Brain Cancer Australia

Australian Brain Cancer Registry Charter and Operating Framework

Table of Contents

Executive Summary

Brain cancer poses a significant health challenge. Clinical Quality Registries (CQRs) have been identified as a key strategy to enhance care and improve outcomes for patients. In response to this, Brain Cancer Australia (BCA) is spearheading the development of a dedicated registry.

The registry, named the Australian Brain Cancer Registry (ABCR), is being designed to improve the quality of care for brain cancer patients. To this end, Clinical Quality Indicators (CQIs) have been established and published. These indicators will serve as benchmarks for assessing the effectiveness of care and guiding improvements.

The governance structure of the ABCR has been carefully designed to ensure effective operation and oversight. The structure involves a collaborative effort between ABCR committees, partners, and supporting organisations.

In terms of operational principles and technical standards, the ABCR aims to adhere to the Framework for Australian Clinical Quality Registries, as set out by the Australian Commission on Safety and Quality in Health Care (ACSQHC), to the greatest extent possible.

This document provides an overview of ABCR's intended operations and governance, detailing the roles and relationships between the various committees, partners, and supporting organisations involved in the registry and will be updated throughout the establishment process. The ultimate goal is to leverage the ABCR to combat the challenge of brain cancer and enhance patient care.

Operational Model Overview

ABCR governance will be overseen by BCA. The role of data coordination for the ABCR will be fulfilled by Cancer Alliance Queensland (CAQ). The ABCR's operational model will be a collaborative effort between BCA, CAQ, health departments and State health data custodians. The objective of the ABCR model is to facilitate electronic data collection as much as feasible at all jurisdictions.

Rationale for an Australian Brain Cancer Registry

Brain cancer poses a formidable public health challenge in Australia. Brain cancer ranks as the sixth leading cause of cancer burden, accompanied by a 22% five-year relative survival rate[1]. In Australia, it is estimated that six people will be diagnosed with brain cancer and four will die every day[2]. Brain cancer causes a disproportionate loss of life years specifically affecting individuals in the prime of their lives[3]. The prognosis for brain cancer is often fatal, and its impact extends beyond mortality, exerting a profound economic toll. The disease not only erodes the affected individual's personality but also diminishes their engagement in employment, community activities and family life.

In Australia, variations in the patterns of care for brain cancer have been observed, stemming from local preferences and disparities in access to treatment[4-6]. These variations may arise due to intrinsic differences in populations, data inaccuracies, or disparities in available resources, such as the absence of PET scanners, stereotactic radiotherapy, and oncologists in regional centres.

Despite these variations, there is a striking lack of data regarding the impact of different treatment approaches on patient outcomes. It remains unknown which treatment practices contribute to the longest survival in the population, and there is a dearth of information on how treatments proven effective in clinical trials translate to improved survival rates in the general population.

Compounding the challenge is the fact that suboptimal management of brain cancer has been associated with shorter survival, increased neurological deficits, and heightened patient distress. Remarkably, as of 2023, there has been no routine monitoring of clinical quality indicators specific to brain cancer in Australia or internationally, highlighting a critical gap in understanding and addressing the impact of this devastating disease.

The Impact of Clinical Quality Registries

Clinical Quality Registries (CQRs) have been repeatedly shown to improve patient care and extend survival [7-10]. Early improvements in survival and reduced unnecessary treatment were seen with the prostate cancer outcomes registry [11-12]. Similarly, the Western Australian Audit of Surgical Mortality achieved a 30% reduction in surgical mortality within 4 years of commencement [13]. Work by CAQ in other cancers has led to significant improvements in mortality, for example in the field of oesophago-gastric cancer [14]. These improvements in patient outcomes are also associated with reduced costs for the healthcare system [8]. The mechanisms for improved care include greater awareness of best practice, changes in management protocols and changes in staff behaviour [8, 15]. Audit and feedback, of the sort provided by a well-functioning registry, is one of the most potent drivers of improvement in the delivery of healthcare [16-17]. The Australian Commission on Safety and Quality in Health Care assessed the economic impact of CQRs and concluded that they were one of the most cost-effective health care intervention with an economic benefit to cost ratio estimated to be typically 4:1[8]. In addition to monitoring the quality of care, CQRs can be used for research to change care over time.

The Value of Electronically Collected Data

Existing cancer and other disease registries mainly rely on manual data collection. The Australian Orthopaedic Association National Joint Replacement Registry [18] and the Australian Shunt Registry use paper forms completed in the operating theatre and then sent to the central registry. Other registries use online forms manually completed by trained data collectors e.g., Prostate Cancer Outcomes Registry of Australia and New Zealand [19], or a combination of online forms and limited automated data capture e.g. Australian and New Zealand Intensive Care Society (ANZICS) Centre for Outcome and Resource Evaluation registries [20]; Australian Stroke Clinical Registry (AuSCR) [21]. This is also true for international brain cancer registries e.g. Japan [22]; Denmark [23].

A feasibility study commissioned by BCA identified that pathways for the treatment of brain cancer are complex, iterative, and involve multiple providers and locations making manual collection of data prohibitive. The study concluded that automated, electronic collection of data was both preferred and feasible. The aim was to have a cutting-edge registry that collected data directly and automatically from Electronic Medical Records (EMRs) as EMRs were implemented in hospitals around Australia, and discussions commenced with IT specialists as to how this would be achieved. In a convergence of independent research, the planned ABCR aligns with the National Strategy for Clinical Quality and Virtual Registries [24].

The implementation of automatic data collection for the ABCR will mean the process becomes systematic and routine, eliminating the need for direct clinician involvement or expenses associated with manual data entry following the initial setup. The systems in place would have advanced to the extent that electronic data collection becomes not only practical but also efficient. Additionally, through the use of data linkage, information can be gathered from diverse systems, effectively capturing the entirety of patients' experiences as they navigate through the various stages of their cancer journey.

Foundation work

ABCR Feasibility Study

Recognising the need for a national brain cancer registry, in 2019, BCA convened a registry working party and commissioned a feasibility study. This project was led by a multi-institutional working group representing, neurosurgery, neuro-oncology, cancer epidemiology, health IT and consumers. The feasibility study, conducted by Montage Systems, examined the scope, management and data collection mechanisms of brain and other disease specific registries locally and overseas to determine an optimal structure for an ABCR.

The feasibility study identified a need for a national clinical data registry of paediatric and adult brain cancers that can capture brain cancer clinical management information from the 45 or more treating hospitals, and provide a framework for improving patient care, improving our understanding of brain tumours and accelerating the design, discovery and testing of new treatments. This had also been identified earlier by the Cooperative Trials Group for Neuro-Oncology (COGNO), in its 2014 "Patterns of Care" report, stating: "A central national registry would be an ideal platform to conduct epidemiological studies and compare practice patterns and patient outcome across different regions. Such information could be used to inform government on future neuro-oncology resource allocations and target areas of need" [5].

The Feasibility Study also identified, at a high level, the typical pathways for brain cancer treatment and the range of clinical record systems that store the administrative, diagnostic, treatment and outcomes data that will be needed for the registry. From this work, it was decided a hybrid clinical registry, collecting data from local systems either at the state or hospital level would be the most feasible. Existing providers of automated electronic data collection were evaluated. Due to their demonstrated track record in cutting edge electronic data collection, Cancer Alliance Queensland (CAQ) and the Australian e-Health Research Centre (AEHRC) at CSIRO were selected as technical partners.

The feasibility study examined the proposed registry having multiple purposes, capturing data to not only drive improvements in the quality of care for brain cancer patients, but also to drive basic research through the provision of high quality data associated with biospecimens stored by biobanks, and the facilitation of registry clinical trials. The feasibility study recommended a registry model that will create a platform to capture data in a series of stages, with Stage 1 being the clinical quality registry (CQR) component, Stages 2 and 3 the basic research and registry trial components.

Development of Clinical Quality Indicators

To determine a set of Clinical Quality Indicators (CQIs) for the ABCR, a database and internet search were used to identify relevant guidelines, which were assessed for quality using the AGREE II Global Rating Scale. Potential indicators were extracted from 21 clinical guidelines, ranked using a modified Delphi process completed in two rounds by a panel of experts and other stakeholders, including consumers, and refined by a multidisciplinary Working Party.

Nineteen key quality reporting domains were chosen, specified by 57 CQIs detailing the inclusion (denominator) and outcome (nominator) characteristics to be reported. Of the 57 indicators, 42 were supported by moderate or strong evidence. The selected CQIs include structural measures such as performing surgery in tertiary centers and availability of neuro-oncology care coordinators, process measures such as availability of specific molecular tests, discussion at an MDT and rehabilitation referral, and outcome measures such as the extent of resection and days spent in hospital between diagnosis and death.

The selected CQIs have been published [25] and will form the framework for the ABCR, benchmarking the data collection, and specifying best practice, with a view to improving care and outcomes for brain cancer patients.

Objectives of the ABCR

Clinical Quality Registry

The main goal of ABCR is to achieve access to optimal, comprehensive care for every patient, which in turn will improve brain cancer patient outcomes. ABCR will use automated data collection for a population wide, clinical quality registry to report on specific brain cancer Clinical Quality indicators. to promote timely access to optimal care, identify management practices associated with longest survival and improve outcomes for patients. The Australian Commission on Safety and Quality in Health Care (ACSQHC) defines CQRs as organisations that “systematically monitor the quality (appropriateness and effectiveness) of healthcare, within specific clinical domains, by routinely collecting analysing and reporting health related information” [26]. CQRs use this systematically collected data to assess and benchmark the quality of care at participating sites.

The ABCR aims to achieve the following objectives:

1. Improve patient outcomes through systematic data collection and contributions to clinical knowledge.
2. Analyse data to assess the clinical effectiveness of treatments in real-world settings.
3. Evaluate patterns of care and related outcomes.
4. Monitor trends in the incidence and survival of brain cancer over time.
5. Generate benchmarked reports on quality of care indicators.
6. Promote evidence-based practice by assessing compliance with best practices.
7. Provide de-identified reports to the public.
8. Supply de-identified reports on data to healthcare providers and the government.
9. Reduce variations in care to ensure consistent quality.
10. Collaborate with outlier organisations to understand reasons for variance and reduce unwarranted variation in care.
11. Provide evidence to inform public health policy and practice.
12. Facilitate the provision of evidence-based information and care for individuals diagnosed with brain cancer.
13. Assure the public of the quality of healthcare for brain cancer in Australia.
14. Promote international benchmarking and collaboration.

Research

Beyond their primary role in elevating care standards, CQRs also serve as invaluable resources for research purposes. They contribute to epidemiological insights and the understanding of patterns of care, serving as crucial repositories of information for post-market drug surveillance. Furthermore, registries play a pivotal role in facilitating registry trials. Conventional clinical trials are laborious and expensive to run. For less common tumor types, such as the different primary brain cancers, the costs are prohibitive. Registry trials can be delivered for 10% or less of the cost of a conventional trial [27] and have the additional benefits of real world applicability, improved patient recruitment and more rapid translation of findings into clinical practice [28-29]. Registries can also enable patient self-enrolment for research studies. Hence, fostering a dynamic and comprehensive approach to advancing medical knowledge and treatment practices.

The ABCR will aim to facilitate brain cancer research through the following objectives: -

1. Provide data for approved research studies.
2. Link clinical data to biospecimens collected and stored by biobanks.
3. Enable clinical registry trials.
4. Accelerate recruitment of participants for research studies.

Partnerships

Technical Partners

BCA will partner with technical partners who have the expertise and systems necessary to collect, analyse and report on the required data for the ABCR.

The initial selected technical partners are:

- Cancer Alliance Queensland (CAQ) and
- Australian e-Health Research Centre (AEHRC) at CSIRO.

CAQ & AEHRC have a demonstrated track record in cutting edge electronic data collection and of previous automated data collection, analysis and reporting.

CAQ has 15 years of reporting on the quality and safety of cancer care and considerable experience in data linkage for cancer reporting, bringing together data from across Queensland to report on individual patient journeys. They currently collect and host patient data from outside Queensland and have systems in place for safe transfer and storage.

CAQ will be supported by stakeholders in each state cancer registry and by the Population Health Research Network (PHRN), a government organisation charged with cross border data linkage for research. We will also work with PHRN and use their extensive national data linkage capability to annotate patient records where care occurs in more than one state.

The Australian e-Health Research Centre (AEHRC) is the leading national research facility applying information and communication technology to improve health services and clinical treatment for Australians. It is a joint venture between CSIRO and the Queensland Government. The ABCR will build on their existing natural language processing software, MedTex®, to enable automated data collection from free text reports and medical record entries.

Cancer Control Agencies, Government and Other Stakeholders

ABCR will work with jurisdictional data repositories, government and non-profit organisations to ensure access to data in every state, without duplication of effort. We have members and commitment from:

- Cancer Alliance Queensland
- Victorian Comprehensive Cancer Centre
- Queensland Health
- Cancer Institute New South Wales,
- Cancer Councils Queensland
- Cancer Council Tasmania
- Cancer Council South Australia and
- Cancer Council Victoria
- Brain Cancer Centre WEHI (BRAINS registry)
- Chris O'Brien Lifehouse (GlioNET registry)

Healthcare Providers

ABCR will work with public and private hospitals to collect data. We have commitments of support from:

- Queensland Health
- NSW Health
- Department of Health and Safer Care Victoria
- Wellbeing South Australia (Department of Health and Wellbeing, SA)
- ACT Health
- Department of Health, Tasmania
- Department of Health, Western Australia
- Ramsay Health Care

Brain Cancer Specialist Associations

ABCR will work with brain cancer specialist associations and has commitments of support from:

- Cooperative Trials Group for Neuro-Oncology (COGNO),
- Royal College of Pathologists of Australasia (RCPA),
- Neurosurgical Society of Australasia (NSA),
- Trans-Tasman Radiation Oncology Group (TROG),
- Clinical Oncology Society of Australia (COSA),
- Psycho-oncology Co-operative Research Group (PoCoG),
- Palliative Care Australia (PCA),
- Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG) and
- Australian Clinical Trials Alliance (ACTA).

Consumer Groups and Charities

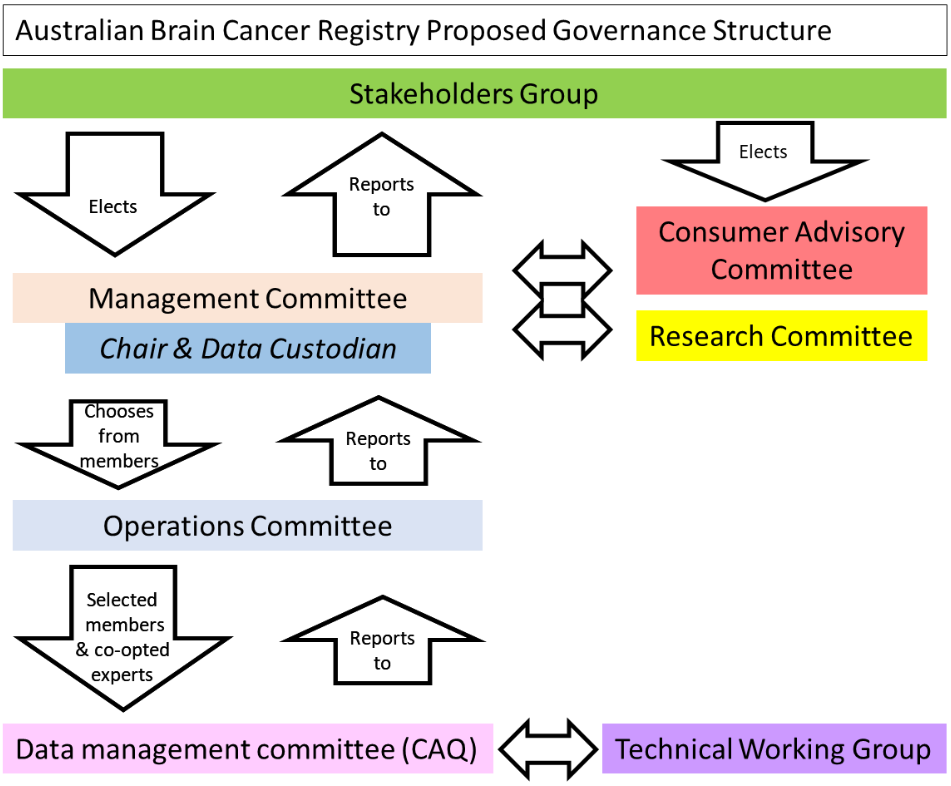
ABCR will work with consumer groups and charities and has commitments of support from:

- Brain Tumour Alliance Australia (BTAA)
- Cancer Voices SA
- Brain Cancer Australia Charity
- Australian Families 4 Genomics (AF4G)

Governance Framework

Rules and Responsibilities of Committees

BCA will be the custodian of the ABCR and its data. The governance structure for the ABCR will include committees to implement standard operating procedures, obtain regulatory approvals, and provide oversight of data collection and analysis. The Stakeholders group will comprise everyone who contributes data or expertise, including clinicians & representatives of hospitals and other health care providers, and representatives of other vested interests including consumer representatives and specialist societies. The terms of reference for each committee will be established by the Registry Management Committee and ratified by the BCA Steering Committee.



The ABCR Management Committee

The ABCR Management Committee has been delegated authority by the BCA Steering Committee to manage the operations of ABCR. The purpose of the ABCR Management Committee is to work together collaboratively and deliberatively to ensure the success of the ABCR. The overarching objectives of ABCR are determined by the ABCR Management Committee which will provide overall governance to ensure that the ABCR achieves set goals and operates in accordance with requirements set out in relevant documents. This ABCR Management Committee will oversee all other ABCR sub-committees and report to the BCA Steering Committee.

The ABCR Management Committee is supported by the:

- Operations Committee – a smaller group selected from the ABCR Management Committee and responsible for the day-to-day running of the registry, including operational activities and reporting.
- Data Management Committee – responsible for data collection, housing, quality, and analysis and comprising the Data Custodian, representative(s) from CAQ, statisticians, clinicians and a representative of the Technical Working Group.
- Technical Working Group – a temporary committee of clinicians and data specialists convened as necessary to guide the development of technical definitions and software.
- Research Committee – a subcommittee of the Management Committee responsible for directing, encouraging, and overseeing research arising from or involving the ABCR.
- Consumer Advisory Committee – a committee of people with lived experience of brain cancer who provide a patient’s perspective on the objectives, direction and operation of the ABCR.

Strategies and Activities

Data Collection

In order to implement automated electronic data collection, CAQ will build on their existing web-based, patient centric, clinical cancer application software. The software interfaces with clinical data systems and health care providers to access the required information. CAQ will work with each jurisdiction to enable collection of brain cancer specific data from existing electronic records. CAQ will work with local stakeholder in each jurisdiction to identify and connect local clinical and administrative data sources e.g. State cancer registries, MDT applications and treatment systems, to form jurisdictional brain cancer repositories. As CAQ already houses cancer data from multiple national clients, they will host the ABCR and assist participating organisations to transfer data.

With this approach, we aim to capture clinical management information for >90% of all brain cancer patients in Australia (approximately 1600 patients/year).

Although the ultimate aim is a single, central ABCR, we are cognisant of the different privacy requirements of different regions and will work with the supporting state cancer registries to produce comparable reports until primary data sharing is approved.

Mechanisms exist for linkage of deidentified data across state borders and we have partnered with the Population Health Research Network (PHRN) to capitalise on their existing expertise in the application, governance, ethics and linkage of data.

Compliance with Ethics and Governance Requirements

Ethics and governance approvals will be sought for each jurisdiction, capitalising on the expertise of CAQ and the PHRN and governance arrangements established by the Australian Commission on Safety and Quality in Health Care as part of their Clinical Quality Registry Framework[27]. Where possible, we will obtain protection as a Quality Assurance Activity. The first data collection and reporting will be from Queensland as the legislative and governance framework is already in place. Data collection from other jurisdictions will be included as appropriate approvals are obtained.

Waiver of Consent

To optimise the validity and utility of the registry, it is important that the data covers the greatest possible proportion of the population. To achieve this, we intend to seek approval for a waiver of consent or alternatively, for data analysis as a quality improvement project, for reports of population wide clinical quality indicators.

Research that involves data from identified patients will only occur with patient consent.

Data Storage and Security

Privacy and confidentiality are essential for public trust in the activities of the ABCR. To ensure this the ABCR will have strict data rules for data handling, storage, oversight and backup. At all times, the registry will comply with current national and state legislation regarding privacy and confidentiality and this data security will be ensured by the Data Management Committee, overseen by the Registry Management Committee.

CAQ has a proven track record of secure data storage, existing processes for separation of data from different jurisdictions where this is required, and mechanisms for ensuring that data is only accessible to authenticated user groups.

Data Governance

BCA is the data custodian for the ABCR. The Chair of the Registry Management Committee will act as the delegated custodian of the data on behalf of BCA. The inaugural chair is Professor R. L. Jeffree, principal investigator on the initial MRFF Infrastructure Grant to establish the ABCR. The Data Management Committee and the Registry Management Committee will establish secure processes for ethically approved release of data where appropriate.

Reporting

The registry will generate reports as recommended by the 'Framework for Australian Clinical Quality Registries' [30], including publicly accessible, aggregated clinical data and compliance with Clinical Quality Indicators. Risk adjusted data will be provided confidentially to contributors but will not identify other sites. De-identified reports, where appropriate, will be provided for ethically approved research.

Staff at CAQ have epidemiological, statistical, software development, project management, health services research, and clinician engagement expertise and will leverage this experience to deliver the analysis and reporting requirements for the ABCR, following established systems in other cancers (e.g. breast and lung cancer [31-32]).

Management of Outliers

The ABCR Management Committee will develop and implement procedures for the management of outlier institutions and any quality or performance issues identified once the registry is established. In the interim, any substantive performance or quality issues that arise will be managed directly with the relevant institution, either through informal feedback or use of formal escalation processes depending on the significance of the concerns.

Outcomes

The ABCR will publish retrospective, then regular prospective, data and analysis of patterns of care of patients with brain cancer and compliance with the selected Brain Cancer Clinical Quality Indicators at a jurisdictional level. We will work with healthcare providers to rectify any deficiencies in care, disseminate evidence based practices associated with best outcomes and highlight areas of greatest scope for improvement. Over time, this will drive changes in practice that improve patient care and lead to better outcomes for patients and the best use of health dollars and inform health service policy.

Acknowledgments

Thank you to the Prostate Cancer Outcomes Registry – Australia & New Zealand (PCOR-ANZ) for sharing their governance documents, and to the Australian Neuromuscular Disorders (NMD) Registry for the opportunity to view their charter.

Abbreviations

ABCR	Australian Brain Cancer Registry
ACSQHC	Australian Commission on Safety and Quality in Health Care
BCA	Brain Cancer Australia
CAQ	Cancer Alliance Queensland
CSIRO	Commonwealth Scientific and Industrial Research Organisation
AEHRC	Australian e-Health Research Centre
CQI	Clinical Quality Indicators
CQR	Clinical Quality Registry

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