



Continuous
Improvement in
Care *cancer*

Annual Outcomes Report

December 2021



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Abbreviations

DoH	Department of Health
FSH	Fiona Stanley Hospital
HREC	Human Research Ethics Committee
HSS	Health Support Services
KEMH	King Edward Memorial Hospital
OCP	Optimal Care Pathway
PCOR	Prostate Cancer Outcomes Registry
PREMs	Patient report experience measures
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

Funding Bodies and Partners



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Summary of progress

The Continuous Improvement in Care - Cancer (CIC Cancer) Project aimed to establish if value-based health care (VBHC) can become part of routine cancer care in WA – improving both the experience and outcomes of care for those affected by cancer, and providing a rich databank for on-going research into improving cancer services and outcomes. The project is well on the way to achieving these aims.

Over the past 12 months, the CIC Cancer project has continued to progress activities across several major thematic areas.

ITC system development and integration

- Data capture via internationally utilised patient-reported outcome and patient-reported experience measures (PROMs and PREMs), and costing collections in the WA environment.
- Enhancements to the bespoke information systems for collection of patient-reported measures and clinical data to minimise duplication of data entry and enhance data security through secure linkage connections.
- Development of data analytics and outcome visualisation dashboards in consultation with clinical leads.
- Identification of new opportunities for data capture – e.g. testing the utility of a unique ovarian cancer dataset in external trials and implementation of breast cancer data collection in an additional site.

Research outcomes for cancer services research and quality improvement

- Exploring value and, through the identification of variation, evaluating adherence to optimal care pathways for patients with breast, colorectal, and lung cancer.

Change management & implementation

- Building awareness and understanding amongst the healthcare workforce, from the Director General of WA Health, to the clinical workforce and administration, and students.
- Leveraging from the core project to seed new aspects of VBHC into cancer care within WA - e.g. proof-of-concept projects for health economics and a model for bundled healthcare in breast cancer.
- Working with the WA Clinical Senate to make VBHC a focus for healthcare services within WA.

Selling the vision

- Successfully hosting Australia's first conference on value-based healthcare.
- Actively collaborating with national and international bodies to enhance knowledge of VBHC implementation and awareness of CIC Cancer work.

Data collection is in place at five hospital sites involving four cancer types, employing a customised informatics platform now in use at SJoG (Midland and Subiaco hospitals) and installed within WA Health (RPH, FSH & KEMH). The robustness of the system in repelling external 'hacking' attempts has been tested by both WA Health's Health Support Service (HSS) and external review and was found to be a highly secure platform with only minor updates required to align with HSS policy requirements. As at the end of 2021, PROMs had been collected from almost 500 patients with PREMs collected from a further 404 patients in collaboration with All.Can – part of a sub-project to understand the impact of COVID-19 on care provision – or student projects. Surveys are also currently underway to capture PREMS for people diagnosed with cancer in 2019 and identify the information needs of consumers but results will not be known until early-mid 2022.

Challenges

Delays with installation of the CIC cancer informatics platform have been encountered given the significant transformation of WA Health IT infrastructure under the HealthNext program – a 3-year phased transition of all clinical and corporate applications from a physical data centre to a cloud-based platform. This was exacerbated with a slowing of the migration of systems at the height of the COVID-19 pandemic in early 2020

in the interest of patient safety during this uncertain period. Due to the delays in installing the system, the expected level of PROM data capture has not been fully achieved.

The impact of these deferrals was largely mitigated, however, by:

- adapting processes and re-prioritising activities;
- commencing other aspects of the program of work earlier than originally envisioned; and
- introducing new opportunities for other related projects that were not initially foreseen (e.g. CIC Cancer inclusion in the state-wide data strategy for cancer data services in WA).

Attainment of 2021 research aims

The key aims for 2021 have predominantly been achieved during this reporting period. Further details about each item have been included throughout this report.

Table 1: Progress for 2021 research aims

Key research aims for 2021	Achieved
Piloting ovarian dataset	✓
Uploading the informatics platform to WA Health	✓
Interoperability with patient administration system	✓
Analytics and visualisation	✓
Integrated capture of prostate cancer data	On hold awaiting external decisions
Data extraction and commencement of data analysis	✓
WA Health Experience Survey	✓
Pilot project to test 'bundles of care' commenced	✓
VBHC Conference	✓
Students trained	✓

Achievement of desired outcomes

Summary of achievement of desired outcomes, milestones and KPIs

Desired Outcome/Milestone/KPI	Phase	Achieved
1. Clinician and consumer engagement and input informs data collection and research needs	1	✓
2. 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	2	✓
3. Inclusion of additional projects within the overall program of research and access to additional funding	All	✓
4. A definition of datasets for each nominated tumour type	2	Mostly - Awaiting prostate cancer dataset from external parties. In place for all other cancers
5. Human Research Ethics Committee approval	All	✓
6. Collaborations locally, nationally and internationally	All	✓
7. Publications, presentations, including scientific, policy and consumer	All	✓
8. Students trained	All	✓
9. Outcomes important to patients are measured and the information is used to benchmark and inform care provision across sites and the disease trajectory	3	In progress
10. Consumer input informs priority setting for research work into improvements in care provision	1	In progress
11. 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	4	In progress
12. Understanding of value-based health care is increased International conference hosted	1 & 4 5	✓ ✓
13. The ICHOM standard datasets are enhanced and improved through the results of WA trials	3	✓
14. ICT systems and personnel operating at each hospital in each nominated cancer	3	Mostly - Awaiting prostate cancer dataset from external parties. In place for all other cancers
15. Capture of relevant PROMs for each nominated tumour type at each hospital	3	Mostly - Awaiting prostate cancer dataset from external parties. In place for all other cancers
16. Data captured on patients treated at nominated institution p.a.	3	Mostly - Awaiting prostate cancer dataset from external parties. In place for all other cancers
17. Numbers of patients with the nominated tumour types involved in the study across participating hospitals	3	Mostly - Awaiting prostate cancer dataset from external parties. In place for all other cancers
18. Full documentation of clinical tumour stage	3	Mostly - Awaiting prostate cancer dataset from external parties. In place for all other cancers
19. Evidence of treatment based on relevant optimal care pathway	4	In progress
20. Patient assessment of service in place	4	In progress
21. Novel interventions, positive results and translations into clinical care demonstrated in each tumour type at each hospital	4	In progress
22. 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	5	Awaiting further data

23. Cost effectiveness measured	5	In progress
24. 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	5	In progress
25. Measurable improvements in care and cost effectiveness are demonstrated		Awaiting further data
26. Local, national, and international collaboration leads to further successful funding opportunities such as a Program Grant or Centre of Research Excellence		Unlikely to be achieved

1. Stakeholder Engagement

Desired outcome: Clinician and consumer engagement and input informs data collection and research needs

Achieved

A focus on collaboration and stakeholder involvement has continued through 41 activities undertaken between January and November 2021. Highlights included:

- clinician and policymaker involvement in the ‘look and feel’ of data visualisation dashboards;
- final consultations with women with ovarian cancer as part of the development of the ovarian cancer dataset;
- a Community Conversation held as part of the VBHC conference in May 2021;
- presentation of findings from the in-depth review of patient pathways to multidisciplinary team meetings at Royal Perth Hospital (see Section 19). This involved discussion of a detailed clinical review of individual patient journeys for colorectal, lung and breast cancer types mapped to the Optimal Care Pathways (OCPs), with itemised costings and length of time calculated between outpatient occasions of service and inpatient episodes; and
- involvement in 2 new projects to capture consumer viewpoints.

The hosting of the Value-based Healthcare Conference was a major initiative to engage stakeholders from within WA, nationally and internationally. The increased interest generated in CIC Cancer as a result of this initiative can be seen in the increase in online and social media activity. Between January and June 2021, there were 11,156 visits (Table 2) to the CIC Cancer website compared to 1,847 for the same period in 2020. The majority of these visitors originated from Australia (67.8%) but significant numbers were also seen from the USA (22.8%). Over 9,200 visits (83%) were made via direct access to the site. Over the period, 21,369 pages were viewed (583% increase on the same period in the previous year). As expected, the conference related pages were the most highly viewed.

Table 2: Visits to CIC Cancer website between January and June 2021

Month	Week 1	Week 2	Week 3	Week 4	Week 5	Total
January	108	139	191	186	60	684
February	322	412	433	671	n/a	1,838
March	268	230	442	710	286	1,936
April	435	661	563	696	n/a	2,355
May	667	674	806	1,386	108	3,641
June	280	193	126	103	n/a	702

Visits to the CIC Cancer Twitter handle were also active during this time with CIC Tweets viewed a total of 10,028 times through direct viewing, being displayed in a follower’s timeline, or as a result of being ‘liked’.

Table 3: Visits to CIC Cancer Twitter handle Jan-June 2021

Month	Tweets	Tweet Impressions	Profile Visits	New Followers	External Mentions
January	1	991	59	3	0
February	5	2,698	243	2	10
March	1	1,109	156	2	2
April	0	328	98	4	2
May	3	1,371	846	24	57
June	3	3,531	55	5	4

Further outcomes of the conference have been discussed in greater detail in Section 12.

2. ICT system development

Desired outcome: 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

Achieved and ongoing

The CIC Cancer informatics platform development has progressed in 2021 through the following activities.

- Implementation of the ovarian cancer dataset within WA Health, SJoG and as an external site for use by an adjunct study.
- Uploading of the platform into WA Health’s new cloud-based system – the first external platform to be uploaded and prior to several of the currently used WA Health platforms.
- Penetration testing and security vulnerabilities identification and assessment.
- Regression testing to verify functionality post-installation at HSS.
- User Acceptance Testing (UAT) to validate end-to-end workflows, system behaviour and functionality for users (staff and patients) post-installation at HSS and with any system changes.
- Development of prototype data analytics and visualisation of outcomes for review by clinical champions.
- Integration with current WA Health enterprise systems.

Ovarian cancer dataset

The ovarian cancer dataset (including both clinical data and PROMs) has been finalised and uploaded to the CIC Cancer informatics platform.

The ovarian dataset developed as part of CIC Cancer is also being externally piloted through an additional project undertaken in collaboration with CIC Cancer called *Getting the MOST out of Ovarian Cancer Follow-Up* – a Phase II multi-centre randomised trial within WA, NSW, Queensland, and Victoria. This additional use of the PROMs instrument within telehealth-based, nurse-led follow-up processes – in comparison to routine clinic-based follow-up – will allow for additional testing and refining of the dataset.

In order to undertake this additional study, patients complete the PROMs via a separate, interstate accessible, version of the CIC Cancer informatics platform that has been specifically set up for this purpose. During the consultation the nurse conducts a semi-structured interview and reviews the patients’ PROMs responses. The nurse asks the patient questions about symptoms, problems with sleep and concentration, and emotional, psychological, and overall wellbeing. The patient’s responses provide a framework for discussion during the nurse-led consultation, focusing on symptoms that have been bothersome in the last 7 days and/or where there has been a deterioration in any symptom score since the previous follow-up consultation. If appropriate, the nurse makes relevant referrals to address problems identified during this consultation.

This secondary use of the CIC Cancer dataset and informatics platform will allow test-retest reliability of the instrument. Semi-structured interviews will also be conducted with patients and nurses to explore the acceptability of the intervention. In addition, a cost consequence analysis will be undertaken that tabulates the healthcare resource use and costs from a health system and patient perspective; and the health benefits of nurse-led follow up compared with standard care to ascertain incremental costs and benefits of the nurse-led telehealth follow up.

Placement within WA Health

The system architecture for CIC Cancer has now been placed in the Health Support Services Zone A (High Security) *HealthNext* cloud that is the new site for major enterprise systems in WA Health. This will provide access, not only to the public hospital sites currently involved in CIC Cancer, but ultimately, all public health settings. CIC Cancer is the first external system within the new WA Health cloud, with upload occurring prior to many of the current WA Health developed systems. The process for this to occur has been lengthy with significant governance requirements. This was largely due to meeting the required assurances that the system a) met stringent security requirements, b) provided absolute security of confidential patient information, and c) was compatible with existing systems.

As an enterprise system, CIC Cancer is suitable for integration with other systems and ideally placed for long term ownership by the Department of Health. Placement within the significantly transformed IT superstructure that forms the HealthNext program has provided CIC Cancer with legitimacy that will allow for easy transference from research to part of every-day care provision.

Penetration testing

The CIC Cancer IT platform stores potentially critical and sensitive information, such as patient data, and other personally identifiable information. To ensure that this is stored safely and securely, penetration testing was completed in 2021 by 1) the Security and Risk Management team at Health Support Services (HSS) on the version placed within WA Health and 2) a private contractor on the underlying system based at Murdoch University and being used by the external intervention trial for ovarian cancer.

These tests sought to identify and exploit any potential vulnerabilities present in the in-scope web applications and web sites with content accessible via a web browser. The testing processes simulated a threat actor attempting to attack the deployed application through web-accessible interfaces. The presence of vulnerabilities was determined by directing a series of requests to a web application and evaluating the responses received. This allowed precise detection of any active and exploitable vulnerabilities that could potentially circumvent business processes and allow access to data.

The testing identified that the CIC Cancer IT platform is of high quality and robustly constructed. The security issues identified were not of high severity (4 medium and 1 low findings) and were easily rectified.

- An issue was found in a component provided and installed by HSS whereby a relatively older and weaker form of encryption was being utilised. This was addressed with an upgrade to a more recent, stronger algorithm.
- A few out of date JavaScript libraries were exposed within the platform. Reference to these was removed from both the PROMs system and Site system.
- Proactive action was taken to incorporate content security policy header metadata to stop a user's browser from accepting malicious JavaScript code that could be injected into the site by hackers.
- Potentially unsafe use of a function in the software was addressed by strengthening the validation rules for applicability conditions.

Following changes and uploading of a new version of the systems, the HSS Security and Risk Management team performed a second vulnerability assessment to verify the remediation of the issues identified. The assessment revealed that all issues had been successfully and swiftly remediated.

Data analytics and visualisation

Access to effective, user-friendly, interactive, graphical interfaces (dashboards) is key to effective utilisation of the data for 1) comparison and visual display of outcomes for use in patient-clinician interactions, and 2) long-term integration of patient-reported outcomes (PROs) into routine care delivery.

Two grant applications were previously submitted (2019 and 2020) to seek additional funding to implement this work but both were unsuccessful. Mitigation of this was enacted through completion of literature reviews through student placements and provision of funding to Notre Dame University to undertake a simpler sub-project to prepare prototype visual representations suitable for review by clinical stakeholders.

The intention of this visualisation tool prototype is to display and report data for four cancer types: colorectal, breast, ovarian and lung from participating hospital sites. The tool will access patient-reported, patient demographic, and clinical information from the CIC Cancer Informatics Platform and display real-time data in a graphical and interactive format. To limit licensing costs and utilise existing business intelligence software within participating sites, the visualisation tool has been created using Tableau™.

Data visualisation requirements were identified through a series of key stakeholder meetings. The resultant tool prototype consists of a series of linked dashboards displaying patient-reported outcomes at baseline and follow-up; clinical information including disease stage, diagnosis and medical history; and pathology data. Users are also keen to obtain reports on data quality and completion (Figure 1).

Outcome scores will adopt a “traffic light” representation to alert users to best-performing and worst-performing outcome areas (Figure 2). Some further datasheets are under development that will report administrative and clinical trends and comparison data in either tabular or graphical format. For graphical display, trend data will likely be represented in line graph format and composition data will be shown in pie or stacked bar/column (Figure 3).

Figure 1: Feedback obtained from clinicians in relation to data visualisation options

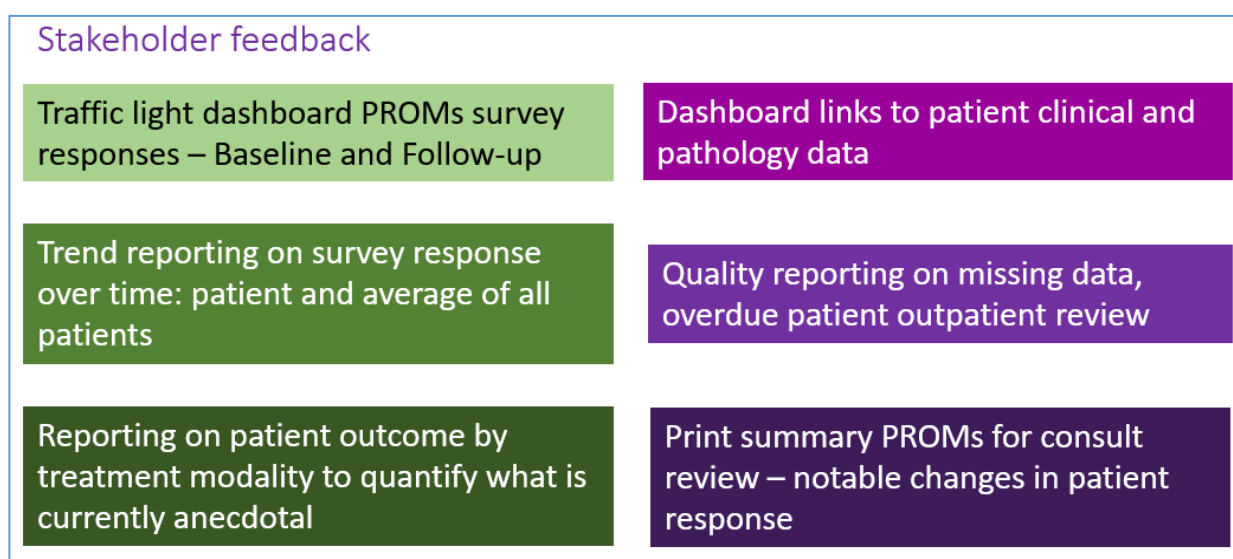


Figure 2: Sample “traffic light” dashboard

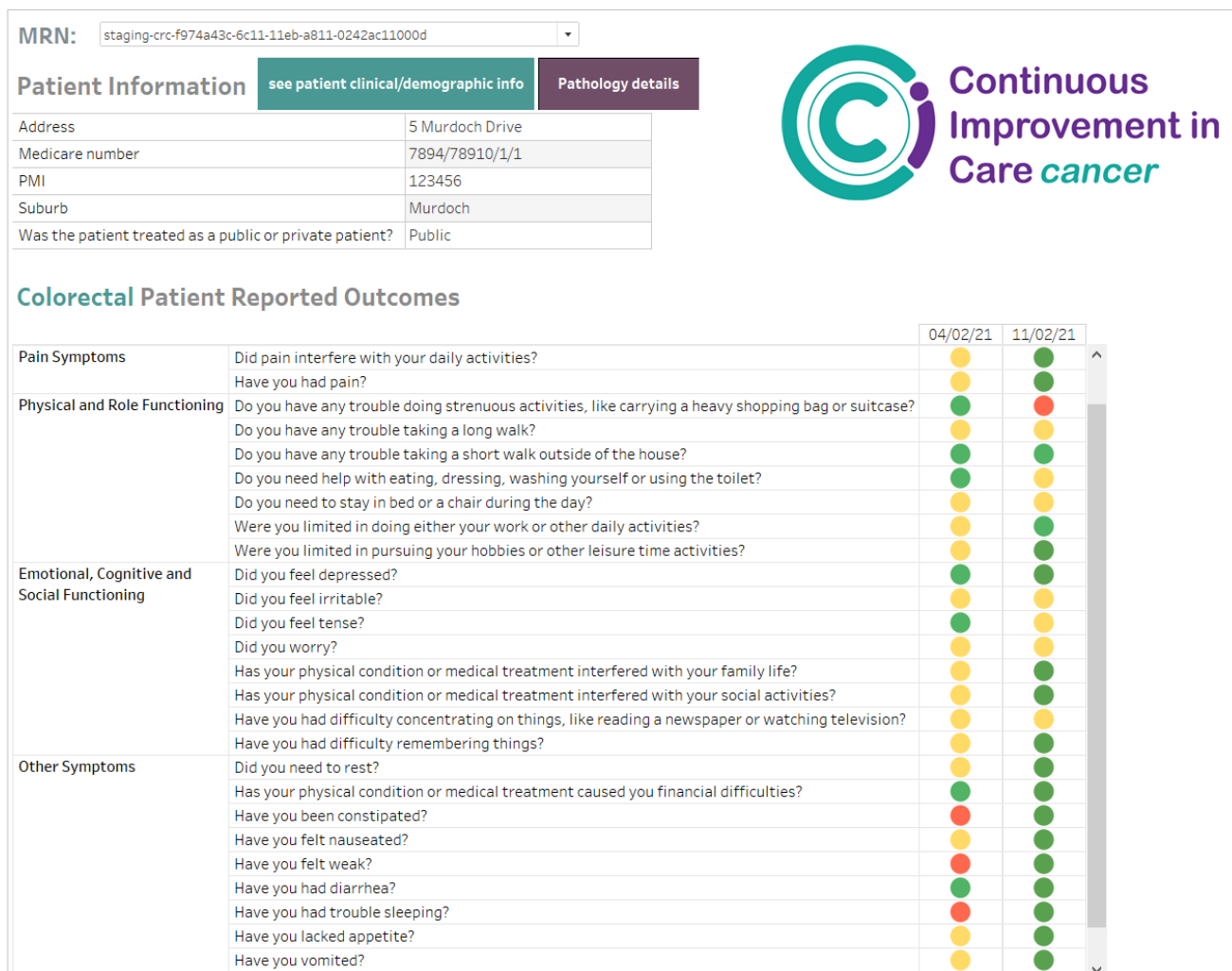


Figure 3: Clinical data presentation

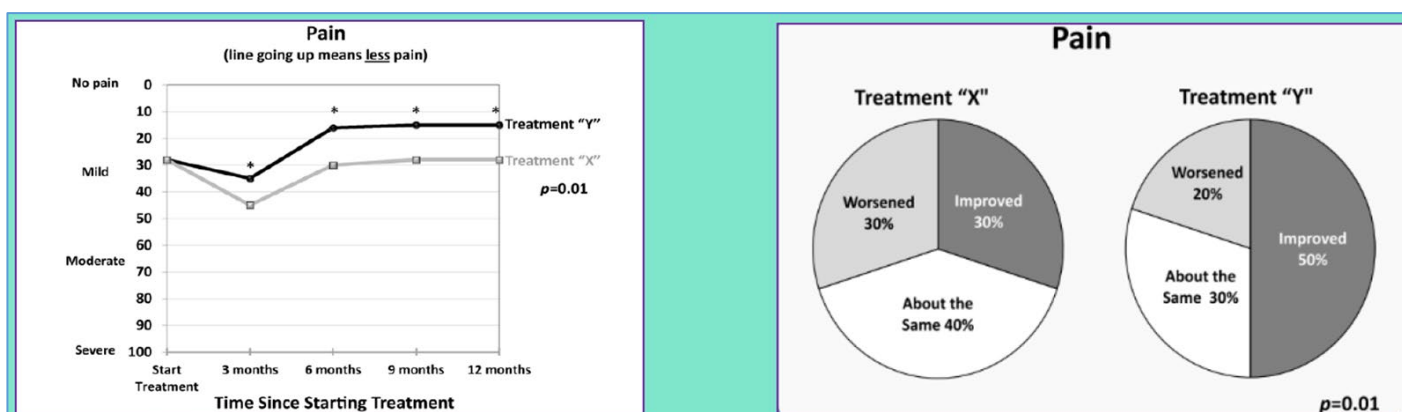


Fig 1. Example of longitudinal PRO displays:

- Multiple points displayed over time
- Simple line graph for patients, more complex data for health professionals
- Line trending up meaning better outcome was most preferred directionality

Fig 2. Example of proportional PRO displays:

- Pie charts were preferred to present proportional changes
- Provides high clarity and well interpreted by both patients and health professionals

Integration with current systems

Access to information already collected within the healthcare services enterprise systems and the ability to pull key demographic and clinical information into CIC Cancer will minimise time inefficiencies, duplication of effort and limit errors associated with double data entry. To this end, integration with other WA Health enterprise systems has commenced, with work completed to pull demographic data from WebPAS, the patient administration system. With demographic data integration in place within the public sector, similar interoperability integrations have commenced with SJoG. Integration to other cancer data collection platforms in both WA Health and SJoG will then be undertaken in a phased approach.

The process of integration with established systems has had to be factored into other HSS priorities, particularly given that not all WA Health systems had been migrated to the HealthNext program. Fortunately, agreement for the WebPAS integration to occur was provided at an earlier point than expected, with only one postponement experienced.

3. Additional Research Projects/Funding

KPI/Milestone: Inclusion of additional projects within the overall program of research and access to additional funding

Achieved

Sub-Projects

A total of 13 sub-projects have been undertaken since implementation of the primary project with 4 commencing in 2021 – two of which were WA Health-funded affiliated projects. In addition, 16 student projects have been undertaken since 2018 with two still underway (see Appendix 1).

Grant Funding

In 2021, two affiliated projects undertaken by the Cancer and Palliative Care Research and Evaluation Unit team received a total of \$344,160 of funding. This brings the total level of additional funding attained by the research team, since the commencement, to \$736,992. Outputs from these projects will feed into the wider CIC Cancer project.

- Understanding Consumers' Needs for Cancer Information, awarded by WA Cancer Network in July 2021
- Provision of Patient Experience Survey, awarded by WA Cancer and Palliative Care Network – Clinical Implementation Unit in February 2021

Two other applications for funding submitted in 2020/21 were unsuccessful – a National Health and Medical Research Council (NHMRC) 2020 Ideas Grants for an Advanced Analytics and Data Visualisation and a WA Cancer and Palliative Care Network 2022 Cancer Related Clinical Fellowship request.

Applications in Progress:

A grant application, for \$2,586,189, for extension and interstate collaboration in the bundled care package project (see Section 11) has been submitted to the Medical Research Futures Fund - 2020 Clinician Researchers: Applied Research in Health grants program. The outcome of this is not yet known.

4. Defined datasets

KPI/Milestone: A definition of datasets for each nominated tumour type

Mostly achieved - Awaiting prostate cancer dataset from external parties. In place for all other cancer types

Ovarian cancer

As noted in Section 2, the sub-project to develop an ovarian cancer dataset is now complete. The goal of this sub-project was to identify an agreed set of case-mix variables and outcome measures to be used in CIC Cancer and other studies pertaining to ovarian cancer. The project was undertaken through 1) a review of the literature; 2) comparison to existing International Consortium for Health Outcome Measures (ICHOM) cancer measures; 3) consumer group consultation; 4) consumer and clinician consultation; and 5) pilot testing.

The “patient voice” was captured through a qualitative descriptive approach which included a community conversation with ovarian cancer patients, their carers, and clinicians together with interviews and focus groups with women with ovarian cancer. Using a “ground-up approach”, the consumer consultation component sought to comprehensively understand the health concerns that matter most to women with ovarian cancer as a first step in generating items for development into an ovarian cancer-specific PROMs. Thirteen women were interviewed individually, and two focus groups were conducted with thematic analysis used to analyse the data. The resulting key themes identified included challenges related to clinical diagnosis, treatment phase, altered relationships with family/friends, financial issues, relationships with health professionals, and coping strategies. Within each key theme, several sub-themes emerged that were identified as various challenges experienced by participants. Diagnostic delay, chemotherapy and surgery-related challenges, negative impact of sexual well-being on partner relationship, and communication challenges with health professionals were among the issues identified. In addition, self-empowerment was identified as a coping mechanism among participants.

This process was then followed by cognitive interviewing, conducted with 14 women to test the questionnaire items. Following thematic analysis, four themes were identified in relation to the questionnaire structure and item comprehension. All these processes combined resulted in a set of 38 health-related quality of life items – 7 physical wellbeing, 21 emotional wellbeing, and 10 social wellbeing items – were identified as having meaning to the participants; creating a new tool specific to women diagnosed with ovarian cancer.

The resultant dataset was incorporated into the CIC Cancer platform for implementation in King Edward Memorial Hospital and the private consulting rooms at SJoG Subiaco Hospital. There is potential to also include patients who have had surgery at Hollywood Hospital and SJoG Murdoch Hospital to increase recruitment numbers.

Prostate cancer

Prostate cancer data collection has yet to start for several reasons. Originally ICHOM datasets (local and advanced prostate cancer) were to be used but these did not meet clinical needs. As such it was decided by the clinical leads to link in with the Prostate Cancer Outcomes Registry (PCOR) Australia which was to be implemented in WA. There were some delays in agreement on how this could be progressed and the most appropriate way for the PCOR and CIC Cancer to merge. This delay coincided with major changes in the framework and contracts for the PCOR nationally, therefore it was agreed that rather than start moving forward immediately it would be more appropriate to wait until the new framework and contracts were developed. It is now anticipated that this work will start in 2022.

5. Ethics Approval

KPI/Milestone: Human Research Ethics Committee approval for the work

Achieved

In this reporting period, additional ethics approval was obtained for amendments to the research protocol.

- Addition of breast cancer at Fiona Stanley Hospital (FSH) to the CIC Cancer Project with changes to research team members to reflect this and the addition of patient information materials to assist in recruitment at the FSH Breast Assessment Clinic.
- Provision of aggregated de-identified breast cancer data to Organisation for Economic Cooperation and Development (OECD) Paris initiative.
- Addition of the ovarian cancer dataset to the Research Protocol and addition of patient information materials to assist in recruitment at King Edward Memorial Hospital (KEMH).
- Update to Recruitment numbers to reflect the delays in commencement.
- Addition of further students to the research team.
- Student-led qualitative sub-study to understand financial decision points when patients opt to undergo cancer treatment in either the public or private sector.
- Integration with other enterprises systems, commencing with the patient administration system.
- Development and integration of data visualisation overlay (dashboards).

6. Collaborations locally, nationally and internationally

KPI/Milestone: Collaborations locally, nationally and internationally

Achieved

A further 24 key activities have been undertaken to enhance opportunities for in-depth collaboration. Outcomes from these discussions have been incorporated into various sections of this report.

Highlights have included:

- The inaugural value-based healthcare conference held in May 2021 in partnership with the Australian Healthcare and Hospitals Association and Australian Centre for Value-Based HealthCare.
- Following the highly successful VBHC conference, Elizabeth Koff, Secretary of the NSW Ministry of Health indicated that NSW Health are keen to work with CIC Cancer to implement more wide-reaching research.
- Provision of aggregated breast cancer PROMs data to the OECD for 2021 data collection. This has assisted in strengthening international measurement of patient-reported outcomes of care.
- Collaboration is underway with the team at the Centre for Health Economics Research and Evaluation (CHERE) led by Prof Jane Hall, based at the University of Technology Sydney, for the implementation of economic and evaluation activities associated with the bundled care package sub-project. This work will be undertaken as a part of the NHMRC's Centre for Research Excellence (CRE) - Value-based Cancer Care Payments and will provide one of the first real-world projects for this new CRE.
- Involvement in the WA Health Clinical Senate session held in October 2021. The focus of this workshop and debate was value-based healthcare and many of the wider project team were involved as presenters or expert witnesses assisting in the deliberations of the Senate.
- Involvement in a new European-based project to determine how to bring together the fields of Person-Centred Health Care and VBHC while ensuring population equity. The CIC Cancer project team were part of the international community of experts to work through a structured methodology for achieving Person Centred Valued Based Healthcare, resulting in the launching of a report (<https://www.sprink.co.uk/pcvbhc-report/>) and proposed Global Centre.

- Participation in the Research Australia Health Economics Roundtable held to discuss value-based care and how it could be used as a means to drive faster translation of research into action.
- Professor Christobel Saunders has been appointed to the board of All.Can International as global Vice-President. This appointment further incorporates CIC Cancer within an international forum. Other board members represent the European Cancer Organisation, European Cancer Patient Coalition, World Bladder Cancer Patient Coalition, and Bristol Myers Squibb.
- Listing of CIC Cancer on the Australian Register of Clinical Registries on the Australian Commission on Safety and Quality in Health Care website. This will facilitate collaboration and awareness of registry activity among key stakeholders.
- Extension of the reach and applicability of the learnings of CIC Cancer through involvement in the Value Based Cancer Care Program Steering Group of the Victorian Comprehensive Cancer Centre (VCCC) Strategic Program Plan 2021-24.
- As part of this work with the VCCC and contacts with the Victorian Department of Health, collaboration will be enacted to expand the CIC model of data capture and feedback on cancer outcomes into Victoria.
- Provision of advice to the Jewish General Hospital in Canada in relation to experience in implementation of the ICHOM colorectal cancer standard dataset, following a targeted request from ICHOM to connect current and emerging users.

Continued collaboration has also been undertaken with national bodies such as the Clinical Oncology Society of Australia and international bodies such as All.Can, ICHOM, and PROTEUS-Practice Consortium (Patient-Reported Outcomes Tools: Engaging Users & Stakeholders - Advancing the Use of PROs in Clinical Practice), to enhance knowledge of value-based healthcare implementation and awareness of CIC Cancer work.

7. Publications, presentations, both scientific, policy and consumer

KPI/Milestone: Publications, presentations, including scientific, policy and consumer
Achieved and Ongoing

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

Table 4: Publications for the reporting period

Title	Submission to	Date	Type
"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 Sept 20 – rejected Published Dec 2020	Peer-reviewed Letter to the Editor
Women diagnosed with ovarian cancer: Patient and carer experiences and perspectives	Patient Related Outcome Measures	Published Feb 21	Peer-reviewed Article
Employing cognitive interviewing to evaluate, improve and validate items for measuring the health-related quality of life of women diagnosed with ovarian cancer	Quality of Life Research - rejected Patient Education of Counselling Health and Quality of Life Outcomes	Submitted Nov 20 – rejected Submitted May 21 – rejected Submitted July 2021	Peer-reviewed Article
Priority Recommendations for the Implementation of Patient Reported Outcomes in Clinical Cancer Care: A Delphi study	Journal of Cancer Survivorship	Accepted for publication Nov 21	Peer-reviewed Article
Life after cancer is more than just survival	Oncology Republic	Published August 2021	Article

Getting the MOST out of follow-up: a randomized controlled trial comparing three-monthly nurse-led follow-up via telehealth, including monitoring CA125 and patient reported outcomes using the MOST (Measure of Ovarian Symptoms and Treatment concerns) with routine clinic-based or telehealth follow-up, following completion of first-line chemotherapy in patients with epithelial ovarian cancer	International Journal of Gynaecological Cancer	Published Sept 2021	Peer-reviewed Article
Co-intelligence: Knowledge exchange overtaking competition to drive global cancer care progress	Oncology News	Published September 2021	Article
The CIC Cancer project: Improving outcomes that patients really want	Research Australia INSPIRE	Submitted Sept 21	Article

Posters/Presentations

In addition to the publications listed above, several presentations were provided at conferences.

Table 5: Posters and presentations provided during the reporting period

Title	Submission to	Date	Type
What is Value Based Health Care and why measure patient-reported outcomes?	Science on the Swan Conference	May 2021	Oral conference presentation
Patient involvement in the development of a patient-reported outcome measure for ovarian cancer	22nd World Congress of Psycho-Oncology & Psychosocial Academy (Japan)	May 2021	Oral conference presentation
Value-based health care in cancer: why it matters and how can we improve it	UWA Medical School Research Day	May 2021	Oral presentation
First steps in patient-reported outcomes data visualisation for breast cancer	VBHC Conference	27-28 May 2021	Oral conference presentation
Reducing out-of-pocket expenses and optimising cancer care through bundled packages	VBHC Conference	27-28 May 2021	Oral conference presentation
Digital collection of outcome data in lung cancer: First steps	VBHC Conference	27-28 May 2021	Oral conference presentation
How patients feel about the collection of PROs	VBHC Conference	27-28 May 2021	Oral conference presentation
PCVBHC: Implementation and recommendations	Launch of Person Centred VBHC	Sept 21	Seminar presentation
What is Value-Based Health Care?	WA Clinical Senate	Oct 21	Seminar presentation
Optimising patient journeys for better value care	Research Australia Health Economics Roundtable	Oct 21	Seminar presentation
Priority Recommendations for the Implementation of Patient Reported Outcomes in Clinical Cancer Care: A Delphi study	Clinical Oncology Society of Australia	Nov 21	Oral presentation
How can we get better value in delivering cancer surgery and care?	Networks in Anaesthesia and Surgery	Dec 2021	Oral presentation
Harnessing data to iteratively improve cancer care	The Economist World Cancer Series	Dec 2021	Seminar presentation

Media

Table 6: Media releases, stories and on-line blogs for the reporting period

Distributed by	Media Title	In relation to	Date
Australian Healthcare and Hospitals Association	Three Australian health services honoured in the Value-Based Health Care Awards	Awards presented at the inaugural Value-Based Health Care Conference	28/5/21
All.Can/The Health Policy Partnership and re-published by European Cancer Patient Collaboration	Cancer organisation All.Can international Publishes landmark report: 'Harnessing data for better cancer care'	Christobel Saunders quoted in a publication of a major new report: <i>Harnessing data for better cancer care</i>	27/5/21
All.Can	Taking forward recommendations from the All.Can Report, 'Harnessing data for better cancer care'	Blog piece	July 21
All.Can	Australian Value Based Healthcare Conference sheds light on great ideas put into practice	Blog piece	August 2021
All.Can	Bundling care in early breast cancer	Blog piece	August 2021
All.Can	Co-intelligence: Knowledge exchange overtaking competition to drive global cancer care progress	Blog piece	23/9/21

8. Students trained

KPI/Milestone: Students trained
Achieved and Ongoing

The CIC Cancer Project 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 2021, students continued to work on research projects commenced in 2020 and started two new sub-projects.

- Clinical and PROMs (quality of life) outcomes in patients with stage one lung cancer undergoing curative surgical therapy and stereotactic radiation therapy (continuation from 2020).
- Public or Private care? Analysis of the financial decision-making process of women with breast cancer (continuation from 2020).
- Exploring patient views about importance of patient reported outcome measures (PROMs) in management of lung cancer patients.
- In-depth review of measurement of adherence to the optimal care pathway for people with colorectal cancer in Western Australia.

Two projects were submitted to the WA Health Graduate Development Program in 2021 as part of an arrangement to host a graduate officer. This program provides leadership development to a diverse group of recent university graduates through a 12-month program, giving graduates an opportunity to work across the WA health system. These EOI applications sought to inform beginning policymaking in the healthcare sector, particularly informing healthcare systems about how to improve health outcomes that matter most to

patients. It was hoped that this work would have a direct influence on the implementation of value-based health care protocols and systems in WA, but as graduate placement opportunities are highly subscribed, neither project was taken up.

PhD Students

Concepts for potential PhD opportunities have been difficult to formulate prior to sufficient data capture and analysis. As CIC Cancer data collection progressed, this was resolved and PhD opportunities and scholarships were advertised in August 2021. To date, interest has been voiced by a clinician involved in CIC Cancer activities, current staff and students involved in the project, and 3 external applicants. Discussion about potential collaboration for PhD students is also underway, but not yet finalised, with:

- Murdoch University; and
- Professors Kees van Gool and Jane Hall at the Paying for Value Centre for Research Excellence at the University of Technology, Sydney.

9. Outcomes Measurement

Desired outcome: Outcomes important to patients are measured and the information is used to benchmark and inform care provision across sites and the disease trajectory

In Progress

Data analysis has commenced for patient-reported outcomes of participants diagnosed with colorectal, breast or lung cancer at Royal Perth Hospital between November 2019 and April 2021. The analysis for colorectal cancer is the most advanced of these three groups and, as such, is presented below.

Data was collected for 44 colorectal cancer participants, but five patients were removed from the group. As a result, the analyses presented here are based on the remaining 39 patients. The calculated scores were compared between baseline, 6-months and 1-year timepoints with means calculated for all available data. Missing data included patients who were not due to respond at the time of the analysis, patients who had died, or patients who had not returned their PROMs at the time of data extraction.

The preliminary results indicate that, for this small sample of participants with colorectal cancer:

- appetite loss was seen to increase between baseline and 6 months;
- the symptom of constipation is approaching significant improvement between baseline and 12 months;
- conversely, the symptom of diarrhoea significantly worsened between baseline and 12 months;
- financial difficulties experienced by participants had significantly worsened at 12 months (Table 7); and
- a patient's ability to provide self-care (washing and dressing) worsened over time (Table 8).

No significant differences were noted between timepoints for any other variable.

It should be noted that the analyses presented here are preliminary and the level of data is insufficient to draw any meaningful conclusions. Further data is needed to confirm these suggestions.

Table 7: Mean scores for EORTC-QLQ-Q30 scoring variables

Variable	Baseline (n=39)		6 months (n=22)		1 year (n=18)		p-value
	Mean (SD)	Friedman Mean Rank	Mean (SD)	Friedman Mean Rank	Mean (SD)	Friedman Mean Rank	
Functional - Higher score = better functioning							
Global Health Status (QL2)	68.80 (24.31)	1.93	71.97 (19.85)	2.11	76.85 (22.32)	1.96	0.84
Physical functioning (PF2)	83.93 (17.95)	2.07	79.09 (23.12)	2.11	79.99 (23.31)	1.82	0.59
Role functioning (RF2)	82.05 (28.45)	2.29	75 (35.16)	1.82	79.62 (33.60)	1.89	0.14
Emotional functioning (EF)	80.56 (16.92)	1.96	82.95 (18.45)	2.18	78.71 (22.90)	1.86	0.63
Cognitive functioning (CF)	83.33 (24.48)		84.09 (19.57)	2.14	76.85 (26.28)	1.86	0.48
Social functioning (SF)	80.34 (28.58)	2.04	78.79 (27.78)	1.96	80.55 (30.38)	2	0.965
Fatigue (FA)	30.77 (29.00)	2.07	35.86 (24.71)	2.07	29.62 (29.27)	1.86	0.787
Symptoms - Higher score = worse symptoms							
Nausea and Vomiting (NV)	7.27 (17.85)	1.86	4.55 (7.59)	1.93	4.63 (9.57)	2.21	0.174
Pain (PA)	22.65 (27.70)	1.82	32.58 (30.20)	2.29	21.30 (32.23)	1.89	0.237
Dyspnoea (DY)	12.82 (23.71)	1.93	10.60 (25.99)	1.93	5.55 (12.78)	2.14	0.135
Insomnia (SL)	19.66 (26.17)	2.04	22.73 (23.87)	1.93	24.07 (27.54)	2.04	0.819
Appetite loss (AP)	12.82 (23.71)	1.71	22.726 (25.99)	2.32	7.41 (18.27)	1.96	0.036*
Constipation (CO)	18.80 (25.12)	2.29	12.12 (21.93)	1.79	12.96 (28.32)	1.92	0.039**
Diarrhoea (DI)	15.38 (18.48)	1.63	19.69 (22.20)	2.13	24.07 (27.54)	2.25	0.072***
Financial difficulties (FI)	18.80 (29.41)	1.86	15.15 (22.36)	1.96	20.37 (36.40)	2.18	0.097^

* Significant only for Baseline vs 6-months (Wilcoxon test p=0.039)

** Nearly significant for Baseline vs 1-year (Wilcoxon test p=0.063)

***Significant for Baseline vs 1 year (Wilcoxon test p=0.034)

^Significant for Baseline vs 1 year (Wilcoxon test p=0.034).

Table 8: Mean and standard deviation for EQ5D

	Mean (SD)	Mean (SD)	Mean (SD)	p
EQ_Mobility	1.46 (0.88)	1.46 (0.77)	1.77 (0.92)	0.28
EQ_Selfcare	1.23 (0.83)	1.31 (1.11)	1.46 (1.12)	0.097
EQ_Usual Activities	1.46 (0.77)	1.69 (1.25)	1.76 (1.16)	0.42
EQ_Pain_Discomfort	1.77 (1.09)	1.77 (0.83)	1.53 (0.66)	0.459
EQ_Anxiety / Depression	1.75 (0.45)	1.41 (0.67)	1.58 (0.99)	0.273
EQ_Health_Rate	76.25 (14.94)	75.8 (17.56)	76.08 (20.72)	0.976

10. Consumer Priority setting

Desired outcome: Consumer input informs priority setting for research work into improvements in care provision

In Progress

Several activities have been initiated during this reporting period to ensure that consumer input informs priority setting for improvements in care provision.

Community Conversation - VBHC

A 3-hour Community Conversation was held as the opening event for a series of discussion forums incorporated into the VBHC Conference Program. This roundtable-style workshop was organised with the aim of enabling consumers to provide input about what is important for the implementation of VBHC and to recommend practical strategies within a WA health services context.

Three questions provided a focus for the Community Conversation.

1. What are the factors you consider when making decisions about health care?
2. How can health providers improve the way they engage with you about outcomes and costs?
3. How can we help people better navigate the health system?

The key issues identified by consumers as shaping their decision-making regarding healthcare are as follows (in priority order).

- Effective communication and engaged dialogue are vital, where both healthcare providers and consumers actively participate. Good communication is also critical to building trust and respect.
- Appropriate Information is required to allow consumers to make informed choices and understand the options available regarding their condition and recommended treatment/care (including short-term & long-term outcomes). This would then ensure that consumers are in a position to 'strike a balance' in making the best decision for themselves or someone they care for.
- Transparency of information is required regarding tests, procedures, medications and outcomes, and in particular, financial implications.

The feedback and recommendations arising from this event were then fed into two healthcare-professional and policymaker focused sessions centred on VBHC in primary care and the wider healthcare sector.

Patient experience of care

A project is underway to identify areas in cancer care that are important to patients and to better understand patient experiences across the cancer journey. The research incorporates a survey, based on the All.Can

survey to collect data reflecting various patient experiences, ranging from cancer diagnosis, care and treatment, to the continuing support and financial implications of cancer on patient quality of life (Section 20).

Consumer information needs

A further project is underway to map available cancer information to the informational needs of consumers and recommend solutions to address any gaps identified. To achieve this, the research will review cancer information currently available to consumers in relation to diagnosis, treatment and provision of supportive care and services, and engage with consumers and key stakeholders to identify unmet needs (see Section 20).

11. Identification and implementation of new interventions

Desired outcome: 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

In progress

CIC Cancer has generated several new and previously unforeseen opportunities in the form of innovative VBHC-specific sub-projects to improve healthcare outcomes for cancer patients in WA. A key activity being the introduction of a bundled care payment model working with other healthcare service providers, such as GenesisCare and private health insurance providers.

Bundled care packages

Despite improving outcomes for people diagnosed with cancer, challenges remain in improving survival and quality of life. Global research has clearly demonstrated that cancer patients/carers commonly perceive four main obstacles to their care and wellbeing: the need to improve efficiency in diagnosis, the need for more “joined up” holistic care, psychosocial challenges and support, and the financial impact of care.

A CIC Cancer sub-project is underway to establish for the first time in Australia, whether it is possible to deliver measurably excellent co-ordinated cancer care and support – including outcomes most valued by patients, at a transparent and efficient cost to both the patient and the healthcare system – through bundled care packages. This work will occur in the private setting, where 50% of cancer care in Australia takes place, funded by private health insurers (PHI), Medicare, and patients themselves.

This project aims to deliver a holistic package of care and support to people newly diagnosed with early breast cancer, at an upfront, known cost, with measurable excellent outcomes and improved efficiencies in the delivery of care. Through focus groups, the value proposition of this bundled care payment approach has been tested with patients who have received their cancer care through the public and private healthcare systems. One participant’s view of the bundled care payment package was:

Patient D: “I think the package is a fantastic idea. I kept an excel spreadsheet. I went through the private system as well. After 3 years, I was \$35,000 out of pocket. When people can look at it as a whole amount and factor it into their decision making this is really important.”

In consultation with insurers, providers and clinicians in WA, treatment bundles were developed for insured patients opting to undergo care privately. These bundles incentivise providers and clinicians to offer the best quality care and outcomes for the most efficient cost possible and incorporate care co-ordination for the patients. This model creates pre-negotiated bundles of care which follow the Optimal Care Pathway and

shifts service utilisation risk from the patient to a patient care navigator and fundholder (GenesisCare). This shift provides patients with:

- upfront knowledge of the cost of their care over a 12-month period including all surgical and allied health services regardless of utilisation;
- support from a patient care navigator throughout all treatment and post-treatment for up to 12 months;
- payment by instalments (if needed) over 12 months; and
- an understanding of the care offered throughout, services available, and how to access them.

12. Enhanced understanding of VBHC/International conference

Desired outcome: Understanding of value-based health care is increased

Achieved

VBHC Conference

In May 2021, the inaugural Value-Based Health Care (VBHC) Conference was held in Perth. The conference demonstrated how VBHC is transforming healthcare nationally and internationally, with a ‘patient first’ approach lying at the heart of all initiatives presented. This event was hosted by CIC Cancer in partnership with the Australian Healthcare and Hospitals Association (AHHA). Sponsorship for the conference was provided by 14 organisations – ranging from State health departments and primary care agencies, the university and research funding sector, corporate sector, health insurance sector, and private hospital sector.

The conference was undertaken with the aim of providing an opportunity for attendees to increase their understanding of all aspects of a patient-centred approach to VBHC and to encourage further innovation and capacity building. The 2-day program incorporated plenary sessions presented by six expert keynote speakers and 55 concurrent sessions. Concurrent sessions were delineated into topic-related streams, with special sessions included to facilitate greater discussion, sharing of ideas, and collaboration on key issues. This sought to provide delegates with an opportunity to hear from others, both across Australia and internationally, about the practical strategies they had used to progress VBHC across a broad range of areas within healthcare systems through innovation, project initiatives, implementation, research, and training.

Outcomes

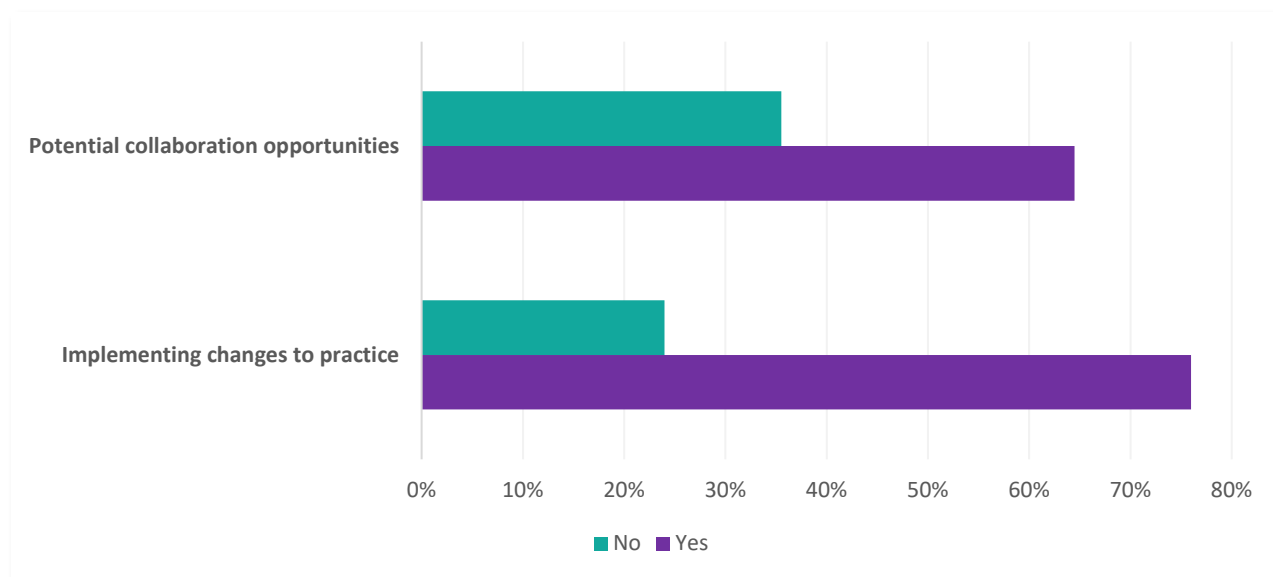
Both informal and formal feedback on the VBHC Conference was extremely positive with the majority of attendees commenting on the value of the conference and the calibre of the keynote speakers. Information gathered from the formal evaluation survey provided to attendees highlighted that despite the challenges COVID-19 posed, the conference achieved its desired outcomes. It provided a high quality, valuable opportunity for attendees to build on their knowledge and understanding of not only VBHC principles, but also the importance of capturing patient-reported outcomes in improving patient care. The key impacts of the conference were reported as:

- the impetus that attendance gave to implementation of changes to practice or future projects; and
- identification of opportunities for potential collaboration on VBHC activities.

When asked if attendance at the conference had proved valuable to current work undertaken, 81.5% of evaluation survey respondents rated attendance as ‘Valuable’ or ‘Very valuable’. Of greater importance, three quarters of respondents (76%) indicated that they would anticipate implementing changes to their practice or future projects, and almost 65% indicated that potential collaboration opportunities had been

identified as a result of attending the VBHC Conference (Figure 5). Almost 9 in 10 respondents (88.16%) indicated that they would be interested in hearing about any future events related to VBHC.

Figure 4: Perceived likelihood of change to practice and collaboration opportunities arising from attendance



An unexpected outcome of the conference is the request from Elizabeth Koff, Secretary of the NSW Ministry of Health, for identification of potential opportunities for CIC Cancer and NSW Health to collaborate in VBHC activities.

Following the success of the May 2021 VBHC Conference, AHHA have commenced activities to continue the momentum by hosting a second conference in May 2023. Their partner for this event is not yet known.

Clinical Senate

Another unexpected outcome of the VBHC conference was the decision by the WA Clinical Senate to focus their October 2021 debate on value-based healthcare, and if agreement by the Senate was reached, to make this the future focus of their work. The Clinical Senate is an independent body and comprises more than 80 members drawn from diverse clinical backgrounds, professional skill sets, and both metropolitan and rural areas of the state. The purpose is to generate informed, impartial and integrated advice for the Health Executive Committee and wider WA healthcare system on system-wide issues requiring diverse perspectives and innovative thinking.

The chair of the Clinical Senate – Associate Professor Anthony Bell – and other members of the Clinical Senate Executive had attended the conference and/or the pre-conference workshop and, following these events, determined that VBHC should form the basis of the 2-day Senate Debate in October 2021 with CIC Cancer playing an important role in these discussions.

The debate aimed to align the principles of Value-Based Health Care to the Strategic Direction of the Clinical Senate in moving forward with the WA Sustainable Health Review, through exploring ways in which clinicians can make small changes towards increasing value for patients. Feedback from the debate suggested that almost 90% of attendees found that the debate contributed to them having a deeper understanding of the topic, and that this will now form the focus of ongoing engagement with WA Health.

13. Enhancement of ICHOM datasets

Desired outcome: The ICHOM standard datasets are enhanced and improved through the results of WA trials
Achieved

Work to assist ICHOM to update and harmonise the breast cancer standard dataset continued in 2021. The information provided drew on the learnings from the CIC Cancer breast cancer pilot and issues experienced with interpretation of the data fields to ensure consistent data capture across all users.

This work has led to CIC Cancer involvement in ICHOM’s development of benchmarks for data collected in the breast cancer standard dataset. The benchmark collaboration will provide the healthcare community with a unique platform to benchmark patient outcomes internationally, enabling faster learning and improvements of healthcare across the globe. It is hoped that standardised outcomes measurement will play a critical role in the development of precision medicine, provide the data needed for informed patient choice and ultimately, alignment around the goals required for the application of machine learning and artificial intelligence to optimise healthcare delivery.

Experience with the CIC Cancer breast cancer dataset also led to two of the researchers being involved in the development of an ICHOM Metastatic Breast Cancer Dataset. This new dataset is currently going through a Delphi process to determine fields for inclusion.

14. ICT systems and personnel operating at each hospital

Milestone/KPI: ICT systems and personnel operating at each hospital in each nominated cancer
Mostly achieved – Awaiting prostate cancer dataset from external parties. In place for all other cancer types

Data collection is underway across hospital sites involving four cancer types. Feedback from clinical staff and consumers using the bespoke IT system indicates that the platform is working well. In addition, the system is also being used for an external interventional trial across several Australian states and other interventional trial research, such as the Intraoperative Radiotherapy Registry.

The robustness of the system in repelling external ‘hacking’ attempts has been successfully tested by WA Health’s Health Support Service (HSS) and by external review.

15. Capture of PROMs at each site

Milestone/KPI: Capture of relevant PROMs for each nominated tumour type at each hospital
Mostly achieved - Awaiting prostate cancer dataset from external parties. In place for all other cancer types

Patient recruitment and capture of PROMs for each nominated tumour type is underway for four tumour types. A further 2 external projects have opted to utilise the dataset and IT platform to capture PROMs for their research projects.

Table 9: Capture of data per site

Cancer type	Site	Dataset use	Additional data collected
Colorectal	SJoG Midland	Yes	
	Royal Perth (RPH)	Yes	Costing data and adherence to Optimal Care Pathways
	SJoG Subiaco	Awaiting new clinical champion	
Lung	SJoG Midland	Clinical champion disengaged prior to commencement	
	RPH	Yes	Costing data and adherence to Optimal Care Pathways
	SJoG Subiaco	Awaiting new clinical champion	
	FSH	New clinical champion to come on board	
Breast	RPH	Yes	Costing data and adherence to Optimal Care Pathways
	SJoG Subiaco	Yes	
	Fiona Stanley (FSH)	Yes	
	GenesisCare	PROMs use in new bundled payment model project in testing	Costing data, patient experience
	<i>External project Intraoperative Radiation Therapy study at SJoG Subiaco</i>	<i>Yes, PROMs only</i>	
Ovarian	King Edward Memorial (KEMH)	To commence early 2022	
	SJoG Subiaco	Yes	
	<i>External project National OVMOST interventional trial project</i>	Yes	
Prostate	FSH	No	
	SJoG Subiaco	No	
	RPH	No	
	<i>Potentially all hospitals once linked with Prostate Cancer Outcomes Register</i>	<i>No</i>	

Unexpected outcomes

On several occasions the completion of the PROMs at RPH has resulted in identification of significant patient concerns about their symptoms and the prompt enactment of processes to have these patients reviewed.

The implementation of data capture has also resulted in some unforeseen opportunities.

- The colorectal nurses at SJoG Midland have implemented the use of the PROMs for other similar conditions by embedding the data capture into their standard assessment/practice.
- Nurse-led and GP-led survivorship clinics are to be implemented for ongoing colorectal cancer care at RPH and they are keen to implement CIC Cancer PROMs capture into their processes as they feel that this will significantly assist in assessment of patient needs.

16. Treatment data capture at each site

Milestone/KPI: Data captured on patients treated at nominated institution p.a.

Mostly achieved - Awaiting prostate cancer dataset from external parties. In place for all other cancer types

Treatment data and other clinical information has been collected for all colorectal, breast, lung and ovarian cancer patients who have completed PROMs. Treatment data evolves across the patient journey, with changes occurring with each treatment modality, and therefore insufficient data is available as yet for meaningful results to be provided. As such, no attempt has yet been made to analyse this information, other than the sub-set of cases that received an in-depth review against optimal care pathways (see Section 19).

17. Numbers of patients across each site

Milestone/KPI: Numbers of patients with the nominated tumour types involved in the study across participating hospitals

Mostly achieved - Awaiting prostate cancer dataset from external parties. In place for all other cancer types

As of November 2021, a total of 494 patients were involved in the project (Table 10).

Table 10: 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	142	29	17%	0	0%
SJoG Midland	Lung [^]	-	-		-	
SJoG Subiaco	Breast	78	7	8%	0	0%
SJoG Subiaco	Colorectal [^]	-	-		-	
SJoG Subiaco	Ovarian*	1	1	50%	0	0%
SJoG Subiaco	Prostate#	-	-		-	
RPH	Colorectal	46	2	4%	6	13%
RPH	Lung	89	4	4%	16	18%
RPH	Breast	127	12	9%	16	13%
RPH	Prostate#	-	-		-	
KEMH	Ovarian*	-	-		-	
FSH	Prostate#	-	-		-	
FSH	Breast*	11	unknown	unknown	0	0
FSH	Lung *	-	-		-	
TOTAL		494	55	10%	38	8%

[^] Disengaged or no longer available clinical champion

* New site or new dataset with processes still in implementation phase

dataset not yet in place

In addition to the CIC Cancer recruited patients, as at October 2021, the Intraoperative Radiation Therapy study at SJoG Subiaco has captured PROMs for a further 68 patients and the national OVMOST interventional trial project have collected PROMs for 4 patients.

18. Documentation of clinical tumour stage

Milestone/KPI: Full documentation of clinical tumour stage

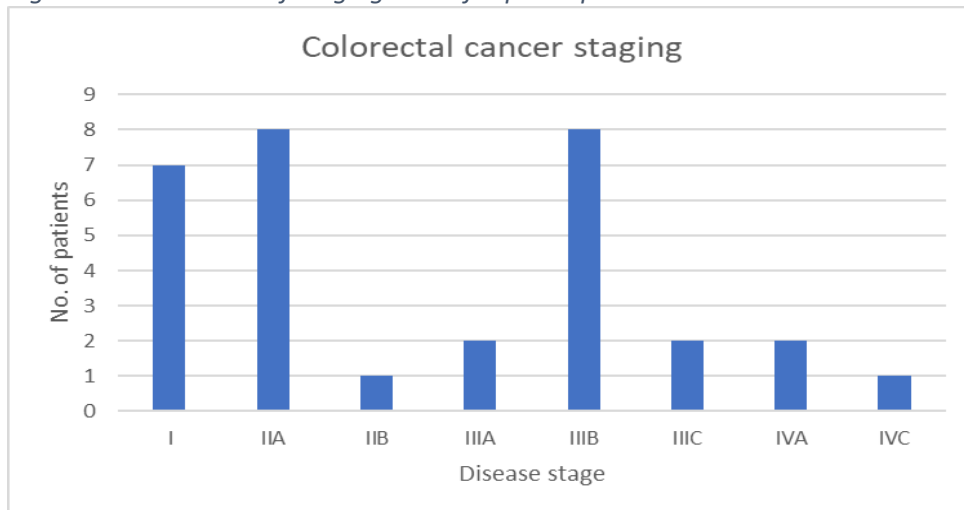
Mostly achieved - Awaiting prostate cancer dataset from external parties. In place for all other cancers

Data collected from more than 250 participants with colorectal, breast and lung cancer, recruited from November 2019 to July 2021, was analysed to identify the cancer stage at the time of initial treatment. Patients were staged using pathological information or, in the absence of this, clinical information. Once clinical and pathological classification was completed the stage group was determined based on the American Joint Committee on Cancer (AJCC) staging system.

Initial results indicate that:

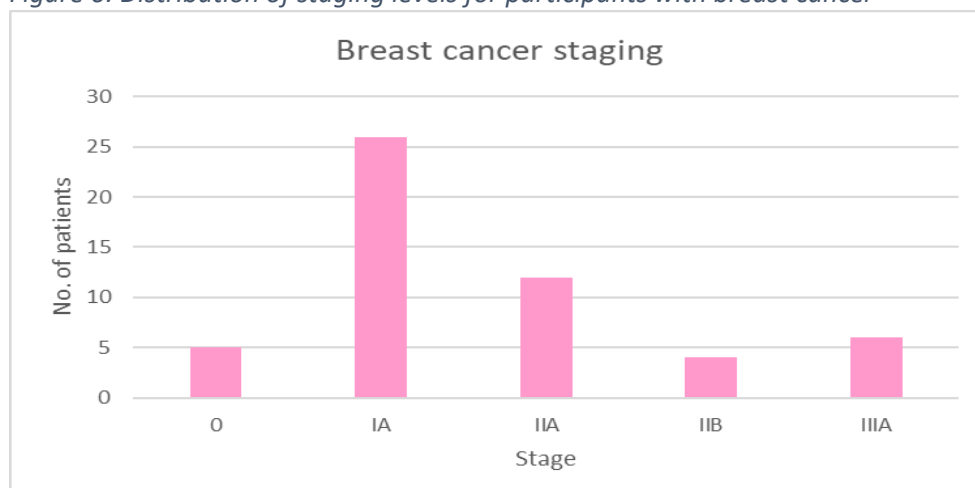
- Of the colorectal cancer patients, 20% were classified as IIA, 20% of patients staged at IIIB, and 17.5% of patients stage I. The remainder of patients were staged at IIB (2.5%), IIIA (5%), IIIC (5%). Metastasis was seen in three patients.

Figure 5: Distribution of staging levels for participants with colorectal cancer



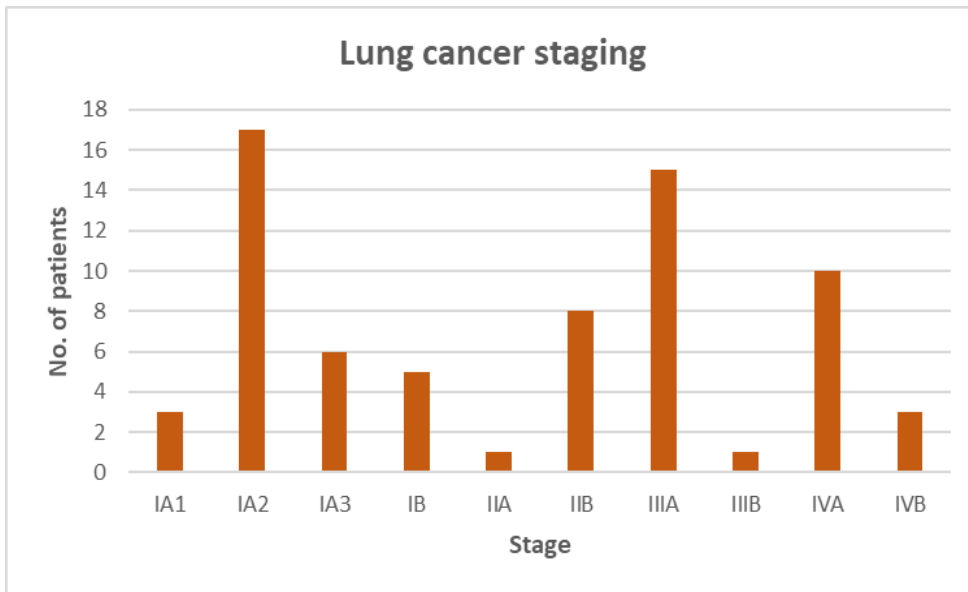
- Of the breast cancer patients, the highest proportion were staged at IA (21.5%), 4.1% were staged at 0, 9.9% at stage IIA, 3.3% at stage IIB and 5.0% stage IIIA. Evidence of metastasis was not recorded among this sample.

Figure 6: Distribution of staging levels for participants with breast cancer



- The highest proportion (21.0%) of patients with lung cancer were staged at IA2, in which, the cancer has not reached the membranes that surround the lungs and does not affect the main branches of the bronchi. This was followed by 18.5% of patients staged at IIIA, (spread to lymph nodes, however no further spread to distant body parts). Stage IVA was determined for 12.3% of patients (distant metastasis in separate tumour nodules in the contralateral lobe, tumour with pleural or pericardial nodules or malignant pleural or pericardial effusion). The remainder of the patient sample were staged at IIB (9.9%), stage IA3 (7.4%) and 6.2% at stage IB.

Figure 7: Distribution of staging levels for participants with lung cancer



19. Comparison with optimal care pathways

Milestone/KPI: Evidence of treatment based on relevant optimal care pathway

In progress

The Optimal Care Pathways (OCPs)¹ are the nationally endorsed standard of care for evidence-based best practice for specific cancer types in Australia. The OCPs detail a model of cancer care that places the patient at the centre of care decisions, whilst defining a national standard of high-quality cancer care that every patient should expect to receive, regardless of where they live or receive cancer treatment.² A key aim of the OCPs is to improve patient outcomes through promotion of high quality cancer care and opportunities to identify and address contributing factors to unwarranted variation, sub-optimal outcomes and costs across the range of services throughout the patient journey (Figure 9).

¹ <https://www.cancer.org.au/health-professionals/optimal-cancer-care-pathways>

² HealthCatalyst Feb 2017 Reducing Unwanted Variation in Healthcare Clears the Way for Outcomes Improvement, Josh Ferguson APRN, ACNP, ANP-BC <https://www.healthcatalyst.com/insights/reducing-variation-in-healthcare-to-boost-improvement/#variation>

Figure 8: Optimal Care Pathway steps for all cancers



OCP sub-project

Patient journey mapping and in-depth case reviews for a random sample of 39 patients were incorporated into the Health Economics sub-project for three cancer types – breast, colorectal and lung cancer – against their respective OCPs. This involved a systematic approach of:

- documenting each encounter or touchpoint with services in an individual patient’s journey through the healthcare system;
- evaluation of adherence against each of the steps of the pathway outlined in the OCP;
- extracting, investigating and assigning the costings of patient encounters.

This resulted in identification of any unwarranted variation from evidence-based best practice and a greater depth of knowledge and understanding of the costs associated with cancer care. These findings will assist in the identification of potential efficiencies, effectiveness, and value in the provision of healthcare.

Outcomes - encounters

During the collection of encounter information and mapping of each patient’s care journey against the relevant OCP, a common theme began to emerge across and within each of the three cancer types related to timeliness of patient assessment and care. Delays were observed and measured at the following key OCP Steps and care points.

1. Between OCP Step 2. and Step 3: Referral to Specialist Care Appointment

Patient Group	Patient: Occasion	Timeframe
Colorectal cancer (n=9)	5 patients: 5 occasions	21 to 63 days (average 43-days) (excludes 1 patient at 106 days)
Breast cancer (n=9)	2 patients: 2 occasions	19 to 45 days (average 32-days)
Lung cancer (n=21)	9 patients: 9 occasions	21 to 40 days (average 28-days)

For the majority of patients across the three cancer groups, GP Referral to Specialist care was found to have occurred in a timely manner following initial investigations, with the exception of one patient where the time interval was 106-days in the community. i.e. between initial review by the GP, investigations and then subsequent referral to Direct Access Gastroenterology by the GP. The factors contributing to this delay are unclear from the documentation available. The point at which delays were observed more frequently was between receipt of the initial referral by the Central Referral Service (CRS) and referral to the relevant hospital or Health Service Provider (HSP), for the scheduling of a specialist care appointment. Each OCP recommends that the timeframe between these two care points should be within 2-weeks; however, for these patient groups the timeframes varied from 19 to 63 days, with an average of 28-days for lung cancer, 32-days for breast cancer and 43-days for colorectal cancer.

2. **Within OCP Step 3. Diagnosis, staging and treatment planning:** Multidisciplinary team (MDT) meeting to new patient appointment for surgery or other procedures before treatment planning finalised

Patient Group	Patient: Occasion	Timeframe
Colorectal cancer (n=9)	2 patients: 2 occasions	21 to 22 days
Breast cancer (n=9)	1 patient: 1 occasion	24 days
Lung cancer (n=21)	3 patients: 4 occasions	17 to 32 days (average 21-days)

Noting that 4-6 weeks is the recommended timeframe between a patient’s MDT review and commencement of their treatment, across the cancer types, delays averaging 21-days were observed between MDTs and appointments required to inform or finalise treatment planning. These delays were observed to contribute to subsequent delays in the commencement of treatment for some patients including surgical intervention or adjuvant chemotherapy or radiotherapy.

3. **Within OCP Step 3. Diagnosis, staging and treatment planning:** Specialist outpatient appointments to Diagnostic imaging or other Speciality for treatment

Patient Group	Patient: Occasion	Timeframe
Colorectal cancer (n=9)	N/A	N/A
Breast cancer (n=9)	N/A	N/A
Lung cancer (n=21)	10 patients: 16 occasions	15 to 68 days (average 31-days)

A number of delays were identified for the same type of appointment and referral process step of the OCP for 10 patients in the lung cancer group (47.6%), namely between the Lung Nodule Review/Specialist Clinic appointment and an appointment with another specialty for further diagnostics or for treatment. Referral from a Lung Nodule Review/Specialist Clinic appointment to the day the patient attended an appointment with another specialty averaged 31-days. For example, one patient encountered 39-days between their Lung Nodule appointment and an endobronchial ultrasound, followed by 43-days between a Pleural Disease Clinic appointment and a pleural biopsy procedure. It is acknowledged that this timeframe may not be considered excessive in isolation within the context of care for this cancer type and the contributing factors to this issue may be unclear to the observer; however, if this occurs on multiple occasions for a number of patients the combined effect on the timeliness of their treatment and care can be significant.

Outcomes - costing

Whilst the costing of patient care journeys was impacted by the timing of where the patient/s were in their care journey and when the reviews were undertaken, the most significant variances in cost were seen in the lung cancer patient group (Table 11). With recognition of the epidemiological nature of lung cancer, the variances in cost were found to correlate strongly with the type of treatment required by the patient and when complications occurred during the patient care journey. For example, in the lung cancer patient group, costs rose substantially when immunotherapy was incorporated into a patient’s treatment regime.

Table 11: Costs per cancer type

	Average	Lowest	Highest
Breast cancer (n=9)	\$21,615.65	\$32,752.03	\$79,359.78
Colorectal cancer (n=9)	\$45,540.77	\$6,496.84	\$71,342.74
Lung cancer (n=21)	\$62,716.63	\$2,960.44	\$303,635.14

An example of the detailed review of a patient’s journey against the OCP is provided below (Figure 10). This is the 154-day journey of a 75-year old patient with lung cancer, from initial presentation to end of life. Three key outcomes are highlighted in relation to referral, diagnostic and treatment issues.

Figure 9: Example #4 of patient pathway mapping against OCP – Lung Cancer

Step in Pathway	Care point	Encounter/s	Location	Timeframe (Days)	ABF Cost/ MBS Assumption		
Prevention & early detection	PMHx Risk factors	PMHx: COPD. Risk factor/s: Smoker					
Presentation, initial investigations & referral	Signs & symptoms	Dysphagia (food sticking retrosternally), weight loss 10kg over 6 weeks, 1 episode of haematemesis					
		Barium swallow	Radiology provider	0	\$140.85		
		CT Chest with contrast	Radiology provider	0	\$406.00		
		Pre-Admission/Pre-Anaesthetic Endoscopy Appointment 1 - Telephone	S/Hosp A	31	\$132.85		
		BOOKED ADMISSION: PANENDOSCOPY to Duodenum	S/Hosp A	6	\$1,575.36		
		HISTOPATHOLOGY					
		DISCHARGED to Home					
		(Day 0-37) 37 days from initial referral to seeing specialist					
		Referral to specialist (within 2-weeks)	Referral to specialist (within 2-weeks)	ED ATTENDANCE for Assessment of Dysphagia and weight loss	S/Hosp A	35	\$1,054.00
				ADMITTED under General Medicine	S/Hosp A	0	\$6,216.63
DISCHARGED to T/Hosp (3-day LOS)	3						
Diagnosis, staging & treatment planning	Diagnosis and staging (within 2-weeks)	ADMITTED to Acute Medical & Referred to Respiratory Med for assessment of dysphagia & investigation of lung mass	T/Hosp1	0	\$51,741.32		
		HISTOPATHOLOGY	T/Hosp2	13	\$2,145.70		
		PET Scan - Whole Body					

		Multidisciplinary team meeting & treatment planning	Dietetics Clinic Appointment	T/Hosp1	9	\$89.93
			DISCHARGED to Home (23-day LOS)		1	
			(Day 98) 23 days & \$55k spent to receive diagnosis & 1st treatment			
Treatment	Surgery	Radiation therapy				
			Commenced Radiation Oncology Planning & Rx	T/Hosp3	2	\$90.93
			Radiotherapy (lungs)	Rad Onc	8	\$244.22
			Radiotherapy (skull)	Rad Onc	0	244.22
			Radiotherapy	Rad Onc	1	\$244.22
			Radiotherapy	Rad Onc	0	\$244.22
			Radiotherapy	Rad Onc	3	\$244.22
			Radiotherapy	Rad Onc	0	\$244.22
			Medical Oncology Clinic Appointment	S/Hosp B	0	\$225.52
			ADMITTED Directly from Medical Oncology Clinic Appointment - with Pneumonia	S/Hosp B	0	\$16,343.09
			Radiotherapy (lungs)	Rad Onc	7	\$244.22
			Radiotherapy (skull)	Rad Onc	0	\$244.22
			Completed Radiation Oncology Rx	Rad Onc	1	\$244.22
DISCHARGED to Home	S/Hosp B	1				
Care after initial treatment & recovery	Transitioning from active treatment	Follow-up care	Dietician Phone Clinic Appointment	S/Hosp B	1	\$0.00
			Dietician Phone Clinic Appointment	S/Hosp B	5	\$0.00
Managing recurrent, residual or metastatic disease	Preventing recurrence	Signs & symptoms of recurrent disease				
			Managing recurrent disease			

		Multidisciplinary team				
		Treatment				
		Advance care planning				
		Palliative care	ED ATTENDANCE for Fevers and general malaise - Cellulitis	S/Hosp B	0	\$1,169.26
			ADMITTED from ED to Hospital (24-day LOS)	S/Hosp B	0	\$73,768.18
			Geriatric ACAT Outpatient Review Appointment - Phone	S/Hosp C	1	\$166.94
End-of-life care		Multidisciplinary palliative care	Care Type Change from Acute to Palliative	S/Hosp B	22	\$7,080.60
			RIP in Hospital		4	

(Day 127) \$75K spent in last few days on End of Life care

NB: Timeframe = Days between Encounters & if >14days font changes to red, with the exception of acceptable limits following review e.g. chemotherapy, outpatient follow-up

Total	\$164,545.15
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T/Hosp = Tertiary Hospital
 S/Hosp = Secondary Hospital
 Rad Onc = Radiation Oncology Provider
 PrivSurg = Private Surgeon
 PrivHosp = Private Hospital

Location

T/Hosp1	S/Hosp A
T/Hosp2	S/Hosp B
T/Hosp3	S/Hosp C
PrivHosp	GP
Radiology provider	PrivSurg
Rad Onc	

20. Patient Assessment of Care

Milestone/KPI: Patient assessment of service in place

In progress

Two projects have commenced this reporting period to better understand patients' assessment of cancer services. Both projects are initiatives arising from WA Cancer Plan 2020-2025 Priorities for Implementation process established in December 2020.

Since commencement of the CIC Cancer project, 404 consumers have provided feedback on their experience; however, these additional projects will considerably increase this level once data collection is complete.

Patient-reported experience of care

The WA Cancer and Palliative Care Network Clinical Implementation Unit (WACPCN CIU) commissioned CIC Cancer to conduct the Cancer Patient Experience Survey (CaPES) as part of an engagement strategy that recognises patient experience as a key pillar of sustainability³. Data is being collected that reflects various patient experiences, ranging from cancer diagnosis, care and treatment, to continuing support and financial impacts of cancer on quality of life. Connectivity between CIC Cancer capture of PROMs and results of this patient-reported experience survey will enhance the overall understanding of what matters to patients. This information will also assist in establishing transparent public reporting of patient-reported experience and outcomes and monitoring of systemwide performance indicators.

Commencing in mid-November 2021, CaPES collected both quantitative and qualitative data; allowing a holistic understanding of the cancer care pathway from the patient perspective, using an adapted version of the validated All.Can International patient experience questionnaire. Participants were identified from newly diagnosed adult cancer cases reported to the WA Cancer Registry from 1 January to 31 December 2019.

Analysis commenced once data collection ceased in December 2021. One component of this analysis will be to compare the WA results with those of the 2018 All.Can international survey (<https://www.all-can.org/what-we-do/research/patient-survey/>) – research that involved almost 4,000 cancer patient and carers across 10 countries, including Australia. Such comparison will provide an understanding of the relevance to WA of the All.Can identified opportunities for improvement in cancer care and inform future iterations of the WA Cancer Plan.

Consumer information needs

In collaboration with the Department of Health WA Cancer Network, the project team are researching cancer information currently available to consumers and whether this information is accessible and of value to consumers and meets their needs.

The project activities focus on:

- a desktop review to map the information resources available to cancer patients in Western Australia through online formats and other modalities such as phone information service, paper-based handouts, support groups, and peer support;

³ Sustainable Health Review: Final report to the Western Australian Government. WA: Department of Health, 2019

- a desktop review to identify national and international cancer information provision models available to consumers; and
- an online consumer survey to better understand what consumer information needs are, when they want to receive the information, whether the information is available and how they would like to access the information.

Information obtained from these activities will be used to make recommendations to support decision-making for improvements to patients' experience with, and understanding of, their cancer care; patient involvement in their cancer care and treatment options; and clarity of information surrounding cancer diagnosis, diagnostics and treatments.

21. New interventions and clinical translation

Milestone/KPI: Novel interventions, positive results and translations into clinical care demonstrated in each tumour type at each hospital

In progress

The project has generated several new and unanticipated opportunities in the form of innovative VBHC-specific sub-projects including, but not limited to:

- measurement of the impact of COVID-19 on patient experiences;
- use of the CIC Cancer Informatics system to capture patient-reported outcomes in a national ovarian cancer project that is exploring a novel approach to the follow-up of women after completion of primary treatment;
- working with PathWest (WA's largest pathology service provider) to incorporate the value equation into its practice to improve patient outcomes and drive down costs;
- introduction of a bundled care payment model working with other healthcare service providers, such as GenesisCare and some private health insurance companies;
- becoming actively involved in several national groups including the Australian Centre for Value Based HealthCare and the Australian Health Review Editorial Advisory Board;
- involvement in a new European-based project to determine how to bring together the fields of Person-Centred Health Care and VBHC, and other international groups such as All.Can, ICHOM Breast Cancer, and OECD Breast Cancer PROMs Data Collection (PaRIS initiative); and
- collaboration with the WA Clinical Senate to assist in implementation of VBHC within WA.

22. Improvements in care

Milestone/KPI: 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

Awaiting further data

In conjunction with work undertaken by All.Can Australia, advocacy is underway for access, by patients and carers, to cancer care navigators. The aim of these navigators is to relieve system-related stress and concern currently experienced by patients trying to access services required for their care. Through a literature scan, stakeholder consultation, and economic analysis, All.Can has developed a "model of care to facilitate equitable access to navigation services for all Australian cancer patients regardless of their cancer

diagnosis, geographic location or socioeconomic status”.⁴ A pilot program has been discussed with the Australian Government to test and evaluate the model within a single jurisdiction and determine its ongoing utility, acceptability, and outcomes.

This use of navigators, as a key facilitator of improved outcomes, is also a key feature of the CIC Cancer bundled care package sub-project with support available from a patient care navigator throughout all treatment and post-treatment for up to 12 months (Section 11). The patient navigator will help guide the patient through the services required for their care and provide support to the patient through the provision of advice or organising support from others. The patient navigator will also organise the completion of the PROMs and PREMs at the appropriate time points. The aim of this is to improve patient outcomes and experience measures, through better support, guidance and understanding of the treatment pathway by the patient and improve adherence to Optimal Care Pathways by ensuring that the patient receives appropriate care within set timeframes.

23. Cost effectiveness measured

Milestone/KPI: Cost effectiveness measured In progress
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Analysis of an evaluation of health economics is currently underway using clinical, PROMs and cost data from 252 patients with colorectal, breast or lung cancer receiving treatment at RPH. Preliminary results are provided below.

Quality of life scores (utility)

The average QLU-C10D scores alongside their 95% confidence intervals (CI) for each cancer type and separated by time point are provided in Table 12.

- There were 109 out of 120 (approx. 91%) breast cancer patients with complete PROMs data used to generate the QLU-C10D scores. Breast cancer patients had the highest utility scores at baseline, 0.824 [0.792, 0.856]. At 6 months, only 38 breast cancer patients had complete PROMs data that was used to generate the utility scores. The average utility score at 6 months for breast cancer patients was 0.767 [0.705, 0.830] which is about 6.9% lower compared to the baseline level. However, the average utility scores for breast cancer patients increased marginally to 0.829 [0.746, 0.912] at the 12-month data collection point with only 13 breast cancer patients having completed PROMS data.
- For colorectal cancer, there were 37 patients with complete (non-missing) PROMs data. The average utility scores at baseline for colorectal cancer patients was 0.756 [0.686, 0.825]. These utility scores declined to 0.683 [0.577, 0.789] as observed at the 6-month point with only 20 patients submitting complete (non-missing) PROMs data. At 12 months, only 13 colorectal cancer patients had complete PROMs data and the average utility score was 0.765 [0.642, 0.888], which represented an imprecise 12% increase from the 6-month value.
- Table 12 also shows that 69 lung cancer patients had non-missing PROMs data to generate utility scores at baseline. The average health utility score was 0.685 [0.633, 0.737] as measured at baseline. A marginal decrease in health utility scores was observed at the 3-month point – averaging 0.658 [0.590, 0.726] – for 40 patients with non-missing PROMs data. The average health utility scores then increased to 0.726 [0.676, 0.777] as measured at the 6-month point with 40 patients having complete PROMs

⁴ All.Can Cancer Care Navigator Analysis – Final report 13 May 2021.

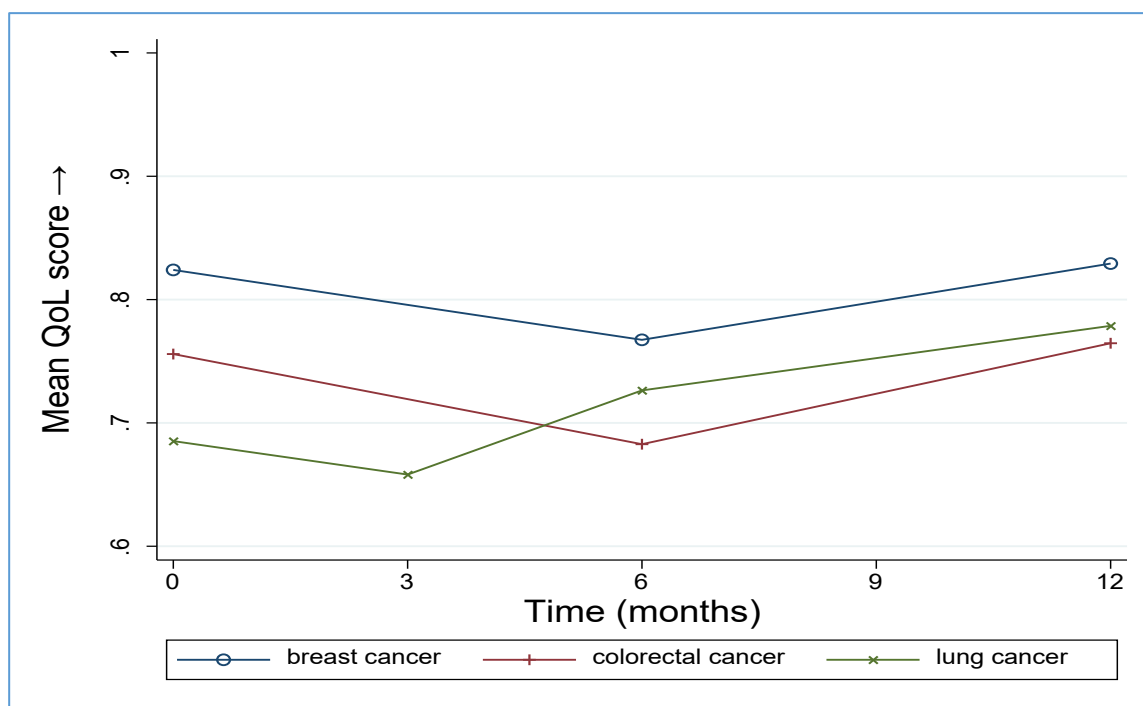
data. However, at the 12-month point only 23 patients had submitted complete (non-missing) PROMs data with an average utility score of 0.779 [0.698, 0.860].

Table 12: Average quality of life (QoL) utility scores by cancer type and data collection point

	Breast		Colorectal		Lung	
	Mean	95% CI	Mean	95% CI	Mean	95% CI
Baseline						
QoL score (QLU-C10D)	0.824	[0.792,0.856]	0.756	[0.686,0.825]	0.685	[0.633,0.737]
Number of patients	109		37		69	
3 months						
QoL score (QLU-C10D)	n/a	n/a	n/a	n/a	0.658	[0.590,0.726]
Number of patients					40	
6 months						
QoL score (QLU-C10D)	0.767	[0.705,0.830]	0.683	[0.577,0.789]	0.726	[0.676,0.777]
Number of patients	38		20		40	
12 months						
QoL score (QLU-C10D)	0.829	[0.746,0.912]	0.765	[0.642,0.888]	0.779	[0.698,0.860]
Number of patients	13		13		23	

Figure 11 displays the same data graphically. In this instance, the average QLU-C10D scores are shown at baseline, 6, and 12 months for breast cancer patients and colorectal cancer patients with lung cancer patients' scores shown at baseline, 3, 6, and 12 months. For breast and colorectal cancer types, the mean QLU-C10D scores initially decrease from their baseline levels before increasing from the 6-month time point. The averages QoL scores at 12 months point for breast and colorectal cancer type patients are slightly higher (marginal increase) when compared to their baseline levels.

Figure 10: Average quality of life (QoL) utility scores by cancer type and data collection point

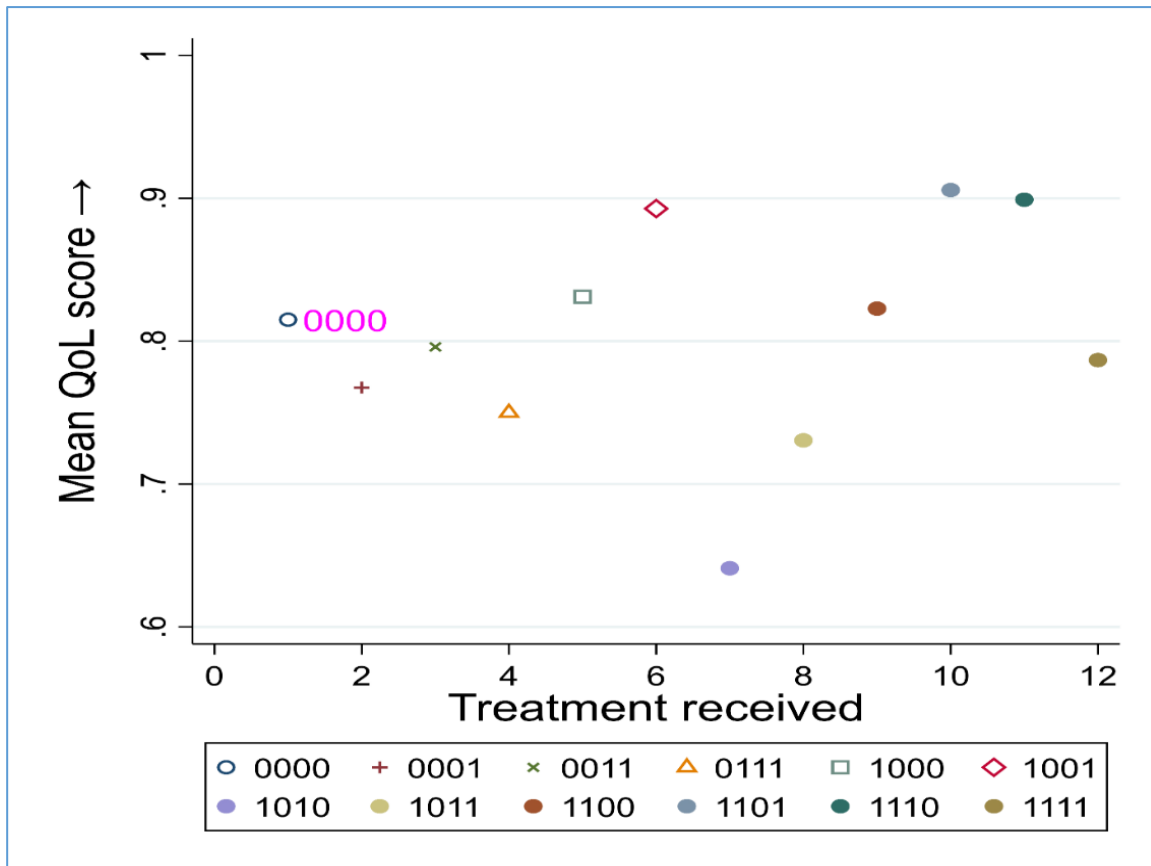


Linking Quality of life with clinical events

Breast cancer example

Figure 12 provides a scatterplot of the average QoL scores for breast cancer patients who received various treatment options namely, surgery, radiation therapy, chemotherapy, and targeted therapy. This uses a categorical variable formed through concatenating the 4 treatment options available to patients. While the figure presents a descriptive summary of QoL scores, it does not suggest any causal associations with the different treatment modalities. Moreover, there is also categories where the number of patients is too small to provide definitive conclusions. Regardless, it gives some indication of which treatment options are potentially associated with a reduced QoL.

Figure 11: Distribution of Quality of Life (QoL) scores (QLU-C10D) by treatment modalities

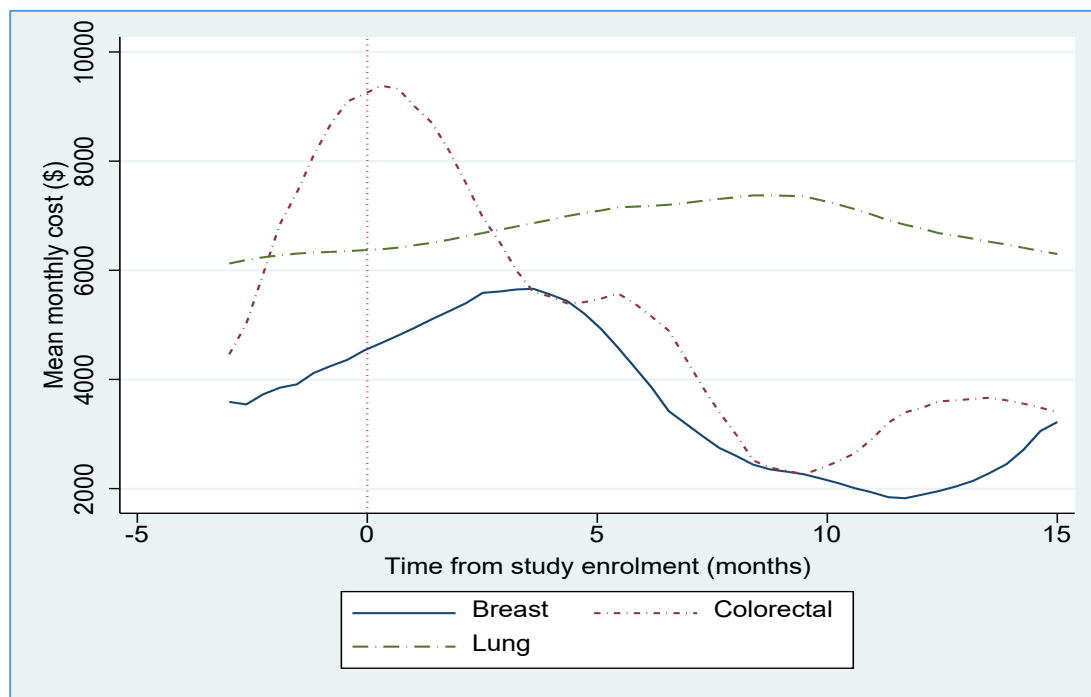


Key: 0000=no treatment received; 0001=Targeted therapy only; 0011=chemotherapy and targeted therapy; 0111=radiotherapy, chemotherapy, and targeted therapy; 1000=surgery only; 1001=surgery and targeted therapy; 1010=surgery and chemotherapy; 1011=surgery, chemotherapy, and targeted therapy; 1100=surgery and radiotherapy; 1101=surgery, radiotherapy and targeted therapy; 1110=surgery, radiotherapy, and chemotherapy; 1111=surgery, radiotherapy, chemotherapy and targeted therapy.

Cost comparison

A review of the rolling mean month cost by cancer is shown in Figure 13. Rolling averages were computed for each patient by firstly, calculating a monthly total cost (using date of service) for each patient, then averaging the costs within a window. Each time point represents the average monthly cost over the one preceding and the month following starting from the time of enrolment into the study.

Figure 12: Rolling mean month cost by cancer type



24. Inclusion in best practice

Milestone/KPI: 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

In progress

The CIC Cancer project is thought to be the first time that value-based healthcare activities have been implemented in public and private health settings simultaneously, and as such this work is both innovative, culturally transformative and has the potential to significantly contribute to the body of knowledge which will ultimately translate into improved patient outcomes. As an enabler of value-based healthcare, the CIC Cancer program of research addresses several of the WA Sustainable Health Review recommendations/priorities for implementation (4, 16, 17 and 28). This alignment, combined with work underway to integrate with other health service systems, will assist in sustainable uptake and assimilation of patient-reported outcomes into standard care.

The completion period of the CIC Cancer project will focus on transferring the project activities to WA Health and SJoG such that the public and private health systems can lead the continued success of this work. Both SJoG and WA Health are highly engaged and fully committed to working to embed the work of CIC Cancer into routine care and thus make outcomes capture a key part of clinical practice. Early discussions have been held and a transition plan is currently being prepared.

25. Measurable improvements in care and cost effectiveness

Milestone/KPI: Measurable improvements in care and cost effectiveness are demonstrated

Awaiting further data

Integrated dataset

Analysis of CIC Cancer data collected to date will facilitate examination of key drivers of cost and patient outcomes over time, such that categories of patients receiving particular interventions who experience a better or worse health trajectory (or increased costs) can be identified. This depth of information enables understanding of how value for cancer patients is delivered – i.e. the equation of patient outcomes over the cost of delivering these.

The project is believed to have the richest source of costed treatment pathways in cancer care data within Australia. Recruitment is increasing across all sites and as such, there is a possibility that external projects could be allowed access to this data for other translational healthcare research (subject to appropriate approvals). This will further embed data collection into practice, enhance and cement the importance of collecting patient reported outcomes, and assist with cultural change and the acceptance of VBHC.

The development of a ‘databank’ with comprehensive patient centred information would result in a significant legacy for the project. Researchers would be able to seek an extract of complete clinical and patient reported outcome data from multiple healthcare sites and services to undertake projects. This would be further enhanced if the platform was expanded to include other disciplines/health conditions and include tumour genomic data. Ongoing collaborations between healthcare and an academic institution will ensure the level of governance currently associated with the databank was maintained.

Decision-support tools

The project team are also in discussions to work with collaborators in Europe who are developing AI-driven precise decision-support tools for cancer care. These will utilise PROMs data to develop AI-driven logic to identify important clinical features, contributing patient factors and correlations to establish a short-form more predictive PROMs alert solution. Algorithms would be developed to analyse the data received from project data sources and identify patients at risk of a comorbidity/late effect. The European team is seeking an academic partner and has approached the CIC Cancer team in this regard. The potential benefits of this collaboration could include:

- improved personalisation, outcomes and experiences for patients;
- timely insights for clinicians to enable more informed decisions and better outcomes;
- healthcare providers being able to achieve fairer reimbursement (e.g. performance based), improved market access/share and margins, plus promote innovation;
- support for early acceptance of drugs/innovations, fairer reimbursement, improved market access, share and margins for pharma and medical technology organisations; and
- improved contracting (performance based), cost clarity, cost risk assessment, improved margins, and improved market share/retention for payers.

Additionally, as outlined in Section 2, CIC Cancer is undertaking a piece of work to develop the first data analytic and visualisation tools for use in cancer care provision in WA. In addition to providing easy to read informatics about individual patients at different care points and over time, the visualisation tool set will increase the efficiency of doctor-patient interactions by identifying the most important issues and using analytical processes to help identify variations from typical patient experiences that may require further investigation. Importantly, the visualisation tool set will utilise already embedded data analytic tools used by the public and private hospitals for other purposes e.g. business reporting.

Bundled care

As highlighted in Section 11, the piloted bundles of care will provide incentives for providers and clinicians to offer the best quality care and outcomes for the most efficient cost possible. The planned evaluation will:

- measure efficiencies (such as shorter length of stay, lower cost with more appropriate care in the home, and optimal radiotherapy);
- measure decreased patient distress through treatment with a known out of pocket expense and smoothed payment process;
- monitor for decreased rates of complication;
- optimise attendances for radiotherapy; and
- ensure access to allied health/nurse-led services where appropriate.

26. Further funding opportunities

Milestone/KPI: Local, national, and international collaboration leads to further successful funding opportunities such as a Program Grant or Centre of Research Excellence

Unlikely to be achieved

It has already been demonstrated that additional funding can be sought and secured by the project team. Activities to obtain additional funding will continue to be pursued through applications for external peer review funding and any other applicable opportunities. The potential for a Program Grant or Research Excellence will diminished with completion of the project in 2023.

Project Aims for 2022

The key project aims for 2022 are focused on completing current activities and preparing for transition to the health services. Given that key Cancer Research Trust funding will cease on 30th June 2022, discussions are in place for any remaining funds to be maintained by the project to allow for a further 12 months of activities beyond this formal endpoint – providing a revised completion date of 30/6/2023.

In anticipation that formal approval for ongoing use of funds will be provided by all funders, the key activities of the projected 18-months duration will be as follows.

- Work closely with WA Health and SJoG to facilitate a transfer of ‘ownership’ of the project and subsequent translation into standard cancer practice within WA.
- Continue to increase the number of patients recruited across the cancer types, thereby expanding the clinical and PROM data collection to allow for early data mining to identify treatment/outcome gaps and areas of improvement.
- Continue integration with WA Health and SJoG enterprise systems to increase the accuracy and level of data capture.
- Begin identification of where the dataset can be made simpler and more relevant, to ensure that what is important to patients is captured efficiently and effectively. This will involve data analysis, strong consumer engagement, and working with survey tool experts and international groups to reduce the current number of questions.
- Continue to implement meaningful data visualisation tools that facilitate clinician use of the system and improve dialogue between patients and their clinical care team, with principles in place to enable WA Health/SJoG to develop additional dashboards for resource and policy use to assist at the meso level (units/hospitals) to improve outcomes through informed value-based decision-making.

Appendices

Appendix 1: CIC Cancer Sub-Projects

Commencement	Research Project Title	Location
2018	Continuous Improvement in Care – Cancer: Identification of WA specific data variables for colorectal cancer	SJoG Midland, RPH, SJoG Subiaco
2018	Patient reported outcome measures (PROMs) in Colorectal Cancer Surgery	SJoG Midland, RPH
2018	All.Can Experience of Care - pilot in WA	Perth Specialist Breast Care
2018	Ovarian cancer dataset development	Notre Dame, SJoG Subiaco, KEMH
2018	Inclusion of VBHC session in UWA MBA - Health Specialisation	UWA
2019	Measuring the cost of continuous improvement in care-cancer at Royal Perth Hospital - a 'proof-of-concept'.	RPH
2019	VBHC Conference	National, International
2020	Survey to identify the impact of COVID-19 on cancer care	RPH, SJoG Subiaco, Statewide
2020	Bundling cancer care: better care at a transparent cost	SJoG Subiaco
2021	OECD data contribution	RPH, International
2021	Testing of ovarian dataset through OVMOST follow up project	National
2021	Optimal Care Pathway Mapping of Patient Journeys	RPH
2021	CIC Data Visualisation Pilot Project	All sites
2021	Cancer Patient Experience Survey (CaPES)	Statewide
2021	Understanding Consumers' Needs for Cancer Information	Statewide
STUDENT PROJECTS		
2018	Implementing ICHOM Breast Cancer Dataset - Feasibility	SJoG Subiaco
2018	Continuous Improvement in Care - Cancer: moving towards the first Western Australian lung cancer Clinical Quality Registry	SJoG Midland, RPH
2018	Does timely care matter to lung cancer patients? A sub-study of the Continuous Improvement in Care – Cancer (CIC-Cancer) Project	SJoG Midland, RPH
2019	Review of literature on Time-Driven Activity Based Costing (TDABC) for evaluating cost of care for cancer patients	
2019	Prostate Cancer care pathway mapping	All sites
2019	Implementation of patient involvement in the development of a patient-reported outcome measure for ovarian cancer	Notre Dame
2019	Literature review - Public or private treatment: Insights into the financial burden of cancer and decisions on treatment pathways in Australia	
2020	Public or Private care? Analysis of the financial decision-making process of women with breast cancer	SJoG Subiaco, RPH, FSH

2020	Patient perspectives on PROMs completion	RPH
2020	Clinical and PROMs (quality of life) outcomes in patients with stage one NSCLC undergoing curative surgical therapy and stereotactic radiation therapy	RPH
2020	Review of the literature comparing patient reported quality of life outcome measures in early stage non-small cell lung cancer patients receiving radiotherapy and surgery with curative intent	
2020	Literature review - Cancer patient experiences during COVID-19 pandemic	
2020	Literature review - Data visualisation of clinical and patient reported outcomes in cancer	
2020	Literature review - Data visualisation of clinical and patient reported outcomes	
2021	Exploring patient views about importance of patient reported outcome measures (PROMs) in management of lung cancer patients	RPH
2021	In-depth review of measurement of adherence to the optimal care pathway for people with colorectal cancer in Western Australia	RPH