



Continuous
Improvement in
Care *cancer*

Outcomes Report

July 2023



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Abbreviations

CaPES	Cancer Patients Experience Survey
CICIS	CIC Cancer informatics system
COSA	Clinical Oncology Society of Australia
CRE	Centre for Research Excellence
FSH	Fiona Stanley Hospital
KEMH	King Edward Memorial Hospital
OCP	Optimal Care Pathway
OECD	Organisation for Economic Co-operation and Development
PaRIS	Patient-Reported Indicator Surveys

PCOR	Prostate Cancer Outcomes Registry
PeCHC	Person-centred healthcare
PeCVBHC	Person-centred value-based healthcare
PREMs	Patient report experience measures
PROs	Patient reported outcomes
PROMs	Patient reported outcome measures
RPH	Royal Perth Hospital
SCGH	Sir Charles Gairdner Hospital
SHR	Sustainable Health Review
SJoG	St John of God
VBHC	Value based healthcare

Funding Bodies and Partners



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1. Executive Summary

The Continuous Improvement in Care – Cancer (CIC Cancer) Project aimed to increase the capture of health outcomes not able to be understood with conventional health measures. The project sought to encourage innovative health service interventions aimed at changing clinical practice to improve patient’s lives in the short to medium timeframe. By the initially agreed end of the project (June 2022), the project’s aims had been met and continues to do so.

During the period between the initial and revised end of project (2022-2023 FY), the project has focused on refinement of systems and processes (Section 2) and further engagement with stakeholders to support the transition of the work into health services as standard care (Section 3).

The following table provides an update on key performance measures achieved within each of the contractual program phases. Given the abovementioned focus of this reporting period, these individual measures are not discussed in detail within this report as more comprehensive information was provided previously.

Table 1: Summary of achievement of performance measures

Performance Measures and Milestones	Status
Phase 1: Engagement of Stakeholders	
Services/clinicians engaged – clinician champions in each hospital and cancer	Achieved
Consumer engagement model in place	Achieved
Breast, lung, colorectal, and ovarian tumour streams engaged	Achieved #*
CIC Cancer project committee in place	Achieved
Phase 2: Development and Identification of data capture tools	
Defined datasets for breast, lung, colorectal, and ovarian tumour type	Achieved
Development of ICT integrated into existing public and private systems	Achieved
Phase 3: Data evaluation	
ICT systems and personnel operating at each hospital for cancer types	Achieved #
Data captured on patients treated at nominated institution p.a. (by treatment)	Achieved #
Documentation of clinical tumour stage for breast, lung, colorectal, and ovarian tumour type	Achieved
Capture of relevant PROMs for each nominated tumour type at each hospital	Achieved #
Phase 4: Feedback, revise, and review including start of service improvement research projects	
Evidence of treatment based on relevant optimal care pathway	Achieved
Patient assessment of service in place	Achieved
Novel interventions, positive results and translations into clinical care demonstrated in each tumour type at each hospital	Ongoing
Phase 5: Program roll out	
Improvements in care demonstrated including disease-free survival after primary treatment, decreased rate of in-hospital death from surgical complications, demonstrated improvement in areas of unmet need	Transition in place
Cost effectiveness measured	Achieved
International conference hosted	Achieved
Over all Phases	
Collaborations locally, nationally, and internationally	Achieved
Grants applied for and gained	Achieved
Publications, presentations, both scientific, policy and consumer	Achieved
Students trained	Achieved

Additional clinical teams have opted to be involved.

* Agreement, from external parties, for WA data collection for prostate cancer has not been achieved. In place for all other cancers.

2. Update on Achievement of Outcomes

The 2017 CIC Cancer project funding application outlined several outcomes against which success of the CIC Cancer project would be assessed.

- Integration of outcome datasets into routine care in the designated cancer types at the nominated services for all appropriate patients.
- Outcomes mapped to treatment based on relevant optimal care pathways.
- Robust clinical research programmes, based on demonstrated gaps and areas of unmet need, will have tested novel interventions, and led to translation into clinical care and measurable improvements in care, demonstrated cost effectiveness and improved value of care.
- Collaboration locally, nationally, and internationally will have been developed leading to further successful grants applications including a Programme Grant or Centre of Research Excellence.
- A trained workforce of health outcomes researchers and engaged clinicians will be in place in WA.
- Consumer engagement will be integral and on-going via a consumer reference panel.

An update on the status of these outcomes, since the intended end of project in June 2022, is provided below.

2.1 Integration of outcome datasets into care

Data capture

To date, patient reported outcomes measures (PROMs) have been collected from 1,067 patients. In addition, patient-reported experience measures (PREMs) have been obtained and reported on for 3,688 patients via WA specific surveys of patient experiences and need for information access; a collaborative project with All.Can; a sub-project to understand the impact of COVID-19 on care provision; or student projects (Table 2).

Table 2: Capture of data per site

Cancer type	Site	Original/New	CIC IT System (CICIS) &/or dataset use	Additional data collected	# Patients (at 1 July 23)
Colorectal	St John of God (SJoG) Midland	Original site	CICIS & dataset in use	• System testing	149
	Royal Perth Hospital (RPH)	Original site	CICIS & dataset in use	• Costing data • Adherence to Optimal Care Pathways (OCPs)	57
	SJoG Subiaco	Original site	CICIS & dataset in place and awaiting new clinical champion		-
Lung	SJoG Midland	Original site	CICIS & dataset in place but clinical champion to be re-engaged		-
	RPH	Original site	CICIS & dataset in use	• Costing data • Adherence to OCPs • Patient experience	88

	Fiona Stanley Hospital (FSH)	Additional team	CICIS & dataset in use Being utilised in the nurse-led clinic		3
	Sir Charles Gairdner Hospital (SCGH)	New site	CICIS & dataset will be in use. Ethics approval only provided June 23		-
Breast	RPH	Original site	CICIS & dataset in use	<ul style="list-style-type: none"> • Costing data and adherence to OCPs • Data submitted to OECD PaRIS data collection in 2021 and 2023 * 	278
	SJoG Subiaco	Original site	CICIS & dataset in use	<ul style="list-style-type: none"> • Pilot site • Patient experience & information needs • Data submitted to OECD PaRIS data collection in 2021 and 2023* 	148
	FSH	Additional team	CICIS & dataset in use		25
	GenesisCare (<i>Bundled Care project</i>)	New project	PROMs dataset only	<ul style="list-style-type: none"> • Evaluation data (managed by Uni. of Technology, Sydney) 	40
	<i>Intraoperative Radiation Therapy study at SJoG Subiaco</i>	External project seeking involvement	PROMs dataset only		124
Ovarian	King Edward Memorial (KEMH)	Original site	CICIS & dataset in use		4
	SJoG Subiaco	Original site	CICIS & dataset in use		1
	<i>National OVMOST interventional trial project</i>	External project seeking involvement	PROMs only in use		29
Prostate	FSH	Original site	Awaiting links with Prostate Cancer Outcomes Register		-
	SJoG Subiaco	Original site			-
	RPH	Additional team			-
All	Statewide	New work (multiple projects)	-	<ul style="list-style-type: none"> • Patient experience • Information needs 	3,866

* Organisation for Economic Co-operation and Development's (OECD) Patient-Reported Indicator Surveys (PaRIS) initiative

In addition to the conditions listed in Table 2 above, two members of the team contributed to the development of the ICHOM Metastatic Breast Cancer standard dataset. This dataset has not been incorporated into CIC Cancer as it is felt that the creation of separate records for patients who develop metastases will add a level of unnecessary complexity.

Prostate cancer

It was determined soon after the commencement of CIC Cancer that the capture of prostate cancer data would be better captured through the national Prostate Cancer Outcomes Registry (PCOR) project rather than create a separate data registry within WA. The fields in the PCOR registry are exactly what is required for the CIC Cancer project and a decision was made to not replicate the system. However, the inclusion of prostate cancer has not yet progressed in WA as there have continued delays in the collaborations undertaken with PCOR. To date, no data has been collected within WA with no predicted date for commencement.

Data visualisation

During this reporting period, user-friendly, interactive, graphical interfaces (dashboards) were migrated from Tableau to PowerBI™ – the business intelligence software recently adopted for use within WA Health and SJoG for reporting purposes. However, the project team were subsequently advised that this software was held by the health service providers themselves, rather than Health Support Services, where the CIC informatics system (CICIS) is housed. Given privacy issues associated with transfer of patient data, a decision was made to fully incorporate the visualisation component within the CICIS. Dashboards for both the full patient cohort per registry (Figure 1) and individual patients (Figure 2) have been developed.

This has resulted in the first PROMs data analytics and visualisation tool for use in cancer care provision in WA. The dashboards provide easy to read information about individual patients at different care points and changes over time. This increases the efficiency of doctor-patient interactions through use of analytical processes to 1) help identify variations from typical patient experiences; and 2) identification of the most important issues or concerns that require further investigation. Combined, these tools aim to improve clinician/patient discussions and assist with shared decision making.

Figure 1: All patients dashboard (test patient cohort with real, de-identified colorectal cancer PROMs)

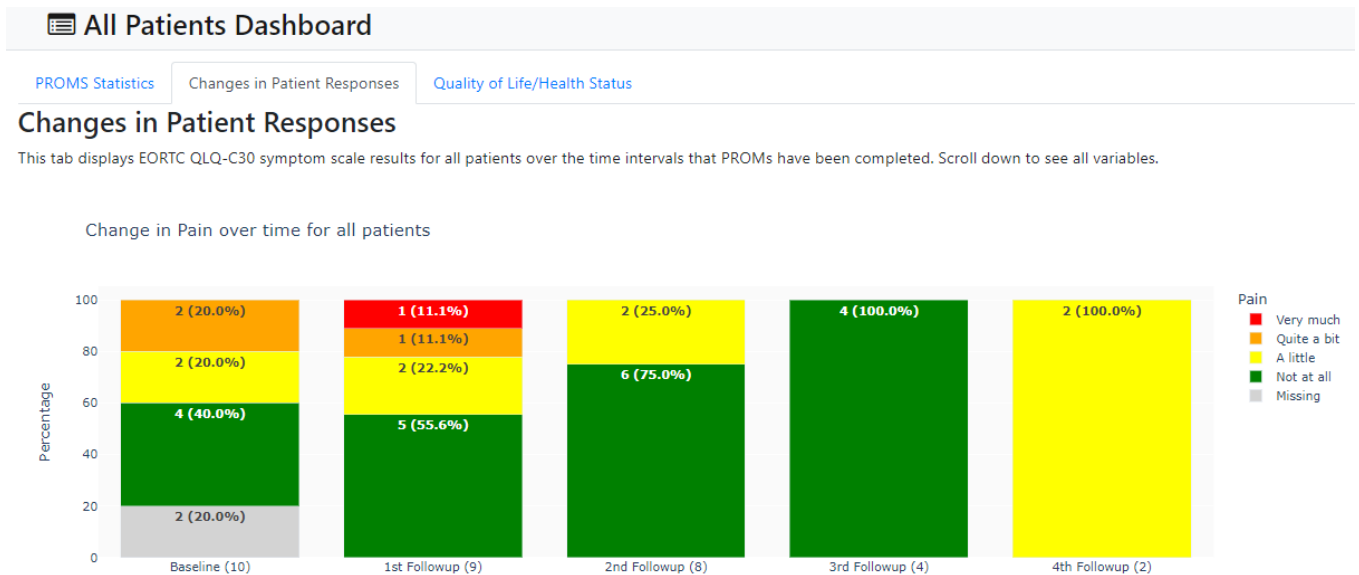
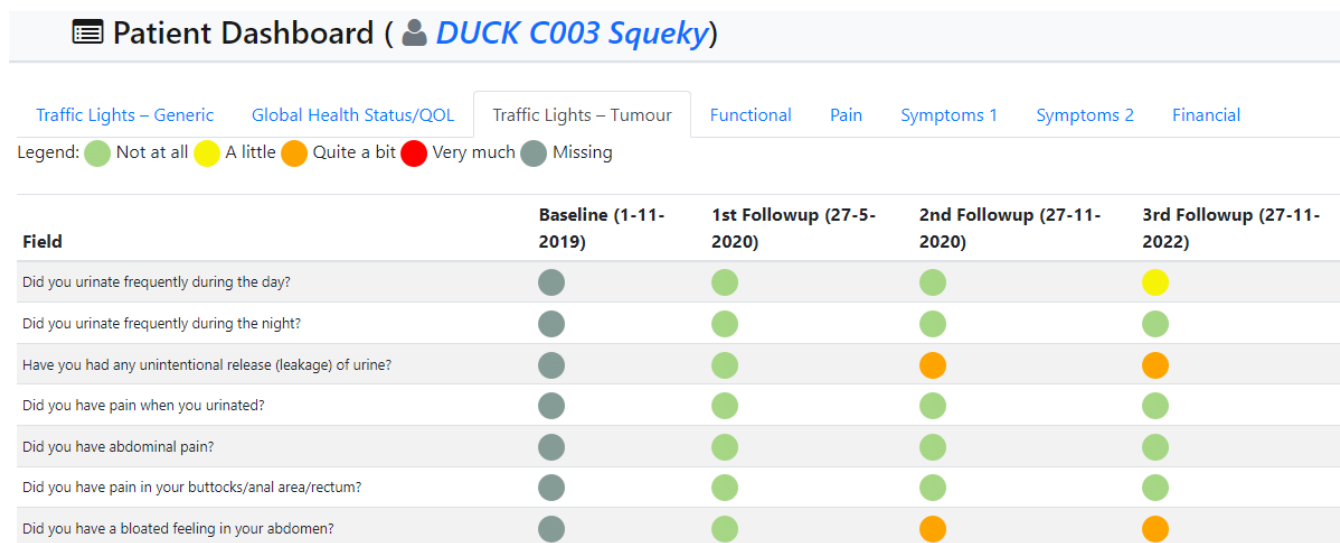


Figure 2: Individual patient dashboard (data for a fictitious colorectal patient with real, de-identified PROMs results)



Research outcomes for cancer services

The clinical and PROMs data collected to date has been used for several purposes: understanding patient outcomes in comparison to treatments; identification of improvements to quality of care; an economic evaluation; mapping of care against the optimal care pathways; submission to the Organisation for Economic Co-operation and Development’s (OECD) Patient-Reported Indicator Surveys (PaRIS) initiative; and understanding patient perspectives on their completion of PROMs.

COSA involvement

The CIC Cancer team have been represented on the Clinical Oncology Society of Australia (COSA) Patient Reported Outcomes (PRO) Working Group since inception. This group was formed as a result of a national Think Tank focusing on patient-reported outcomes in cancer survivorship care and follow-up that was held in August 2018. The Think Tank participants recommended that COSA should lead work to develop recommendations about how to plan a coordinated approach to PRO monitoring in cancer care.

The PRO working group is seen as an important component in the development of a national advocacy strategy for PRO implementation, with a view to consistently embedding PROs into clinical practice across state jurisdictions. At their March 2023 meeting COSA Council endorsed the proposal to develop a national advocacy strategy for PRO implementation across Australia. An important component will be to host a further workshop with key stakeholders to inform this advocacy strategy and refine and tailor the approach to different settings and targets. To this end, a grant application has been submitted to support a national PRO advocacy workshop prior to the 2023 COSA Annual Scientific Meeting.

Challenges

Implementation of this data collection system, as a research project, identified that resourcing was required in a number of the sites to ensure maximum recruitment of patients and follow-up at the required timepoints. To this end, 0.4 FTE of research officer time was placed within key sites through CIC funding from mid-2022. Within one of the sites this responsibility has been embedded within the role of the nurse specialist as the data collection has formed a key function within their patient assessment activities as part of a nurse-led clinic. The challenge is to further identify effective options within the transition planning to ensure sustainability (see Section 3).

2.2 Outcomes mapped to treatment based on relevant optimal care pathways

Mapping of care received against optimal care pathways for a pilot group of patients was achieved in 2021/22 and reported.

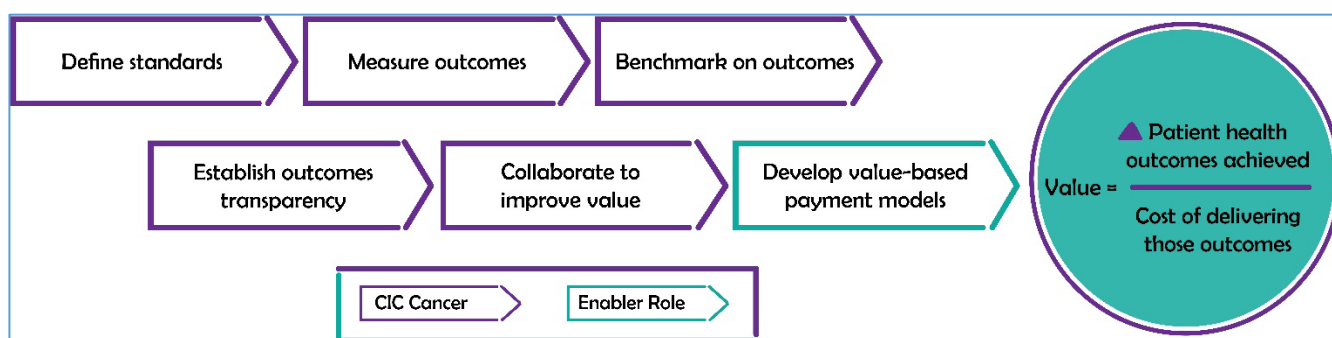
Further updates to analysis of data occurred during the 2022-2023 financial year and were fed back to both clinicians and health service executives. Outcomes achieved through this feedback loop have included the following.

- Discussions within Royal Perth Hospital and SJoG Midland Hospital colorectal teams to explore new interventions to address the identified distress and symptoms through improvements in screening, nurse-led assessments, case management, and referral processes.
- Based on the findings for lung cancer – statistically significant changes seen in appetite loss, dyspnoea, haemoptysis, sore mouth, dysphagia, peripheral neuropathy, alopecia, and pain in chest – site stakeholders explored interventions to address the distress and symptoms expressed by patients. Consequently, changes were made to improve patient care. This included a new role of Lung Nodule Clinical Nurse Consultant to provide a pivotal role in case management, establishment of relationships early in the care pathway, incorporation of screening tools, and development of referral pathways for persistent symptoms.
- The provision of this analysis of PROMs and costs of care to East Metropolitan Health Service was thought to be of such value by senior executives that when Assoc. Professor George Eskander was appointed as the Area Director Clinical Services, North Metropolitan Health Service, an approach was made to the research team to implement CIC Cancer within the lung cancer service at Sir Charles Gairdner Hospital (SCGH). To this end, ethics approval has been obtained for the nurse-led lung cancer clinic to utilise CICIS and arrangements are underway to commence involvement.
- East Metropolitan Health Service are preparing to implement widespread capture of PROMs prior to adoption by WA Health. Discussions have been held regarding the possible utilisation of CICIS as a test bed site prior to, and over and above, the proof-of-concept project proposed by the Department of Health (see 3.2 Transition planning).

2.3 Tested novel interventions, and led to translation into clinical care and measurable improvements

As mentioned in earlier outcome reports, whilst initially only seeking to improve cancer healthcare in both the Western Australian public and private hospital sectors, the project has also proved to be an effective enabler for the introduction of value-based healthcare (VBHC) into WA, and as an influencer of VBHC in cancer nationally and internationally (Figure 3). In part, this is because many of the processes and strategies of the CIC Cancer project align with the recommendations of the National Health Reform Agreement 2020-2025, the WA Sustainable Health Review (SHR) 2017, the WA Cancer Plan 2020-25, and the Australian Cancer Plan currently being finalised by Cancer Australia (Appendix 1). 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.

Figure 3: CIC Cancer role in VBHC implementation



Bundled care packages

One of the most important and innovative, VBHC-specific, CIC Cancer sub-projects to improve health outcomes for cancer patients in WA has been the introduction of a bundled care payment model in collaboration with insurers and healthcare service providers. This seeks to establish, for the first time in Australia, whether it is possible to deliver measurably excellent co-ordinated cancer care and support through bundled care packages. The project is a collaboration with GenesisCare, University of Technology Sydney, SJoG Subiaco, HBF, Medibank, and multiple service providers across the early breast cancer treatment pathway and provides a key example of a novel intervention for implementation of improvements in care for an unmet need.

The care 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. The model creates pre-negotiated bundles of care which follow the Optimal Care Pathway and shift service utilisation risk from the patient to a patient care navigator and fundholder (GenesisCare). This shift will provide patients with 1) upfront knowledge of the cost of their care over a 12-month period including all surgical and allied health services regardless of utilisation; and 2) an understanding of the care offered throughout, services available, and how to access them.

The project commenced in July 2022 with 40 patients now recruited to the project. Only one patient declined to be involved. As of June 2023, thirty-eight of these are participating in the evaluation. As a result of recent issues related to the GenesisCare payment systems, recruitment to the program was temporarily put on hold in early June 2023.

There is a great deal of interest in this work as it is the first of its kind in Australia and results to date are very positive.

- Patients have accessed surgery, anaesthetics, medical oncology, radiation oncology, imaging, and pathology services based on clinical need. Most patients have utilised lymphoedema physiotherapy, six have accessed clinical psychology services, seven have accessed dietetics, and 20 have utilised the exercise clinic.
- Providers interviewed as part of the evaluation processes were very positive about their involvement and the approach to the development and implementation of the bundle. Many commented on the lengthy development period but understood the complexity of the task and delays caused by COVID but were complimentary about the persistence of the start-up team. Additional providers have joined the project since inception.

- Allied health, imaging, and pathology providers see the bundle as an important referral pathway as private patients often don't access optimal physiotherapy and psychological services as these are often viewed as 'another bill to pay'.

Patient Feedback

"The role of the patient navigator (Nicky) has been very important as it gave you someone to talk to about anything that you were unsure of no matter how small or big the problem was. No question was silly and if they weren't sure they always found out promptly and got back to you. The check-ins were just right. It made you feel that someone cared and was always looking out for your needs or just to have a chat, but you also knew that you could ring them at any time."

"I can't emphasise enough how critically important the Patient Navigator has been throughout my whole breast cancer journey. There's a lot to take in and having a dedicated person to explain the paperwork, the financial side of the package and the various treatment procedures in simple, easy to digest chunks is invaluable. Having someone like Nicky to coordinate all the appointments with various medical specialists and keep track of everything was an absolute godsend. Specialist medical professionals can be a bit daunting and intimidating to approach. It's difficult enough coming to terms with a shock cancer diagnosis without having to connect to services and having Nicky as one central point of contact takes away all the stress and worry associated with that. I firmly believe the Patient Navigator is an essential factor in the success of the Early Stage Breast Cancer Care Bundle program. I wish the program continued success."

The economic evaluation sub-project undertaken in 2021 – the first of several pieces of work related to costs – provided early results only. The Optimal Care Pathway review for a subset of the RPH patients also revealed initial information related to costs and effective use of funds. The early breast cancer bundled care project will provide further, more detailed information as it progresses. It's likely that results across all sub-projects will need to be triangulated to determine a more in-depth understanding and causality related to any early improvements in care.

Pathology services

Pathology as a health care resource is vitally important across medical specialties and used in the majority of episodes of patient care. Pathology analysis is needed for differential diagnosis of most diseases; to allow prompt and accurate treatment; monitor the effects and efficacy of treatments; and ultimately reduce morbidity and mortality and ensure the best health outcomes for the community. Accurate pathology data also leads to cost benefits, for example by ensuring the patient has the correct anti-microbial medication or cancer treatment, and changes to treatment if a response is not seen. The complex work that goes into pathological analysis, however, is often not clearly articulated as part of the patient healthcare journey, and this can lead to both an undervaluation of pathology as a discipline and a mismatch between required tests and those that are ordered or carried out. This leads to inefficiencies and costs and, importantly, sees pathology viewed as a "cost" and an adjunct to quality care rather than a primary contributor to value.

Efforts to better understand pathology as a creator of value rather than a source of value loss have resulted in implementation of a "Pricing and Costing" project within the public pathology service (PathWest) aimed to better understand the value of pathology test provision. This project aims to deliver both a cost of performing a test and evidence-based guidelines on when and how a test should be undertaken across pathology modalities such as anatomical pathology, immunology, biochemistry, and microbiology. This should improve the overall value to the health system by discouraging low value care and supporting high value investigations.

Challenges

Specific to the early breast cancer bundled care project, the identification of hidden costs, complex relationships between insurers and hospitals, and recent price rises across all sectors, has resulted in an increase in the overall bundle price. This has risen from \$2,500 to \$3,000 for patients with HBF insurance and from \$3,000 to \$3,300 for patients insured by Medibank.

The key challenge with development and implementation of these innovative projects was the time taken to fully engage the multiple stakeholders and carefully work through processes to analyse and/or manage feasibility, planning, and potential risk. This was highlighted in the bundled care project when addressing stakeholder concerns about potential implications to financial operations and management for service providers. It is vital, however, to implement effective preparation, planning, and collaboration to ensure maximum utility and effectiveness is gained from this pilot.

2.4 Collaboration leading to further successful grants applications

Both value-based healthcare (VBHC) and person-centred healthcare (PeCHC) are important approaches to care delivery that aim to improve outcomes that matter most to the consumers and providers of care. VBHC integrates outcome and cost data to perform comparisons, learning from those with better outcomes at the same or lower costs. Person-centred care takes a more individualistic view that relates to the context, goals, and preferences of a single person. It is recognised that consumers strongly value a person-centred approach¹. To address this, an application for a *Centre for Research Excellence in Value-based and Person-Centred Planned Care – Developing new models of healthcare delivery to meet future challenges*, based within the University of Melbourne has been put forward. Should the application be successful, the CIC Cancer team will be involved. The knowledge already gained through the CIC Cancer project is seen as an important input to what will be Australia's first cross-disciplinary research hub to explore what a value-based healthcare system should look like when applied to several disease areas and accelerate the translation of data-driven research into value-based care.

The aim of the proposed centre is to generate the evidence needed to support the integration of equitable person-centred value-based healthcare (PeCVBHC) into practice in five health conditions/care areas which span different layers of healthcare and include service providers in both the health and social systems. These conditions/care areas are breast cancer; planned or elective surgery; colonoscopy; oral disease; and cardiovascular disease.

The program of work brings together multiple disciplinary approaches and leaders – including consumers – capable of driving change. It aims to answer emerging questions in a timely way and harness the benefits of interdisciplinary research, including identification of redesign principles to optimally address the chosen health conditions. An education program will also be developed covering the key principles of PeCVBHC and health equity, along with the skills needed for implementation. New knowledge will be delivered through four research streams across the five health conditions.

1. Define if, and how, healthcare systems approach to care is aligned with personal preferences/goals, and the extent to which this is linked to captured data. Are care pathways appropriate, do they achieve the outcomes that matter most to the consumers and providers of care? What areas need

¹ Little P, et al. Preferences of patients for patient centred approach to consultation in primary care: observational study. *BMJ* 2001;322:1–7.

attention? What drives inappropriate care (appropriate defined as achieving outcomes that matter most to recipients and providers of care)?

2. Define and address areas of inequity in these care pathways so distribution of resources will target or reflect the areas where the greatest health benefits can be gained at a population level, including for those from disadvantaged groups with worse health outcomes.
3. Trial innovative models of care within and across Australia's complex healthcare system. What interventions would fit workflow and be feasible to improve practice? What interventions work, are sustainable to change behaviour, and provide seamless patient journeys? What policy levers are needed to enact these and strengthen the system overall?
4. Develop strategies for scaling models of care at a system level.

2.5 Trained workforce of health outcomes researchers and engaged clinicians

CIC Cancer has continued to engage with clinicians, health service providers and health service educators. Involvement in the proposed Centre for Research Excellence (CRE; see 2.4) and Christobel Saunders' role as Co-Chair and Board Member of All.Can Australia Ltd will increase the reach of CIC Cancer activities across Australia.

Placement of a CIC Cancer research team member within the Department of Health WA Health Networks in mid-2022 and completion of the current state of patient reported measures with WA (see 3.1 Current State Analysis) has also assisted in cementing the work undertaken.

2.6 Consumer engagement

Engagement activities with consumers have been an important component of the CIC Cancer project and such collaboration has resulted in an improved understanding of issues of importance to patients. In light of the transition of activities to Department of Health WA, the CIC Cancer Consumer Reference Group has now been disbanded and consumer oversight role passed to the consumer group within WA Health. Two of the CIC Cancer Consumer Reference Group members have since joined the Department of Health WA consumer group. This will ensure that the importance of patient-reported measures continues to be voiced.

Understanding patient experiences

Variations in patient experience across their cancer journey were captured through the *Cancer Patients Experience Survey* (CaPES) project undertaken in late 2021 as part of the wider CIC Cancer program. Utilising an adapted version of the patient experience questionnaire developed by All.Can International, this survey collected both quantitative and qualitative data from 3,238 respondents – representative of all WA people diagnosed with cancer in 2019 in respect of age, sex, cancer type, and where they lived. This provides a holistic understanding of patient experiences, ranging from cancer diagnosis, care, and treatment to the continuing support and financial impacts of cancer on quality of life from the patient perspective.

The finalisation of data analysis during the latter half of 2022 identified that the majority of respondents were happy with their cancer experience, and many wanted to let people know that this was the case, particularly because of the negative stories that are often heard about care. The results have provided a very rich data source, particularly as this was the first time that a survey such as this had been completed across WA. Findings are currently being made available at many levels, including academic publications and consumer-specific items.

Key areas of patient concern

- Rural and remote respondents had additional costs compared to metropolitan respondents if they were treated in Perth, as they dealt with dual household costs and as would be expected, had greater travel costs.
- There was an expectation from younger respondents that every area of their care could be improved, possibly because of higher expectations.
- Issues reported by respondents or areas noted for improvement, all related to poor communication. This was interwoven with issues related to lack of empathy, poor continuity of care, limited understanding of information provided and/or inability to manage expectations.

These inadequacies were reported at many points in the care trajectory between first presentation and follow up, however, respondents also provided positive feedback on how some of these could be alleviated. The two main areas where respondents had suggestions to improve the experience were around continuity of care and support.

Efficient and timely access - Trying to negotiate an unfamiliar, often complex, health system when dealing with a life limiting illness can lead to needless additional stress. In particular, delays in diagnosis and access to a health professional or treatment, without explanation, were frustrations for patients particularly if they were working, feeling unwell, were travelling long distances, or treatment itself took a prolonged time. Implementing options to allow all appointments to occur on the same day would alleviate some of these concerns, particularly if patients are repeatedly travelling long distances for appointments, needing to take time off from work, or caring for others.

Support - To improve the overall experience of patients dealing with a cancer diagnosis a patient navigator service could assist in dealing with treatment, psychological, and social issues. This could consist of a team of people with knowledge of the health system and cancer experience who could answer questions or facilitate contact to the appropriate service or person. Such a central service and contact telephone number could prevent missed appointments, feelings of isolation, and people not knowing who to ask. Care navigation is also likely to improve access.

Challenges

It is important to ensure that all consumer types are well represented in a project such as this with sufficient diversity of social and cultural identities, particularly people who may feel unable to take part in consumer engagement activities. This can, however, be difficult to achieve.

3. Transition to Health Services

In late 2021, permission was sought from, and granted by, all project partners for continuation of the CIC Cancer project until June 2023 and use of residual funds for this purpose. The key project aims for these additional 12 months of the project were focussed on transition of the project activities to health services. This involved working closely with health service providers to understand how best to facilitate a transfer of 'ownership' of the project and subsequent translation into standard cancer practice within WA. Both SJoG and WA Health are highly engaged and committed to working to embed the work of CIC Cancer into routine care and thus make outcomes capture a key part of clinical practice.

Following discussions with the Department of Health WA about the best way to work through the governance issues associated with a transition, an additional \$90,000 grant was received in June 2022. These funds were

for 0.6 FTE UWA personnel resource over a 12-month in-reach arrangement with the team member based physically at the Department of Health, Health Networks. The aim was to:

1. undertake an analysis of the current state of validated PROMS and PREMS utilised across WA; and
2. develop a detailed transition plan and the requirements that will inform the readiness for the future transition of the CIC Cancer research project into the WA Health ICT environment.

3.1 Current state analysis

The current state analysis evaluated the status of PREMs and PROMs, with a view to identifying and understanding their actual and potential use, associated processes, issues, and any opportunities for improvement. The outcomes of the current state analysis provide a recent snapshot of both PROMs and PREMs to inform:

- the WA Health Executive Committee's Safety and Quality Committee about the current approach in WA; and
- development of a detailed Transition Plan for the future transition of the CIC Cancer Project as a 'proof of concept' project – including a custom-built information system that supports the collection, use and reporting of PROMs – into WA Health.

The process used to understand the current state incorporated a desktop review, literature review, and targeted stakeholder engagement across the WA health sector. Input from other Australian jurisdictions was also sought, both individually and through the Australian Commission of Safety and Quality in Health Care's PROMs Roundtable opportunities in late 2022.

Findings

It was identified that stakeholders engaged across the WA health sector exhibit a high level of enthusiasm for patient reported measures with recognition of the important role these can play in promoting the provision of patient-centred care at both the individual and system level. The analysis found that there is significant activity across the WA health system which aligns with state (e.g. the WA Sustainable Health Review), and national priorities (Australian Cancer Plan); however, this activity is not necessarily cohesive or immediately visible.

Well-coordinated work is already underway for PREMs and there is a strong appetite – demonstrated by both clinicians and organisations during consultation – for the implementation of PROMs projects. Whilst there is currently a fragmented approach to patient reported measures, there is an opportunity for the WA Department of Health to take the lead in establishing a consistent and coordinated approach with WA health service providers. As seen in other jurisdictions and countries, this can effectively drive change to improve patient care and outcomes whilst reducing service delivery costs.

Patient reported experience measures (PREMs)

The current state analysis found that the WA Health system has a long history of evaluating patient satisfaction and experience to inform improvements in care delivery and other services. Within the private sector this is often facilitated through the *Voice of the Patient* survey. For WA Health, considerable work has been achieved more recently with PREMs through the successful development and introduction of the *MySay* Healthcare Survey led by South Metropolitan Health Service Safety, Quality and Consumer Engagement to measure patient experience for all overnight and same-day patients. The initiative is coordinated through an established governance model and agreed collaborative approach between health service providers and the WA Department of Health. The *Your Experience of Service (YES)* survey – developed through the National Mental Health Consumer Experiences of Care Project – was commenced state-wide in 2018 by the WA

Mental Health Commission for use with paediatric, adolescent, and adult consumers across all public-funded community and inpatient mental health services.

Patient reported outcome measures (PROMs)

A number of PROMs activities currently occur across the health system in WA. At the health service provider level, the majority of PROMs related initiatives have originated from translational research or clinical quality projects aimed at driving improvements in patient-centred care. Unlike PREMs, these activities are not integrated nor is there any overall coordination or oversight. Currently, therefore, there is no capability for the Department of Health to ensure that effective governance has been established and that any data outcomes or learnings from PROMs captured at a local level are being used to inform and effect change across the system. The fragmented nature of this approach means that there is no agreed framework, guiding principles, or business rules to ensure improvements are being informed by evidence-based best practice and data collected is accurate and able to be benchmarked now and in the future.

It was determined that considerable gains could be achieved through the development and application of a cohesive and coordinated approach to patient reported measures. This approach would be best facilitated by the WA Department of Health working collaboratively with health service providers to establish, coordinate, and integrate a statewide program, in line with evidence-based best practice. The following next steps are recommended towards a state-wide approach to PROMs.

- a) Development of a WA CIC Project Transition Plan with a PROMs proof-of-concept project, to inform future transition into WA Health and the business requirements necessary to sustainably support an ongoing program. This proof-of-concept project should work with health service providers to evaluate the CIC PROMs framework and its custom-built information system for the ongoing collection, use, and reporting of PROMs from point of care through to the service and system levels.
- b) A common set of guiding principles and processes (toolkit) should then be developed that is informed by current practice with PREMs, the outcomes of the proposed proof-of-concept project for PROMs, and consultation with health service providers. This would create a consistent and systematic approach to patient reported measures across the WA health system, such that these could be used to accurately and reliably inform care delivery, drive improvements, and inform change in patient-centred care.

3.2 Transition planning

Delays within the WA Health Department have resulted in a change to the due date for the transition plan, which is now due in September 2023. The plan will outline a methodology to support the uptake of a simplified version of the CIC project and informatics system into WA Health for the collection and use of PROMs as part of standard care for cancer patients treated for breast, lung, colorectal and ovarian cancer within WA public hospitals as a proof-of-concept. This has potential for future translation to capture PROMs for other health conditions.

This transition strongly aligns with the strategic goals and priorities of the WA Department of Health and the National Health Reform agenda. The collection of PROMs will provide solutions which directly assist achievement of the following recommendations and strategies.

- Recommendation 4 of the WA Sustainable Health Review.²

² Sustainable Health Review. (2019). Sustainable Health Review: Final Report to the Western Australian Government. Department of Health, Western Australia.

- Priority 3, Strategy 8 WA Cancer Plan 2020-2025.³
- WA Digital Health Strategy.⁴
- Action 4.2.1 of the Australian Cancer Plan.⁵
- Work currently underway to develop a WA Cancer Data Strategy

Once the transition plan has been accepted by the Department of Health, a similar and complementary plan will be devised for St John of God sites. This will help to ensure that the required systems continue to be implemented in parallel.

Methodology

It is proposed that the transition will be achieved in a phased approach over 2 years. This includes phase 1 – 12 months (2023/24) to prepare and set up the transition – whilst still under the auspices of UWA; and the second year (Phase 2, 2024/25) for the Department of Health WA to embed and evaluate the proof-of-concept project and consider expansion and applicability options beyond 2025.

Inclusion of phase 1 in the transition process will allow implementation and testing of planned simplification of the CIC PROMs collection system and processes to ensure the application is fit for purpose for the proof-of-concept project within phase 2 and ongoing sustainable use. Funding for phase 1 will be provided by UWA and university partners. Data for current and new patients at current sites – both public and private – will continue to be collected in phase 1. All changes will also be reflected in the CIC informatics system (CICIS) embedded within SJoG.

Phase 1

In phase 1 the activities of the CIC Cancer research project will be simplified to capture PROMs only data for the existing patient cohort for a further 12 months with funding and support provided by the current CIC Cancer project. As the 12 months of phase 1 progress, simplified methodologies for data collection, analysis and reporting will be determined. Work will also be undertaken to identify the requirements necessary to capture patients with similar health conditions (e.g. non-lung cancer specific respiratory conditions) managed in the outpatient clinic settings.

This simplification is proposed because a greater level of resource provision is required for the manual transfer of clinical data to CICIS than is sustainable in the long term. The ability to enter clinical data into the system will remain but this will not be collected as part of the transition and proof-of-concept work. Whilst clinical data capture is important to understand the cause or effect of changes in PROMs responses over time (cancer diagnosis, treatment, and post treatment), the collection of clinical data is more complex and will need to be considered further. It is possible for clinical data to be extracted electronically from other systems, but this is currently difficult because of variability in systems and data definitions and the use of pdf reports to convey clinical information rather than atomic level data. However, this may be made simpler following the implementation of recommendations that may arise from the future WA Cancer Data Strategy and the proposed electronic health record.

Currently, the data capture process is managed by CIC project funded staff within the clinical setting and is time consuming. Simplification of the data capture process is, therefore, paramount in order for the proof-of-

³ Western Australian Department of Health. WA Cancer Plan 2020–2025. Perth: Health Networks, Western Australian Department of Health; 2020

⁴ Department of Health Western Australia. WA Health Digital Strategy 2020-2030. Perth: Strategy and Governance Division, Department of Health. 2020

⁵ As of 4/7/23 the document is still in draft form (<https://engage.australiancancerplan.gov.au/>)

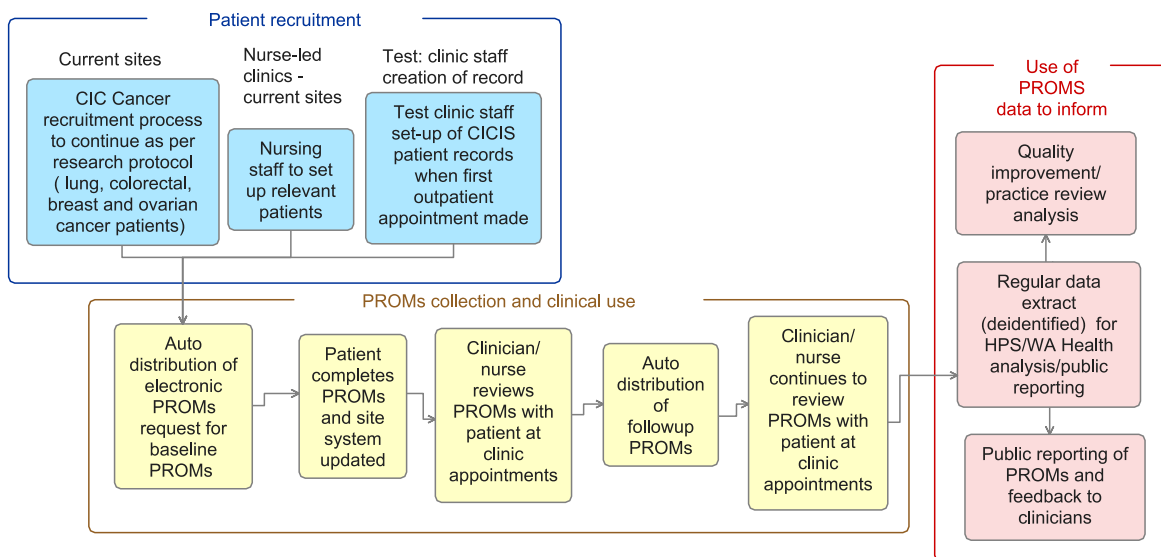
concept to be successfully implemented in phase 2. This will occur through full automation of the PROMs survey processes once a patient record is set up. Activities will also be undertaken to identify any additional ways to further refine processes to ensure resource minimisation and sustainability.

In phase 1, as a test case, the CIC team will seek to work with site staff at RPH/East Metro Health Service towards a process whereby outpatient department clerical staff in at least one applicable clinic (lung, colorectal, or breast) complete the CICIS patient record creation process for all new referrals to the clinic, not just those with a cancer diagnosis. Implementation of this test case will identify how well the capture of PROMs data can be extended to patients with similar health conditions who are also managed within the outpatient clinics that provide care to cancer patients. For example, patients with lung cancer attend the clinic alongside patients with other respiratory conditions that would also benefit from review of PROMs during clinical consultations. Prior to commencement of the test case, enhancements will be made to CICIS to address the capture of consent and to ensure that the patient facing components of CICIS have no mention of the term 'cancer'.

Relevant nursing staff will continue to create patient records for new patients managed within a nurse-led clinic within the public sites. Private sites will also continue to set up patients and operate as they do under the CIC Cancer research project.

Preparation work for the transition (phase 1) and proof-of concept project (phase 2) will test feasibility for standard care but success will not be fully attained until CICIS is owned, and managed, by the Department of Health (WA) under appropriate governance arrangements. Consent will need to be investigated and resolved during phase 1 to ensure ethical considerations and future research/analytical requirements are met in phase 2 and beyond. Currently, patients provide written consent at baseline. Ongoing consent is also provided whenever a PROMs form is completed and, as such, consent can be withdrawn at any follow up PROMs review. During phase 1, therefore, advice will be sought to confirm the appropriate approach for ethics and governance surrounding consent and data utilisation.

Phase 1: simplified CIC Cancer Methodology - PROMs only



Phase 2

The purpose of phase 2 is to implement a proof-of-concept project, under full control of the Department of Health WA. It is suggested that this involves current CIC Cancer project sites with consideration given to expansion to other sites and conditions beyond 2025. This 12-month trial should incorporate activities to both embed the application and evaluate the implementation.

The process for collection of PROMs will remain as it was for phase 1, the only change being that, based on the results of the possible RPH test case in phase 1, use of CICIS could be extended to other conditions managed by outpatient clinics caring for people with lung, colorectal, breast and ovarian cancer across all current sites. Inclusion of all patients attending specific clinic settings will improve processing and take-up by outpatient clerical staff as there would be no requirement (by non-health professional staff) to determine which of the referrals could relate to a possible cancer diagnosis. Should other public hospital sites providing colorectal, breast, lung, or ovarian cancer care express an interest in being involved, the collection of PROMs can be extended to additional sites with minimal additional work. In addition to achievement of strategic policy requirements, this will provide a rich data registry – with an understanding of what is important to patients – with some PROMs data captured over 5 years or more.

Phase 2 activities will also focus on resources and processes required for full implementation to standard care for cancer patients and appropriate others across all public sites and potential methodologies to access PROMs data from current private sector sites. This will allow the sustainable capture of PROMs through building on an already functioning project.

Early investigation, in phase 2, of the potential for future links with the private sector will provide an understanding of ways to access comparable de-identified PROMs for analysis. Longer term, data merged through such link processes will provide an understanding of the ‘whole story’ for patients and enhance sustainability and utility. Further investigation of how clinical data can be extracted electronically from other systems to complement PROMs capture will also need to occur.

Integrated dataset

The CIC Cancer project is believed to have the richest source of costed treatment pathways in cancer care data within Australia – including approximately 170 data points and economic information for patients with lung, colorectal and breast cancer. The CICIS has been set up in such a way that de-identified data can be easily extracted from the system for the purpose of approved research. The way in which this will work, once the transition occurs, should form part of ongoing planning and governance recommendations.

Possibilities will exist for external projects to access to this data for other research (subject to appropriate approvals) and access to this ‘databank’ of patient centred information will result in a significant legacy for the project. It is hoped that 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. Researchers would be able to seek an extract of patient reported outcome data from multiple health sites 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 health services and an academic institution would ensure the level of governance currently associated with the databank was maintained.

Appendices

Appendix 1: Alignment with strategic/policy directions

State Health Priorities

WA Sustainable Health Review

The ongoing use of the CIC Cancer methodology and infrastructure to capture PROMs directly addresses Recommendation 4 of the WA Sustainable Health Review.

SHR Recommendation

Strategy 1, Rec 4

Transparent public reporting of patient and carer reported experience and outcomes (PREMs and PROMs) by July 2021 with ongoing development of measures in line with emerging best practice

WA Cancer Plan 2020-2025

Implementation of the CIC Transition proof of concept project directly addresses the PROMs component of Priority 3, Strategy 8 WA Cancer Plan 2020-2025.

WA Cancer Plan Recommendation

Priority 3, Strategy 8

Establish transparent public reporting of patient reported experience and outcomes and monitoring of systemwide performance indicators.

WA Cancer Data Strategy

The need to provide a sustainable approach to cancer data collection, analysis and reporting was identified as a priority within the WA Cancer Plan 2020-2025. Work is currently underway to develop a WA Cancer Data Strategy with patient reported measures (PREMs and PROMs) considered in the broader WA policy framework.

WA Digital Health Strategy 2020-2030

The WA Digital Health Strategy identified a need to improve the quality of information available to clinicians. The survey metrics collected through PROMs provide information to health teams that informs patient interactions, promotes communication, allows shared decision-making, and improves the quality of care. This information provides the greatest benefit at point of care; however, it can also be used in aggregated form – at both service and system levels – to drive continuous improvement, encourage sharing of innovative and effective practices, and inform value-based health care models. Whilst the WA Digital Health Strategy does not specifically refer to PROMs, patient related information requires input from the patient to be seen as truly comprehensive. The ICT platform integrations already in place within the CIC Cancer infrastructure will easily allow PROMs to become an integral part of any electronic medical record and provide measures which are consistent – with data that are comparable across time (and between patients) – and reportable.

WA Digital Health Strategic theme

2. Informed clinicians – Ensuring clinicians are informed to make effective decisions that advance quality and safety (...*access to real-time comprehensive patient information*)

National Health Priorities

National Health Reform Agreement

There are a number of national health priorities which the CIC proof-of-concept project also addresses. This includes, but is not limited to, strategic priorities and associated reform objectives of the 2020–25 Addendum to National Health Reform Agreement⁶.

- Delivering safe, high-quality care in the right place at the right time, including long-term reforms in:
 - paying for value and outcomes through use of *appropriate data and performance measures, including from enhanced data and performance reforms (e.g., patient reported measures)*.
- Prioritising prevention and helping people manage their health across their lifetime, including long-term reforms in:
 - empowering people through health literacy - *Systematically measure patient reported health outcomes and care experiences*.
- Driving best practice and performance using data and research, including long-term reforms in:
 - enhanced health data - *Develop and implement a consistent approach to the collection and use of Patient Reported Measures*.

National Cancer Plan

The routine capture of PROMs directly addresses Action 4.2.1 of the Australian Cancer Plan.⁷

WA Cancer Plan Recommendation

Strategic Objective 4, Strong and dynamic foundations/Action 4.2.1 – Design and embed patient reported experience and patient reported outcomes into a national performance monitoring and reporting for all providers, to assess services for all population groups and establish evidence base

⁶ Australian Health Ministers. The National Health Reform Agreement (NHRA) Long Term Reforms Roadmap: Australian Government, Department of Health and Aging; 2021. <https://www.health.gov.au/our-work/2020-25-national-health-reform-agreement-nhra>

⁷ As of 21/7/23 the document is still in draft form (<https://engage.australiacancerplan.gov.au/>)

Appendix 2: Update to publications, presentations, media, and reports since commencement

Note: Items above the bold, double line in each table are an update to previous information provided.

Publication Title	Submission to	Publication Date	Type
International development of a patient-centered core outcome set for assessing health-related quality of life in metastatic breast cancer patients K.M. de Ligt, B.H. de Rooij, E. Hedayati, M.M. Karsten, V.R. Smaardijk, M. Velting, C. Saunders, L. Travado, F. Cardoso, E. Lopez, N. Carney, Y. Wengström, A. Ives, G. Velikova, M.D.L. Sousa Fialho, Y. Seidler, T.A. Stamm, L.B. Koppert, L.V. van de Poll-Franse, on behalf of the Innovative Medicines Initiative - Health Outcomes Observatory (H2O) consortium	Breast Cancer Research and Treatment (https://doi.org/10.1007/s10549-022-06827-6)	Jan 2023	Peer-reviewed Article
Cancer efficiency Metrics Study All.Can Secretariat	Cancer world Magazine (https://cancerworld.net/wp-content/uploads/2022/10/Cancerworld_96-100.pdf)	Dec 2022	Article
Breast Cancer Bundle of care: a pilot study Zissiadis Y, Wise S, Saunders C, Ives A	COSA 2022 Abstracts Booklet. Asia-Pacific Journal of Clinical Oncology. 18:S3.pp39-52. 2022. (https://doi.org/10.1111/ajco.13868)	Nov 2022	Peer-reviewed Article
An Australia first: best-practice bundle for private breast cancer treatment Sarah Wise	CREST Newsletter - Centre for health Economics Research and Evaluation (https://www.uts.edu.au/sites/default/files/2022-10/CREST-Newsletter-September-2022.pdf)	Sept 2022	Article
Employing cognitive interviewing to evaluate, improve and validate items for measuring the health-related quality of life of women diagnosed with ovarian cancer Boban S, Codde J, Downs J, Cohen P, Bulsara C	BMC Women's Health (https://doi.org/10.1186/s12905-022-01966-w)	Sept 2022	Peer-reviewed Article

<p>Taking bill shock out of cancer care</p> <p>M Attard, C Saunders</p>	<p>Oncology Republic (https://www.oncologyrepublic.com.au/taking-bill-shock-out-of-cancer-care/2298)</p>	<p>Aug 2022</p>	<p>Article</p>
<p>Creating a breast cancer care package based on Person-Centred Value-Based Health Care principles</p> <p>C Saunders, A Ives</p>	<p>https://www.sprink.co.uk/creating-a-breast-cancer-care-package-based-on-person-centred-value-based-health-care-principles/</p>	<p>July 2022</p>	<p>Article</p>
<p>Data-driven efficiency across the cancer care pathway</p> <p>Shannon Bolden and Suzanne Wait on behalf of All.Can International</p>	<p>Brain Tumour Magazine: World Edition 2021/2022 (https://issuu.com/ibta-org/docs/ibta_magazine_2020)</p>	<p>Jan 2022</p>	<p>Article</p>
<p>Priority recommendations for the implementation of patient-reported outcomes in clinical cancer care: a Delphi study</p> <p>C Mazariego, M Jefford, R J Chan, N Roberts, L Millar, A Anazodo, S Hayes, B Brown, C Saunders, K Webber, J Vardy, A Girgis, B Koczwara, COSA PRO Working Group</p>	<p>Journal of Cancer Survivorship (https://pubmed.ncbi.nlm.nih.gov/35107792/)</p>	<p>Feb 2022</p>	<p>Peer-reviewed Article</p>
<p>The CIC Cancer project: Improving outcomes that patients really want</p>	<p>Research Australia INSPIRE (https://issuu.com/researchaustralia/docs/research_australia_inspire_issue_22_final)</p>	<p>Dec 2021</p>	<p>Article</p>
<p>Priority Recommendations for the Implementation of Patient Reported Outcomes in Clinical Cancer Care: A Delphi study</p> <p>C Mazariego, M Jefford, R J Chan, N Roberts, L Millar, A Anazodo, S Hayes, B Brown, C Saunders, K Webber, J Vardy, A Girgis, B Koczwara</p>	<p>COSA 2021 Abstracts Booklet. Asia-Pacific Journal of Clinical Oncology. 17;S9.pp60-109 (https://doi.org/10.1111/ajco.13715)</p>	<p>Nov 21</p>	<p>Peer-reviewed Article</p>
<p>Co-intelligence: Knowledge exchange overtaking competition to drive global cancer care progress</p> <p>Christobel Saunders</p>	<p>Oncology News (https://oncologynews.com.au/co-intelligence-knowledge-exchange-overtaking-competition-to-drive-global-cancer-care-progress/)</p>	<p>Sept 2021</p>	<p>Article</p>
<p>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</p>	<p>International Journal of Gynaecological Cancer (https://ijgc.bmj.com/content/early/2021/09/21/ijgc-2021-002999)</p>	<p>Sept 2021</p>	<p>Peer-reviewed Article</p>

<p>clinic-based or telehealth follow-up, following completion of first-line chemotherapy in patients with epithelial ovarian cancer</p> <p>Paul A Cohen, Penelope M Webb, Madeleine King, Andreas Obermair, Val GebSKI, Phyllis Butow, Rachael Morton, Wanda Lawson, Patsy Yates, Rachel Campbell, Tarek Meniawy, Michelle McMullen, Andrew Dean, Jeffrey Goh, Orla McNally, Linda Mileskin, Philip Beale, Rhonda Beach, Jane Hill, Cyril Dixon, Sue Hegarty, Jim Codde, Angela Ives, Yeh Chen Lee, Alison Brand, Anne Mellon, Sanela Bilic, Isobel Black, Stephanie Jeffares and Michael Friedlander</p>			
<p>Patient involvement in the development of a patient-reported outcome measure for ovarian cancer</p> <p>Bulsara C, Boban S, Codde J, Cohen P, Downs J.</p>	<p>IPOS 2021 Abstracts Booklet. Journal of Psychosocial Oncology Research and Practice, 3, e054. (https://doi.org/10.1097/OR9.0000000000000054)</p>	2021	Peer-reviewed Article
<p>Life after cancer is more than just survival</p> <p>CIC Cancer Team</p>	<p>Oncology Republic (https://oncologyrepublic.com.au/life-after-cancer-is-more-than-just-survival/963)</p>	Aug 2021	Article
<p>Women diagnosed with ovarian cancer: Patient and carer experiences and perspectives</p> <p>Boban S, Downs J, Codde J, Cohen PA, Bulsara C</p>	<p>Patient Related Outcome Measures (https://doi.org/10.2147/PROM.S272688)</p>	Feb 2021	Peer-reviewed Article
<p>Implementation of patient involvement in the development of a health-related quality of life patient-reported outcome measure for ovarian cancer</p> <p>Sharolin Boban</p>	<p>A thesis submitted in fulfilment of the requirements for Master of Health Science by Research (https://researchonline.nd.edu.au/theses/302/)</p>	2021	Thesis
<p>“Nothing beats the doctor's face to impart trust in their judgement” – the role of telehealth in cancer care</p> <p>Neli S. Slavova-Azmanova, Lesley Millar, Angela Ives and Christobel M. Saunders</p>	<p>Australian Health Review (https://www.publish.csiro.au/AH/AH20314)</p>	Dec 2020	Peer-reviewed Letter to the Editor
<p>Measuring the cost of continuous improvement in care in cancer</p>	<p>The Health Advocate</p>	Nov 2020	Article

Lesley Millar, Claire Smith, Marshall Makate, Angela Ives and Christobel M. Saunders	(https://issuu.com/aushealthcare/docs/the_20health_20advocate_20-_20november_202020/s/11243272)		
Moving towards value-based, patient-centred telehealth to support cancer care Neli Slavova-Azmanova, Lesley Millar, Angela Ives, Jim Codde, and Christobel Saunders	Deeble Institute for Health Policy Research Perspectives Brief #11 (https://ahha.asn.au/health-policy-perspective-briefs)	Aug 2020	Health Policy Perspectives Brief
Towards value based healthcare: Lessons learnt from implementing outcomes measures Christobel Saunders, Lesley Millar, Angela Ives, Neli Slavova-Azmanova, Matthew Bellgard, Jim Codde	Deeble Institute for Health Policy Research Perspectives Brief No: 5 (https://ahha.asn.au/health-policy-perspective-briefs)	Oct 2019	Health Policy Perspectives Brief
CIC Cancer - Evaluating outcomes that matter most to patients and improving care Lesley Millar, Neli S. Slavova-Azmanova, Angela Ives, and Christobel M. Saunders	The Health Advocate (https://ahha.asn.au/publication/health-advocate/health-advocate-june-2019)	June 2019	Article
Towards Value Based Healthcare – modelling an answer for cancer care delivery Christobel Saunders	Australian Health Review (https://www.publish.csiro.au/ah/pdf/AHv43n2_ED)	March 2019	Peer reviewed editorial
Measuring what's important to our patients: The Continuous Improvement in Care - Cancer (CIC Cancer) Project Ives A, Millar L, Slavova- Azmanova N, Bellgard M, Codde J, Saunders C	COSA 2018 Abstracts Booklet. Asia-Pacific Journal of Clinical Oncology. 2018 14;S7, pp91-202 (https://doi.org/10.1111/ajco.13088)	Nov 18	Peer-reviewed Article
When is 'enough' data really too much? Data capture in the CIC Cancer Project Theophilus M, Ives A, Millar L, Bowland G, Render L, Saunders C	COSA 2018 Abstracts Booklet. Asia-Pacific Journal of Clinical Oncology. 2018 14;S7, pp91-202 (https://doi.org/10.1111/ajco.13088)	Nov 2018	Peer-reviewed Article
Patients First: The Continuous Improvement in Care Cancer Project in Western Australia	The Health Advocate (https://ahha.asn.au/publication/health-advocate/health-advocate-december-2017)	Dec 2017	Article

Neli S. Slavova-Azmanova, Angela Ives, Niloufer J. Johansen, and Christobel M. Saunders			
Value-Based Care in the Worldwide Battle Against Cancer	Cureus Journal of Medical Science (https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5356991/)	Sept 2017	Peer-reviewed Article
Niloufer J. Johansen, Christobel M. Saunders			

Presentation Title	Presentation to	Date	Type
Cancer Patient Experience Survey (CaPES) in WA	2023 COSA Annual Scientific Meeting	May 2023 for Nov 23 event	Conference abstract submission
Person-centred value-based breast cancer care	2023 Victorian Health Sector Summit	Mar 2023	Presentation
VBHC Visiting Lecture – Strategic Management and Innovation in Health unit of UWA MBA (Health)	Students of UWA MBA (Health)	Mar 2022	Seminar presentation
Introduction of PCVBHC to University College London Hospital	University College London Hospital and NHS Board	Mar 2023	Seminar presentation
Strategies for sustainability: Implementation insights for long-term sustainment of programs that routinely collect Patient Reported Outcomes (PROs) in cancer care clinical settings	National Cancer Survivorship Conference 2023	Mar 2023	Conference Poster presentation
Breast Cancer Bundle of care: a pilot study	2022 COSA Annual Scientific Meeting	Nov 2022	Conference Poster presentation
Value Based Health Care in Cancer	Perth Dermatology Research Collaborative	Oct 2022	Seminar presentation
WA CIC Transition Project 2022-23 - Driving improvements in outcomes that matter most to patients and healthcare efficiencies through a patient-centered, value-based approach	WA Health Network Leads Meeting WA Survivorship Network Meeting WA Cancer Leads Meeting	Oct 2022 Sept 2022 Aug 2022	Seminar presentations
Hearing the patient voice in identifying gaps and priorities for change	Breast Cancer Foundation New Zealand/Breast SIG Conference	Aug 2022	Oral conference presentation
Funding for the future: Investigating and implementing innovative funding models in Australia'	Independent Hospital Pricing Authority Seminar Series (https://www.youtube.com/watch?v=SmZPbnSAhgk)	June 2022	Seminar presentation
Adding value to surgical and peri-operative care	Networks in Anaesthesia and Surgery	May 2022	Oral conference presentation

VBHC Visiting Lecture – Strategic Management and Innovation in Health unit of UWA MBA (Health)	Students of UWA MBA (Health)	Mar 2022	Seminar presentation
Harnessing data to iteratively improve cancer care	The Economist World Cancer Series	Dec 2021	Seminar presentation
How can we get better value in delivering cancer surgery and care	Networks in Anaesthesia and Surgery	Dec 2021	Oral conference presentation
Priority Recommendations for the Implementation of Patient Reported Outcomes in Clinical Cancer Care: A Delphi study	Clinical Oncology Society of Australia	Nov 2021	Oral conference presentation
Optimising patient journeys for better value care	Research Australia Health Economics Roundtable	Oct 2021	Seminar presentation
What is Value-Based Health Care	WA Clinical Senate	Oct 2021	Seminar presentation
PCVBHC: Implementation and recommendations	Launch of Person Centred VBHC (https://www.sprink.co.uk/launch-event/#videos)	Sept 2021	Seminar presentation
How patients feel about the collection of PROs	VBHC Conference	May 2021	Oral conference presentation
Digital collection of outcome data in lung cancer: First steps	VBHC Conference	May 2021	Oral conference presentation
Reducing out-of-pocket expenses and optimising cancer care through bundled packages	VBHC Conference	May 2021	Oral conference presentation
First steps in patient-reported outcomes data visualisation for breast cancer	VBHC Conference	May 2021	Oral conference presentation
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
What is Value Based Health Care and why measure patient-reported outcomes?	HBF Grand Rounds	Aug 2020	Seminar presentation

Patient Reported Outcome Measures in a Western Australian Pilot Group of Lung Cancer Patients: Implementation of the Continuous Improvement in Care - Cancer (CIC Cancer) Project	Australian Lung Cancer Conference	Feb 2020	Conference Poster presentation
'Proof of Concept': Implementation of a patient outcomes data capture and analytics system	8th Annual NHMRC Symposium on Research Translation	Nov 19	Conference Poster presentation
'Proof of Concept': Implementation of a patient outcomes data capture and analytics system	NHMRC Symposium 2019	Nov 2019	Conference Poster presentation
Should PROMs and PREMs be standard in clinical care	Australian Clinical Trials Alliance (ACTA) International Clinical Trials Symposium	Oct 2019	Oral conference presentation
In Pursuit of Value-Based Health Care in Cancer: the CIC Cancer Project	UWA Medical School Research Day	Oct 2019	Oral conference presentation
CIC Cancer Project and Value Based Health Care	2019 Gynaecologic Oncology Strategic Review meeting	Sept 2019	Seminar presentation
Improving patient outcomes to improve value	SJoG Research Week	Aug 2019	Seminar presentation
Understanding outcomes important to patients – benefits for quality improvement and challenges in implementation	SJoG Ethics seminar	June 2019	Seminar presentation
Buy or Build? Comparison of commercially available data capture systems for cancer against a specifically designed platform	ICHOM International Conference - Rotterdam	May 2019	Conference Poster presentation
Implementing patient reported outcomes: measuring what really matters to patients and the healthcare system – Value Based Healthcare	South Metro Health Service Breakfast Research Forum - 'Use of Patient Databases in Research and Clinical Decision Support'	May 2019	Seminar presentation
Implementing patient reported outcomes: measuring what really matters to patients and the healthcare system – Value Based Healthcare	Royal Australian and NZ College of Radiologists Conference	April 2019	Oral conference presentation
Implementing patient reported outcomes: measuring what really matters to patients and the healthcare system – Value Based Healthcare	Department of Human Services - Victoria Health Innovations Conference	April 2019	Oral conference presentation
How to implement patient reported outcomes in the real world: measuring what really matters to patients and the healthcare system	SJoG Grand rounds	Feb 2019	Seminar presentation
Measuring what's important to our patients: The Continuous Improvement in Care - Cancer (CIC Cancer) Project	Clinical Oncology Society of Australia annual scientific meeting	Nov 2018	Conference Poster presentation
When is 'enough' data really too much? Data capture in the CIC Cancer Project	Clinical Oncology Society of Australia annual scientific meeting	Nov 2018	Conference Poster presentation

Placing Patients First - The Continuous Improvement in Care - Cancer (CIC Cancer) Project'	International World Hospital Federation World Hospital Congress in Brisbane	Oct 2018	Conference poster presentation
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Report produced	In relation to	Distributed to	Date
WA Continuous Improvement in Care (CIC) Transition Project – Transition Plan	Transition Plan	WA Health stakeholders including WA Health Executive Committee	Draft submitted May 2023
Breast Cancer data submission to Organisation for Economic Co-operation and Development's (OECD) Patient-Reported Indicator Surveys (PaRIS) initiative	International survey for data collection required to inform the OECD Health at a Glance 2023 report	OECD and subsequent international access (For example: OECD (2021), Health at a Glance 2021: OECD Indicators, OECD Publishing, Paris, https://doi.org/10.1787/ae3016b9-en)	April 23
WA Continuous Improvement in Care (CIC) Transition Project - Current State Report	Current state analysis of validated Patient Reported Measures (PRMs) as part of the transition activities	WA Health stakeholders including WA Health Executive Committee; health service providers	Feb 2023
All.Can at 6 years - Improving Systems and Pathways Globally and Locally	Contribution to All.Can Annual Report 2022	International stakeholders (worldwide)	Feb 2023
Cancer Patient Experience Survey Report	Analysis of results	Funder	Nov 2022
Understanding Consumer Needs	Analysis of cancer information currently available to consumers and their access to this	Funder and stakeholders	Aug 2022
Annual HREC reports	Program activities and outcomes achieved	HREC committees, public health, private health sites, and Universities	3rd quarter annually since 2018
CIC Cancer annual outcomes report	Program activities and outcomes achieved	Stakeholders and national/international audiences via website access	Sept 2018, 2019, 2020, 2021, 2022, 2023
CRT annual progress report	Program activities and outcomes achieved	CRT, CCWA	July 2018, 2019, 2020, 2021, 2022, 2023

Staging Results – Breast Cancer	Analysis of cancer staging at RPH	Hospital executives and clinical stakeholders	2022
Staging Results – Colorectal Cancer	Analysis of cancer staging at RPH	Hospital executives and clinical stakeholders	2022
Staging Results – Lung Cancer	Analysis of cancer staging at RPH	Hospital executives and clinical stakeholders	2022
In-depth Review Report – Patient Care Journey Mapping	Comparison of care against Optimal Care Pathways, costs of care, and PROMs	DoH, Health service and hospital executives, and clinical stakeholders	2022
Breast Cancer PROMs Report	Analysis of PROMs collected at RPH	DoH, Health service and hospital executives, and clinical stakeholders	2022
Colorectal Cancer PROMs Report	Analysis of PROMs collected at RPH	DoH, Health service and hospital executives, and clinical stakeholders	2022
Lung Cancer PROMs Report	Analysis of PROMs collected at RPH	DoH, Health service and hospital executives, and clinical stakeholders	2022
Grant specific reports (progress and annual) - Multiple	Project activities and outcomes achieved	Funders and stakeholders	2019-2022
Health Economics Report	Analysis of costing data ad PROMs	Health executive and clinical stakeholders	2022
Student presentations and research reports (Multiple)	Write up and presentation of research projects undertaken	Academics, clinicians, and students	2019-2022
Annual Scorecard	Summary of progress towards outcomes and KPIs	Funders, stakeholders (incl consumer group), public (via website)	2019, 2020, 2021
Breast Cancer data submission to Organisation for Economic Co-operation and Development's (OECD) Patient-Reported Indicator Surveys (PaRIS) initiative	International survey for data collection required to inform the OECD Health at a Glance 2021 report	OECD and subsequent international access (OECD (2021), Health at a Glance 2021: OECD Indicators, OECD Publishing, Paris, https://doi.org/10.1787/ae3016b9-en)	April 21
VBHC Conference evaluation report	Outcomes of VBHC Conference	Attendees, sponsors, event partners, Keynote speakers, stakeholders (incl consumer group), public (via website)	2021
Collated VBHC Conference Abstracts	Presentations at VBHC Conference	Sponsors, event partners, public (via website)	2021
Community Conversation report	Outcomes of discussion during community event held prior to VBHC conference	Attendees, event partners, stakeholders (incl consumer group), public (via website)	2021
Patient Flyer/Poster	Patient facing communications to assist in recruitment	Potential participants in clinics at various sites	2019-2021
CIC Cancer Activities Update Jan-Aug 2020	Update to program activities and outcomes achieved	CIC Cancer Evaluator – T Slevin	2020

CIC Cancer Outcomes Flyer	Program summary	Stakeholders (incl consumer group), public (via website)	2019
CIC Cancer Fold Over Flyer	Program summary taken to accompany poster presentation at international conference	Conference attendees	2018
Data Capture and Analyse Model flyer	Program summary taken to accompany poster presentation at international conference	Conference attendees	2018
CIC Cancer Graphic Flyer	Program summary	Potential partners/collaborators, stakeholders (incl consumer group), public (via website)	2018
Bouquets and Brickbats	Lessons learnt from program activities	Funders, stakeholders (incl consumer group), public (via website) PLUS distribution through subsequent progression to development of a Deeble Health Policy Perspectives brief	2019

Media item distributed by	Media Title	In relation to	Date
Sprink Global Centre for Person-Centred Value-Based Health Care	Creating a Bundle of care for patients with breast cancer	Case study blog piece	June 2022
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	28/5/2021
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: Harnessing data for better cancer care	27/5/2021
All.Can	Taking forward recommendations from the All.Can Report, 'Harnessing data for better cancer care'	Blog piece	July 2021
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	23/9/2021