Continuous Improvement in Care *cancer*

Outcomes Report

July 2022

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Abbreviations

DoH	Department of Health
FSH	Fiona Stanley Hospital
HREC	Human Research Ethics Committee
HSS	Health Support Services
ICHOM	International Consortium of Health Outcomes Measurement
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

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Executive Summary

The Continuous Improvement in Care – Cancer (CIC Cancer) Project aimed to develop increased capacity for the capture of variations in health outcomes not able to be understood with conventional health outcome measures. This sought to lead to innovative health service interventions aimed at clinical practice change necessary to improve patient's lives in the short to medium timeframe. At the time of reaching the initially agreed end of the project – June 2022 – the project has achieved these aims together with working towards a transition of the work into health services as part of standard care provision for patients and families experiencing cancer. In addition, the following key performance measures have been achieved within each of the contractual program phases.

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
All nominated tumour streams engaged	Achieved*
"CIC Cancer" project committee in place	Achieved
Phase 2: Development and Identification of data capture tools	
Defined datasets for each nominated 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 in each nominated cancer	Achieved*
Data captured on patients treated at nominated institution p.a. (by treatment)	Achieved*
Documentation of clinical tumour stage	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	Ongoing
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

* Awaiting prostate cancer dataset from external parties. In place for all other cancers.

Achievement of Outcomes

The 2017 CIC Cancer Project application for Cancer Research Trust funding 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.

These outcomes are discussed below, together with discussion about any challenges encountered.

1. Integration of outcome datasets into routine care

Data capture

A bespoke informatics data collection and visualisation system has been designed, developed, and tested for the CIC Cancer project and placed in the WA Health Support Services Zone A (High Security) HealthNext cloud and St John of God (SJoG) Healthcare IT infrastructures. This will provide access, not only to the hospital sites currently involved in CIC Cancer, but ultimately, all public health settings and all SJoG hospitals. Placement within these IT architectures has also provided CIC Cancer with legitimacy that will allow for easy transference from research to part of every-day care provision.

Clinical and patient-reported outcomes data is being captured via internationally utilised patient-reported outcome measures (PROMs) developed by the International Consortium for Health Outcomes (ICHOM). The capture of patient-reported experience measures (PREMs) and health costing data are also contributing to the understanding of cancer service provision and opportunities for quality improvement. This has led to data analysis for cancer staging, identification of significant changes in patient outcomes, patient pathway mapping, and a health economic understanding. Using information from such analysis, work can commence on research activities to consider the level of burden on patients against the understanding of health outcomes achieved.

To date, PROMs data has been collected from 701 patients. Patient-reported experience measures (PREMs) have been collected from a further 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. In addition, 80 consumers have been involved in project implementation activities. A sub-project undertook an economic evaluation within Royal Perth Hospital (RPH) by obtaining associated cost information to allow quantification of both quality of life and cost-effectiveness to inform assessment of ongoing sustainability. A further 2 external projects have opted to utilise the dataset and CIC IT platform to capture PROMs for external research projects (Table 1).

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

- The colorectal nurses at one of the sites have implemented the use of the PROMs for other similar conditions by embedding the data capture into their standard nurse-led assessment/practice.
- Implementation of nurse-led and GP-led survivorship clinics for ongoing colorectal cancer care at one of the sites with use of CIC Cancer PROMs capture to assist in assessment of patient needs.

Table 1: Capture of data per site

Cancer type	**Site**	**CIC IT system &/or dataset use**	**Additional data collected**	**Recruitment as at 1 July 22**
Colorectal	SJoG Midland	Yes	System testing	151
	Royal Perth (RPH)	Yes	Costing data and adherence to Optimal Care Pathways (OCPs)	48
	SJoG Subiaco	Awaiting new clinical champion		-
Lung	SJoG Midland	Clinical champion to be re-engaged		-
	RPH	Yes	Costing data and adherence to OCPs, patient experience	91
	SJoG Subiaco	Awaiting new clinical champion		-
	Fiona Stanley (FSH)	New clinical champion coming on board		-
Breast	RPH	Yes	Costing data and adherence to OCPs	193
	SJoG Subiaco	Yes	Patient experience & information needs	121
	FSH	Yes		18
	GenesisCare	PROMs use in new bundled payment model project	Costing data, patient experience	-
	External: *Intraoperative Radiation Therapy study at SJoG Subiaco*	*Yes, PROMs only*		*68*
Ovarian	King Edward Memorial (KEMH)	Yes		1
	SJoG Subiaco	Yes		1
	External: *National OVMOST interventional trial project*	*Yes*		*9*
Prostate	FSH	Awaiting links with Prostate Cancer Outcomes Register		-
	SJoG Subiaco			-
	RPH			-
All	Statewide	-	Patient experience & information needs	3,654

Data visualisation

User-friendly, interactive, graphical interfaces (dashboards) have been developed to ensure effective utilisation of the data. This visualisation tool will access patient-reported, patient demographic, and clinical information captured through the CIC Cancer Informatics Platform and display real-time data for 1) comparison and visually display of outcomes for use in patient-clinician interactions; and 2) long-term integration of PROMs into routine care delivery.

Engagement with clinicians and policymakers has highlighted the importance of providing clear, meaningful integration of hospital and patient specific information in a simple, clear manner to assist with ongoing clinician utilisation of the data. To further ensure effective integration, the visualisation tool has been created using PowerBI™ – business intelligence software already utilised within WA Health and SJoG for purposes such as business reporting.

Research outcomes for cancer services

Preliminary analysis of PROMs and costs of care has provided an initial understanding of what is important to patients about their cancer care, outcomes experienced for different treatment types, timepoints at which symptoms develop or worsen/improve, and the potential relationship between quality of life and health costs for the breast, lung, and colorectal cancer patient cohort studied. The longer-term aim is that this model will be utilised routinely in clinical practice, easily used across other health settings; and as a gold standard for follow-on projects and service evaluations as health services move to embed patient-reported outcomes into routine data collection in the WA public and private health systems.

These early findings provide an opportunity for clinicians to identify potential areas for care improvements and identify when the experiences of other patients can be used in clinical settings to reassure patients that how they are feeling is ‘expected’ for that point in the treatment pathway. They were also utilised by health service executives within one site to propose the piloting of patient navigators to improve how patients are guided and supported to navigate the multiple services they require for their care.

Work to develop the first data analytic and visualisation tools for use in cancer care provision in WA provides easy to read informatics about individual patients at different care points and over time. This 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.

Challenges

The process for implementation of such a data collection system has been lengthy with significant governance requirements to meet the required assurances that the system a) meets stringent security requirements, b) provides security of confidential patient information, and c) is compatible with existing systems. The complex, 3-year phased transition of all clinical and corporate IT applications from a physical data centre to a cloud-based platform under the WA Health HealthNext program resulted in several adjournments to installation of the CIC system. As a result, the expected level of PROM data capture has not been fully achieved. Delays also occurred with installation of the CIC Cancer informatics platform due to significant changes to systems architecture by both public and private health and the effect of the COVID-19 pandemic on many non-COVID specific health-related initiatives.

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;
- collaborating with other projects to capture similar data or utilise the CIC Informatics System so that comparisons can be made; and
- introduction of new opportunities that were not initially foreseen.

Prostate cancer data collection has yet to start for several reasons: including ICHOM datasets not fully meeting clinical needs; and implementation of links with the national Prostate Cancer Outcomes Registry (PCOR). Furthermore, delays in agreement on how this could be progressed coincided with major changes in the PCOR framework and contracts, and 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. Once further information is available, capture of ongoing prostate cancer outcomes data will be reviewed.

2. Outcomes mapped to treatment based on relevant optimal care pathways

Patient journey mapping and 39 in-depth case reviews were incorporated into the Health Economics sub-project for breast, colorectal and lung cancer to compare care provision against Optimal Care Pathways (OCPs) – nationally endorsed standards or models of care for evidence-based best practice for specific cancer types in Australia. This involved a systematic approach of chronologically mapping each encounter with health services during an individual patient's care journey through the healthcare system against each of the steps of the pathway of the relevant OCP. To achieve this, information was obtained from multiple clinical information systems used to routinely collect data in the inpatient, outpatient, and emergency department settings. Unwarranted variation from evidence-based best practice was identified through 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; and
- extracting, investigating, and assigning the costings of patient encounters.

The following common themes identified were presented to multidisciplinary team meetings and hospital executives.

- Issues with timeliness of patient assessment and care, particularly with delays between 1) receipt of a referral and scheduling of the specialist care appointment or 2) referral from a Specialist Clinic appointment to an appointment with another specialty for further diagnostics or treatment.
- Delays between Multidisciplinary team (MDT) meetings and appointments necessary to inform or finalise treatment planning. These delays were also observed to contribute to subsequent delays in the commencement of treatment for some patients.
- Variances in cost correlated strongly with the type of treatment required by the patient and any complications occurring during the patient care journey.

Overlay and analysis of the PROMs with the patient care journeys did not demonstrate any distinct patterns or correlations with regard to patients' average overall quality of life. It should be noted, however, that this is a very small cohort.

Incorporating itemised costing data for each encounter within the patient care journey enabled identification of:

- similarities in the cost of care for different cancer types, irrespective of the grade or stage of the disease and treatment regime; and
- lack of correlation between variations in costs and the OCP step or patient's grade of disease, yet direct correlations between increased costs and 1) complications of care, and/or 2) the inclusion of immunotherapy treatment.

This work resulted in discussions with health services and clinicians to explore interventions to address the identified distress and symptoms through improvements in screening, nurse-led assessments, case management, and referral processes.

Challenges

Limitations exist with full access to costing data for patients receiving part of their care in other sites. Whilst every endeavour was made to source information from other validated data sources this was not always possible, and approximations based on costs associated with similar items were utilised.

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

Whilst initially only seeking to improve cancer healthcare in both the Western Australian public and private hospital sectors, the project has also proved an effective enabler for the introduction of value-based healthcare (VBHC) into WA, and as an influencer of VBHC in cancer nationally. 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 2020-2015, the WA Sustainable Health Review (SHR) 2017, and the WA Cancer Plan 2020-25. 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.

CIC Cancer has generated several new and previously unforeseen opportunities in the form of innovative VBHC-specific sub-projects to improve health outcomes for cancer patients in WA.

- Introduction of a bundled care payment model working with other healthcare service providers, such as GenesisCare and private health insurance providers.
- Early work to test the use of cancer care navigators and decision support tools.
- Development of an important integrated dataset.
- Working with PathWest (WA's largest pathology service) to incorporate the value equation into its practice to improve patient outcomes and drive down costs.
- Use of the CIC Cancer Informatics System to capture patient-reported outcomes in a national Phase II multi-centre randomised trial within WA, NSW, Queensland, and Victoria exploring a novel, nurse-led approach to the follow-up of women after completion of primary ovarian cancer treatment.

Bundled care packages

Despite improving outcomes for people diagnosed with cancer, challenges remain in improving survival and quality of life for those on the cancer journey. 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. To move towards addressing these obstacles, 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 through bundled care packages.

In consultation with insurers, providers and clinicians in WA, treatment bundles are in place 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 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.

Care Navigators

In conjunction with work undertaken by All.Can Australia, advocacy is underway for patient/carer access to cancer care navigators. The aim of these navigators is to relieve system-related stress and concern currently experienced. All.Can Australia has developed a pilot program and is discussions 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 for up to 12 months. 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 1) improve patient outcomes and experience, through better support, guidance and understanding of the treatment pathway by the patient, and 2) improve adherence to Optimal Care Pathways by ensuring that the patient receives appropriate care within set timeframes.

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 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.

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. Possibilities now exist for external projects to access to this data for other 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 such comprehensive and patient centred information will also 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 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.

Challenges

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.

4. Collaboration leading to further successful grants applications

Collaboration and shared research activities have been a key component of CIC Cancer with activities continually implemented to seek additional funding through applications for external peer review funding and any other applicable opportunities. Efforts have also focussed on ways to leverage from the core project to seed new aspects of VBHC into cancer care within WA. This has resulted in 16 additional sub-projects undertaken since 2017 (see Appendix 1) with access to grant funding of $827,901 to conduct 7 of these projects (Appendix 2).

Significant in-kind funding has also been leveraged for the development of project concepts. For example, over the two years of preparatory work for the bundled care project it is estimated that up to $350,000 has been provided by GenesisCare for senior project staff and legal advice to identify feasibility, negotiate with providers, enact agreements with private health insurers, and calculate costs.

Successful collaborative activities have been undertaken both nationally and internationally.

- Collaboration with the Centre for Health Economics Research and Evaluation (CHERE) at the University of Technology Sydney, for implementation of economic and evaluation activities associated with the bundled care package sub-project. This work will be undertaken under the umbrella of the NHMRC's Centre for Research Excellence (CRE) - Value-based Cancer Care Payments and will provide the first 'real-world' project for this new CRE.
- Active involvement with government bodies such as the Medicare Review Advisory Committee and Independent Hospital Pricing Authority.
- Active involvement in national groups including the Australian Centre for Value Based HealthCare and the Australian Health Review Editorial Advisory Board.
- 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.
- 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.
- Work to assist the International Consortium of Health Outcomes (ICHOM) to update and harmonise the breast cancer standard dataset, develop benchmarks for data collected in the breast cancer standard dataset, and develop the ICHOM Metastatic Breast Cancer Dataset.
- 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, resulting in the launching of a report (https://www.sprink.co.uk/pcvbhc-report/) and proposed Global Centre.
- Provision of aggregated breast cancer PROMs data to the Organisation for Economic Cooperation and Development (OECD) for 2021 and 2023 data collections (PaRIS initiative). This has assisted in strengthening international measurement of patient-reported outcomes of care.

- Input to the activities of international bodies such as PROTEUS-Practice Consortium (Patient-Reported Outcomes Tools: Engaging Users & Stakeholders - Advancing the Use of PROs in Clinical Practice).
- Involvement in international fora following Professor Christobel Saunders' appointment as All.Can International's Global Vice-President. Other board members represent the European Cancer Organisation, European Cancer Patient Coalition, World Bladder Cancer Patient Coalition, and Bristol Myers Squibb.

Challenges

External factors such as the impact of COVID have affected government grant funding processes. For example, a major grant of over $2.5million was sought in 2020 but the results of this were not known until the 2nd quarter of 2022. Whilst the research team has demonstrated that additional funding can be sought and secured, the potential for a Program Grant or Research Excellence is diminished with completion of the project.

5. Trained workforce of health outcomes researchers and engaged clinicians

The CIC Cancer project has extensively focussed on awareness raising and capacity building activities through engagement with health services, research, and consumer communities to raise awareness of both the project and value-based healthcare. The research team have also actively collaborated with local, national, and international bodies to enhance knowledge of VBHC implementation and awareness of CIC Cancer work. In addition to major events discussed below, as of June 2022, the team has produced seven peer reviewed journal articles, six non-peer reviewed articles, two policy perspective briefs, a Masters thesis, 13 oral conference presentations, 11 seminar presentations, seven conference-presented posters, five blog articles, multiple reports and communications collateral, and two media releases (Appendix 3).

VBHC Conference

In May 2021, CIC Cancer – in partnership with the Australian Healthcare and Hospitals Association (AHHA) – successfully hosted Australia's first conference on value-based healthcare. 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 facilitated discussion, sharing of ideas, and collaboration on key issues through opportunities to learn from teams and experts, both across Australia and internationally, about the practical strategies they had used to progress VBHC across a broad range of areas within healthcare systems. The event 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.

Clinical Senate

Due to the success and high level of interest of the VBHC conference, the WA Clinical Senate decided to build on this and focus their October 2021 debate on value-based healthcare. The Clinical Senate is an independent body and comprises more than 80 members drawn from diverse clinical backgrounds, professional skill sets, and from both metropolitan and rural areas of the state. Their purpose is to generate informed, impartial, and integrated advice for the Health Executive Committee and wider WA health system on system-wide issues requiring diverse perspectives and innovative thinking.

The chair of the Clinical Senate and other members of the Clinical Senate Executive had attended the conference and pre-conference workshop and, following these events, determined that VBHC should form a future focus of their work. The debate aimed to align the principles of VBHC to the Strategic Direction of the Clinical Senate in progressing the Sustainable Health Review. Feedback from the debate suggested that almost 90% of attendees found that the debate contributed to them having a deeper understanding of the topic.

Students

The CIC Cancer Project is a program of work that aims to build capacity for emerging/future clinicians and researchers. As such, medical students and pre-med students who are keen to undertake health services research within their scholarly activities are involved in assisting with activities such as data collection, data entry, literature reviews, and simple data analysis. Each of the 16 student projects and a Masters by Research degree undertaken (see Appendix 1) has raised awareness through involvement of academic and clinical supervisors and presentations to clinical teams and fellow medical students.

Challenges

Concepts for potential PhD opportunities were difficult to formulate prior to sufficient data capture and analysis; however, as data collection progressed this was resolved, and PhD opportunities and scholarships were advertised in late 2021. Initial interest was voiced by a clinician involved in CIC Cancer activities, current staff, and 3 external applicants but the closure of borders due to COVID affected these opportunities.

6. Consumer engagement

Engagement activities with consumers has been an important component of the CIC Cancer project with this collaboration resulting in an improved understanding of issues of importance to patients.

Understanding patient experiences

Variations in patient experience across their cancer journey were captured through the *Cancer Patients Experience Survey* (CaPES) project in 2021/22. Utilising an adapted version of the patient experience questionnaire developed by All.Can International, this survey collected both quantitative and qualitative data to provide 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. Surveys were mailed to 10,348 people who were reported to the WA Cancer Registry as diagnosed in the calendar year 2019. Of these, 3,121 surveys were returned and analysed. Results indicated that generally, cancer patients believe the services provided for them in the WA public and private setting are very good and better than reported from other countries in the All.Can International Survey. Many of the issues that were identified could be rectified by better communication between all levels of healthcare, the patient and their family, improved continuity of care, access to information at the patient’s tempo and ensuring that the information is understood. This would not only improve care but increase efficiencies in the health system and lead to more positive experiences for both patients and providers.

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.

An additional project was also undertaken in 2021/22 to better understand the level of cancer information currently available to consumers and explore whether this is accessible and of value to consumers and meets their needs. Results were used to make recommendations to support decision-making for improvements to:

- patients' experience with, and understanding of, their cancer care;
- enhance consumers involvement in their cancer care and treatment options; and
- clarity of information related to cancer diagnosis, diagnostics, and treatment plans.

A student project also involved interviewing participants to understand their experiences in participating in the CIC Cancer Project, particularly their experience with completing PROMs questionnaires. Twenty-three lung cancer patients were asked questions regarding how successfully the PROMs questionnaires assessed their symptoms and concerns and how they preferred to complete the questionnaires. Participants were also asked if they had experienced any difficulties navigating their care and what these difficulties were. Findings identified the most important aspect of healthcare to be clear communication, with areas of improvement in the healthcare system to be patient education and post-surgical pain management. Additionally, this study suggested an urgent need to develop protocols to maintain efficiency and the standard of care for cancer patients as the impact of COVID-19 continues.

A further student project used a qualitative research approach to explore the decision-making process by patients diagnosed with breast cancer regarding their choice to access public or private treatment and their experience with receiving treatment in their chosen sector. Findings identified that the decision to receive care in the public or private sector is based on both patients' own core values and advice from others. These decisions are also influenced by personal factors such as financial status, life stage and life experiences and cancer factors such as stage of disease and proposed treatments. Information regarding the costs involved in cancer care in the private sector is poor, patients often enquire with their private health insurance company, surgeons, or nurses with the resultant estimates variably accurate. More information regarding estimated costs of treatment in the private sector is required for improved patient experiences and this information would be most valuable if available from referring clinicians such as general practices and public breast clinics.

Understanding patient needs

A 3-hour Community Conversation was held as the opening event for a series of discussion forums incorporated into the 2021 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. The feedback and recommendations arising from this event were then fed into two health-professional focused sessions centred on VBHC in primary care and the wider healthcare sector. The key issues for consumers in shaping their decision-making regarding healthcare are 1) effective communication and engaged dialogue; 2) appropriate Information to allow consumers to make informed choices and understand the options available regarding their condition and recommended treatment/care; and 3) transparency of information regarding tests, procedures, medications and outcomes, and in particular, financial implications.

In-depth consultations with women with ovarian cancer resulted in identification of an agreed set of case-mix variables and outcome measures and development of a dataset for use in CIC Cancer and other studies pertaining to ovarian cancer. The "patient voice" was also captured through a qualitative descriptive approach including a community conversation with ovarian cancer patients, their carers, and clinicians together with interviews and focus groups with women with ovarian cancer. The resultant health-related quality of life items – incorporating physical wellbeing, emotional wellbeing, and social wellbeing –

reflected a range of personal experiences and provided a new tool specific to women diagnosed with ovarian cancer.

A 3-phase consultation was also undertaken with the CIC Cancer Consumer Reference Group to identify consumer needs in relation to the 'look and feel' of the data visualisation dashboard prototype. The intention of this prototype is to display and report real-time data in a graphical and interactive format for the participating cancer types and sites through access to patient-reported, patient demographic, and clinical information within the CIC Cancer Informatics System. The key finding was that the group felt that comparisons with other patients should be carefully considered by the clinical team and any reassurance on the 'normality' of an issue experienced is better provided by the medical staff rather than displayed in a graphical format.

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.

Status of the 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 are focussed on transition to the health services and increased data collection. This involves working closely with WA Health and SJoG 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 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.

WA Health

Discussions with the Health Networks Division of WA Health resulted in the provision of additional funding for UWA to provide personnel resources – as an in-reach arrangement with the resource based physically at the Department of Health, Health Networks – for a 12-month period, commencing 1 July 2022. This aims to develop a detailed DoH transition plan and associated requirements to inform the future readiness of CIC Cancer to be transitioned into the WA Health ICT environment (with ongoing support), and the development of a current state analysis of the use of validated PROMS and PREMS across WA Health and to identify existing pilot projects. This plan will focus on requirements for progression of the CIC Cancer framework from a research project to WA Health Data Collection and consider the possibilities of shared data between public and private whilst identifying all legal and legislative requirements necessary for these changes to occur.

One of the CIC Cancer team is now located within the Health Networks Branch of DoH and working alongside DoH staff responsible for implementation of the Cancer Data Strategy and implementation of Recommendation 4 of the WA Sustainable Health Review – "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".

St John of God

Early transition planning has commenced with SJoG. A recent change of CEO has put this work on hold until August 2022 when the new CEO is available.

Appendices

Appendix 1: CIC Cancer Sub-Projects

Date	Research Project Title	Site
2022	Continuous Improvement in Care – Cancer (CIC Cancer) transition planning and WA Health Patient Reported Experience and Outcomes Measures (PREMS/PROMS) current state	Statewide
2021	Cancer Patient Experience Survey (CaPES)	Statewide
2021	Understanding Consumers' Needs for Cancer Information	Statewide
2021	Optimal Care Pathway Mapping of Patient Journeys	RPH
2021	CIC Data Visualisation Pilot Project	All sites
2021	Testing of ovarian dataset through OVMOST follow up project	National
2021	OECD data contribution	RPH, International
2021	VBHC Conference	National, International
2020	Bundling cancer care: better care at a transparent cost	SJoG Subiaco
2020	Survey to identify the impact of COVID-19 on cancer care	RPH, SJoG Subiaco, Statewide
2019	Measuring the cost of continuous improvement in care-cancer at Royal Perth Hospital - a 'proof-of-concept'.	RPH
2018	Inclusion of VBHC session in UWA MBA - Health Specialisation	UWA
2018	Ovarian cancer dataset development	Notre Dame, SJoG Subiaco, KEMH
2018	All.Can Experience of Care - pilot in WA	Perth Specialist Breast Care
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
STUDENT PROJECTS		
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
2020	Lit review - Data visualisation of clinical and patient reported outcomes in cancer	
2020	Lit review - Data visualisation of clinical and patient reported outcomes	
2020	Lit review - Cancer patient experiences during COVID-19 pandemic	
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	Clinical and PROMs (quality of life) outcomes in patients with stage one NSCLC undergoing curative surgical therapy and stereotactic radiation therapy	RPH
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
2019	Lit review - Public or private treatment: Insights into the financial burden of cancer and decisions on treatment pathways in Australia	

2019	Implementation of patient involvement in the development of a patient-reported outcome measure for ovarian cancer	Notre Dame
2019	Prostate Cancer care pathway mapping	All sites
2019	Review of literature on Time-Driven Activity Based Costing (TDABC) for evaluating cost of care for cancer patients	
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
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

Appendix 2: Grant Funding Since Commencement

AWARDED			
Date	**Project Title**	**Amount**	**Institution/Funder**
2022	Continuous Improvement in Care – Cancer (CIC Cancer) transition planning and WA Health Patient Reported Experience and Outcomes Measures (PREMS/PROMS) current state	$90,909	WA Cancer Network
2021	Understanding Consumers' Needs for Cancer Information	$149,919	WA Cancer Network
2021	Patient Experience Survey – Cancer	$194,241	WA Cancer and Palliative Care Network Clinical Implementation Unit (WACPCN-CIU)
2019	Measuring the cost of continuous improvement in care-cancer at Royal Perth Hospital - a 'proof-of-concept'	$211,500	Medical Research Future Fund, RART Grants 2019, R3
2018	Patient reported outcome measures (PROMs) in Colorectal cancer surgery	$11,500	WAPCN-CIU Tumour Collaborative Grants - iPads
2018	Continuous Improvement in Care - Cancer: identification of WA specific data variables for colorectal cancer	$19,832	WAPCN-CIU Tumour Collaborative Grants - data variables
2018	CIC Cancer Project Lung Cancer	$150,000	WACPCN-CIU – 2019 Cancer Related Clinical Fellowships
TOTAL GRANT FUNDING RECEIVED (to date)		**$827,901**	
UNSUCCESSFUL			
2021	Bundling cancer care: better care at a transparent cost	$2,586,189	MRFF 2020 Clinician Researcher
2021	Analysing and correlating variables associated with care received by cancer patients, their associated costs and implications of outcomes	~$150,000	WA Cancer and Palliative Care Network Clinical Implementation Unit (WACPCN-CIU) – 2022 Cancer Related Clinical Fellowships
2020	Data visualisation for continuous improvement in cancer care in Australia – a 'proof-of-concept'	$446,357	Cancer Council NSW Project Grant
2020	Continuous Improvement in Care (CIC) – Cancer Project: Striving for best value in radiotherapy	USD$50,000	MSD Oncology Policy Grant Program
2019	Data visualisation for continuous improvement in cancer care at Royal Perth Hospital – a 'proof-of-concept'	$575,585	Royal Perth Hospital Research Foundation Grants 2020
2019	'Proof of Concept': Implementation of the CIC Cancer data capture system within St John of God Healthcare	$47,638	ARDC Transformative data collections
2017	Improving health care for breast cancer patients by using patients reported outcomes in routine clinical practice	$50,000	Collaborative Cancer Grant Scheme for early to mid-career investigators (CCGS)
2017	Value Based Health Care in Cancer	$20,000	Research Impact Grants

Appendix 3: Publications, Presentations, Media, and Reports since commencement

Publication Title	Submission to	Publication Date	Type
The CIC Cancer project: Improving outcomes that patients really want	Research Australia INSPIRE (https://issuu.com/researchaustralia/docs/research_australia_inspire_issue_22_final)	Dec 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 (https://ijgc.bmj.com/content/early/2021/09/21/ijgc-2021-002999)	Sept 2021	Peer-reviewed Article
Co-intelligence: Knowledge exchange overtaking competition to drive global cancer care progress	Oncology News (https://oncologynews.com.au/co-intelligence-knowledge-exchange-overtaking-competition-to-drive-global-cancer-care-progress/)	Sept 2021	Article
Life after cancer is more than just survival	Oncology Republic (https://oncologyrepublic.com.au/life-after-cancer-is-more-than-just-survival/963)	Aug 2021	Article
Employing cognitive interviewing to evaluate, improve and validate items for measuring the health-related quality of life of women diagnosed with ovarian cancer	Health and Quality of Life Outcomes	Submitted July 21, resubmitted March 2022	Peer-reviewed Article
Women diagnosed with ovarian cancer: Patient and carer experiences and perspectives	Patient Related Outcome Measures (https://doi.org/10.2147/PROM.S272688)	Feb 2021	Peer-reviewed Article
Implementation of patient involvement in the development of a health-related quality of life patient-reported outcome measure for ovarian cancer	A thesis submitted in fulfilment of the requirements for Master of Health Science by Research (https://researchonline.nd.edu.au/theses/302/)		Thesis
“Nothing beats the doctor's face to impart trust in their judgement” – the role of telehealth in cancer care	Australian Health Review (https://www.publish.csiro.au/AH/AH20314)	Dec 2020	Peer-reviewed Letter to the Editor
Measuring the cost of continuous improvement in care in cancer	The Health Advocate (https://issuu.com/aushealthcare/docs/the_20health_20advocate_20-_20november_202020/s/11243272)	Nov 2020	Article

Moving towards value-based, patient-centred telehealth to support cancer care	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	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	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	Australian Health Review (https://www.publish.csiro.au/ah/pdf/AHv43n2_ED)	March 2019	Peer reviewed editorial
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
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

Presentation Title	**Presentation to**	**Date**	**Type**
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
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	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

Report produced	**In relation to**	**Distributed to**	**Date**
CRT Annual Progress report	Program activities and outcomes achieved	CRT, CCWA, stakeholders (incl consumer group), public (via website)	2018, 2019, 2020, 2021
Annual Scorecard	Summary of progress towards outcomes and KPIs	Funders, stakeholders (incl consumer group), public (via website)	2019, 2020, 2021
CIC Cancer Activities Update Jan-Aug 2020	Update to program activities and outcomes achieved	CIC Cancer Evaluator – T Slevin	2020
Grant specific reports (progress and annual) - Multiple	Project activities and outcomes achieved	Funders and stakeholders	2019-2022
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
Patient Flyer/Poster	Patient facing communications to assist in recruitment	Potential participants in clinics at various sites	2019-2021
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
Annual HREC reports	Program activities and outcomes achieved	HREC committees, public health, private health and Universities	Annually since HREC approval
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
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
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
Understanding Consumer Needs	Analysis of cancer information currently available to consumers and their access to this	Funder and stakeholders	2022
Cancer Patient Experience Survey Report (DRAFT)	Draft Analysis of results	Funder	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

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