Australian Brain Cancer Registry (ABCR)

Brain Cancer Challenge

Brain cancer is a significant health issue in Australia, ranking as the sixth leading cause of cancer burden. It has a low five-year survival rate of 22%, and it disproportionately affects individuals in the prime of their lives, leading to a substantial loss of life years and economic impact. In Australia, variations in the patterns of care for brain cancer have been observed, stemming from local preferences and disparities in access to treatment. 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.

Clinical Quality Registries (CQRs)

CQRs have been repeatedly shown to improve patient care and extend survival. Recognising the need for a national brain cancer registry, in 2019, Brain Cancer Australia (BCA) convened a registry working party and completed a feasibility study. In 2021 the registry working party developed Clinical Quality Indicators (CQIs) which was published and will form the framework for the ABCR. These CQIs help benchmark the data collection, and specifying best practice, with a view to improving care and outcomes for brain cancer patients.

ABCR Goal

The ABCR aims to improve the quality of care and outcomes for brain cancer patients by systematically collecting and analysing data on treatment and outcomes. This data will help identify best practices and guide improvements in patient care.

ABCR Objectives

1. **Quality of Care**: The primary objective is to 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 in turn improve outcomes for patients.

2. **Research**: The ABCR will support research by providing high-quality data to help advance medical knowledge and improve treatment practices.

ABCR Operational Model

Governance

The registry is managed by Brain Cancer Australia (BCA) with data coordination by Cancer Alliance Queensland (CAQ). The operational model involves collaboration between BCA, CAQ, health departments, and state health data custodians.

Data Collection

The ABCR focuses on automated, electronic data collection from hospitals across Australia. This approach aims to ensure comprehensive and accurate data collection, minimising the need for manual data entry and reducing the burden on healthcare providers. The registry will also use data linkage to gather information from diverse systems, capturing the entirety of patients' experiences throughout their cancer journey.

Governance Framework

Committees and Responsibilities

The governance structure includes several committees, such as the Management Committee, Operations Committee, Data Management Committee, Research Committee, and Consumer Advisory Committee. These committees oversee various aspects of the registry's operations, data management, and research activities and ensure effective operation and oversight.

Stakeholders Group

The registry involves a wide range of stakeholders, including healthcare providers, cancer control agencies, specialist associations, consumer groups, and charities. These stakeholders contribute data, expertise, and support to the registry.

Technical Partners

The ABCR collaborates with CAQ and the Australian e-Health Research Centre (AEHRC) for data collection and analysis. These partners have expertise in electronic data collection, secure data storage and reporting.

Data Management and Security

Ethics and Privacy

The ABCR adheres to strict ethical guidelines and privacy laws to protect patient data. Ethics and governance approvals are sought for each jurisdiction, and data security is ensured by CAQ through robust data handling, storage, and oversight processes.

Reporting

The registry will generate regular reports on treatment quality and outcomes. The registry will provide publicly accessible, aggregated clinical data and confidential, risk-adjusted data to contributors. These reports will provide valuable insights to healthcare providers, policymakers, and the public.

Outcomes and Impact

Improved Care

By leveraging data-driven insights, the ABCR aims to enhance patient care and survival rates. The registry will identify management practices associated with the longest survival and promote timely access to optimal care.

Policy Influence

The data collected by the ABCR will provide evidence to inform public health policies and resource allocation. This will help ensure that brain cancer patients receive the best possible care and support.

Research and Innovation

Facilitating Research

The ABCR will serve as a valuable resource for research, contributing to epidemiological insights and understanding patterns of care. The registry will support registry trials, which are more cost-effective and have real-world applicability compared to conventional clinical trials.

Accelerating Recruitment

The registry will enable patient self-enrolment for research studies, accelerating the recruitment of participants and facilitating the translation of research findings into clinical practice.