoing follow-up of these women and increase the pool of participants, enhancing the validity of the results.

2.1.2 Lung Cancer

It is anticipated that initial data analysis for the almost 75 patients who have had clinical data collected and 25 patients who have had PROMs collected will commence in December 2019. This will include a comparison of clinical data between SJoG Midland and RPH.

2.1.3 Ovarian cancer

Work is underway to collaborate with an external project - *Getting the MOST out of Ovarian Cancer Follow-Up* through provision of the CIC Cancer Informatics system to capture the patient-reported outcomes for this additional research. This will thereby 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 surgery and chemotherapy. Patients will have nurse led follow-up with three-monthly telephone calls and complete a patient-reported symptom assessment called the Measure of Ovarian Symptoms and Treatment concerns (MOST) questionnaire at home on a personal computer or mobile device. This will allow assessment of the health-related quality of life of women undergoing this new type of follow-up compared to conventional hospital clinic-based follow-up with completion of the MOST questionnaire. This study will also inform the design of a larger phase III randomised controlled trial.

Both the pilot and subsequent phase III trials will investigate patient satisfaction, quality of life and fear of cancer recurrence, the proportions of women diagnosed with recurrence, the number of patients referred for treatment of symptoms such as anxiety and fear of recurrence, and whether the nurse led follow-up method is more cost-effective than the conventional follow-up model.

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.

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)

Planning has commenced for an international value-based healthcare (VBHC)/health outcomes conference. This aims to showcase the research project findings and cement WA as a key player in this 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 postgraduate research students.

Activities and achievements to date include:

- a briefing note and Project Blueprint have been written;
- a partnership with the Australian Healthcare and Hospitals Association (AHHA) is in place to co-host the event;
- dates have been selected (23-24 March 2021 for a pre-conference workshop followed by 25-26 March 2021 for the conference);
- a Conference Planning Working Group has been implemented;
- discussions have been held with the Value Institute at Dell Medical School Texas about providing a 2-day introductory workshop on VBHC;
- marketing collateral is being developed;
- early promotional activities and marketing have commenced;
- a Sponsorship Prospectus has been developed and early work has commenced to seek sponsorship;
- an event budget has been prepared; and
- the venue (Parmelia Hilton) has been secured.

The event will target clinical health professionals; health service managers; policymakers; consumers; academics; and researchers. The aim is for registration levels of 250-350 with focus given to appealing to local, national and South East Asian and New Zealand interests.

Focus will be given to practical applications of VBHC rather than a theoretical approach with innovative opportunities for registrant involvement and discussions about how to put VBHC into practice. An Australian version of the Dell Medical School Value Institute VBHC 2-day introductory program will be provided as a pre-conference workshop. This will act as the launch of the AHHA managed VBHC education programs.

2.5 Enhancement of ICHOM datasets (Phase 3)

Work is underway to assist ICHOM to update and harmonise the breast cancer standard dataset. This draws 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 has also identified that inconsistencies exist between the ICHOM Reference Guide and the list of fields.

ICHOM have identified issues experienced by other users and are keen to increase the level of detail regarding relevant comorbidities and incorporate the American Joint Committee for Cancer (AJCC) staging updates.

ICHOM have also indicated that the remaining standard datasets will be reviewed in 2020. The work of CIC Cancer will contribute to these processes.

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.

2.7 Capture of PROMs at each site (Phase 3)

Capture of relevant PROMs for each nominated tumour type has now commenced at several hospitals, across a limited number of tumour types, but much of the information collected has been via paper-based processes. As noted in previous sections of this report, electronic data capture has now commenced in one site.

Table 7: Data capture per site and tumour type

Site	**Cancer type**	**Data collection as of 18/11/19**			
		Baseline Clinical	Baseline PROMs	F/up PROMs	Pt experience
SJoG Midland	Colorectal	-	6	-	
SJoG Midland	Lung	39	-	-	4
SJoG Subiaco	Breast	26	23	12 (at 6 months post diagnosis/treatment)	217
SJoG Subiaco	Colorectal	-	-		
SJoG Subiaco	Ovarian	-	-	-	-
SJoG Subiaco	Prostate	-	-	-	-
RPH	Colorectal	-	-	-	-
RPH	Lung	35	25	-	2
RPH	Breast	-	3	-	-
KEMH	Ovarian	-	-	-	-
FSH	Prostate	-	-	-	-
TOTAL		**100**	**57**	**12**	**223**

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 (Table 7).

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 and analysis 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 analysis of treatment provided against that recommended by the relevant Optimal Care Pathway.

2.12 Patient Assessment of Care (Phase 4)

WA involvement in the All.Can patient survey conducted internationally (http://www.all-can.org/patientsurvey-en/) targeted breast cancer patients of the Perth Specialist Breast Care clinic at SJoG Subiaco. In total 217 surveys were collected – approximately 25% of the total participants within Australia (n=850). Because a WA specific link to the survey was created these responses were isolated from those elsewhere, thereby providing WA specific results. The WA input also contributed significantly to the tumour profile of the respondents with 68 per cent of the Australians who took part in the survey reporting having had breast cancer, seven per cent had lymphoma and five per cent had prostate cancer while the remaining 20 per cent had various other cancer types.

Results

Results from Australia (see Attachment 2) identified that whilst the majority of respondents reported their needs were sufficiently addressed during their care, four crucial areas were identified to in need of improvement:

- swift, accurate and appropriately delivered diagnosis with identified delays in diagnosis and managing ongoing side effects as the biggest cause of inefficiency;
- information, support and shared decision-making;
- integrated multidisciplinary care; and
- the financial impact of cancer with 79% reporting out-of-pocket cost and 27% reporting a loss of income.

One in eight (12 per cent) respondents whose cancer was detected outside a screening program waited more than six months to be diagnosed while half reported not receiving enough support to deal with ongoing symptoms and side effects during, and after, treatment.

Some respondents said they felt overwhelmed because too much information was given at once and would have preferred to receive relevant information at appropriate points along the entire care pathway. In addition, 41 per cent said they had not received enough understandable information about the signs and symptoms that may indicate that their cancer might be returning or getting worse.

Some reported a lack of empathy from physicians and poor timing – such as being told they had cancer without a family member present or having to wait several days to speak to a specialist. Lack of access to psychological support was also a common finding with 64 per cent of respondents reporting they needed some kind of psychological support during or after their cancer care but, of those, 35 per cent said it was not available. Another common finding was respondents felt there was often a lack of coordination in care – reporting they had no written care plan nor a primary point of contact to whom they could direct questions.

In many of these areas, the WA results were more favourable than those of the full Australian cohort but as this sub-survey only included only 1 tumour type within one site, these are not necessarily representative and so will not be analysed separately from those of the Australian results.

The launch of the International All.Can patient survey findings was covered by various outlets, including the BMJ through an opinion piece about the survey from BMJ Senior Editor Tessa Richards (who is also one of the former patients who responded to it). This interesting piece was seen as a big win for All.Can as the editor generally has freedom to write about whatever they want in opinion pieces and will choose something that genuinely interests them, not simply something they've received a press release about. The article is online at https://blogs.bmj.com/bmj/2019/08/06/tessa-richards-my-view-and-that-of-3980-other-patients/

Findings

This pilot will be used to inform any future patient experience of care surveys – most notably a potential project to be undertaken by WA Cancer and Palliative Care Network. Learnings from this pilot include:

- ensuring, where possible, that IT systems 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 Cancer Council WA or hospital-based cancer centres).

The results of the WA, Australian, and International results have been discussed with the Advisory Group tasked with developing the WA Cancer Plan 202-2025. As a result, many of the findings have been used to inform the recommendations within the Plan – for example boosting clinical trial participation; access to psychosocial support; and navigating cancer care. The plan is in final draft with a scheduled release date of February 2020.

2.13 New interventions and clinical translation (Phase 4)

Nil to report at this time as data is not yet available to demonstrate implementation of novel interventions, generation of positive results or 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, decreased rate of in-hospital death from surgical complications – have not yet been identified.

2.15 Cost effectiveness (Phase 5)

Health economic evaluation has commenced with recruitment of the project officer, project planning, and HREC approval now complete and data collection commenced. It is anticipated that this work will refine how both resource use and patient outcome data are collected and utilised, as we move to embed patient-reported outcomes into routine data collection in the WA public and private health systems.

The analysis of key drivers of cost and patient outcome over time is important so that 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.

An understanding of quality-adjusted life years (QALYs) gained will allow comparison of the benefit and cost of health care programs or interventions when undertaking cost-utility analysis – health program evaluation data widely accepted by policymakers. In preparation for this, an additional instrument (EQ-5D-5L) was included in the PROMs to allow for analysis of QALYs. Inclusion of the EQ-5D instrument however, further increases the size of the patient-reported outcomes survey. Furthermore, when combined with the ICHOM patient-reported measures, duplication exists with similar or near similar questions across the different instruments. This has necessitated inclusion of additional text within the survey forms to notify patients of the reasons behind the seemingly repetitious questions. To better understand the effectiveness of these instruments, a comparison will be undertaken to inform ongoing practice and possibly reduce the need to collect data via both instruments.

Funding of $211,500 has been provided under the Medical Research Future Fund Rapid Applied Research Translation (RART) Grants 2019 Round 3 through the WA Health Translation Network (WAHTN). This will fund:

- Project officer @ 0.5FTE for 18 months at RPH. This is to undertake data collection, identification of processes to be costed, collection of cost data, medical record review, and data cleansing.
- Junior health economist @ 0.4FTE for 18 months at Curtin University. This is to undertake economic evaluation through data analysis and exploration of patterns in quality of life across the patient population, identification of a model, report writing, and dissemination.

Further funding has been provided to Curtin University from the CIC Cancer Project for supervision, identification of a model, report review and dissemination, and translation activities.

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.