

# Data and Services Discovery projects - Transformative Data Collections

## Title

Towards the Development of Clinical Quality Indicators for a National Paediatric & Adult Brain Cancer Clinical Registry

## Approach

The BCBA consortium intends to develop a national paediatric and adult brain cancer clinical registry. The proposed registry will have 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. BCBA has completed a feasibility study for a national brain cancer clinical registry in a project led by a multi-institutional working group representing, neurosurgery, neuro-oncology, cancer epidemiology, health IT and consumers. The recommended registry model 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 trials components. Phase 1 of the CQR - and subject of this application - was to establish the process for identifying and refining a set of clinical indicators to measure quality of care across the entire trajectory of the brain cancer patient journey. A BCBA working group will lead the project with a multi-disciplinary panel of brain cancer experts convened to participate in a Delphi process (survey/feedback technique) to prioritise and gain consensus on the final paediatric and adult clinical benchmarks. The indicators developed will be used to build a national clinical registry. Once established, the data collected will guide clinicians, hospitals and other stakeholders in activities to reduce variations in care, ultimately optimising quality of life and survival for brain cancer patients Australia-wide.

The aspect of the project funded by ARDC grant application focused on delivering the following three key outputs:

### 1. Formalise a leadership group for the Delphi Process

Aim: Establish a BCBA clinical quality registry working group with the relevant expertise to lead this project.

Achieved: BCBA has formalised a CQR working group expertise in the fields of both paediatric and adult brain cancer clinical care. The group has provided feedback regarding the literature review process and has been updated on the progress of the literature review. The preliminary clinical quality of care indicators identified through the literature are being reviewed and refined by the working group prior to establishing the next stage of the project - the Delphi process.

## 2. Conduct literature review

Aim: Search and identify research articles and clinical guidelines related to quality of care indicators in brain cancer using various databases.

Achieved: We employed a research officer to undertake an extensive literature review of the clinical care guidelines. The screening and auditing process has been completed and the preliminary set of quality of care indicators has been assembled for review by the registry working party.

## 3. Identify preliminary list of indicators

Aim: Guided by the appropriate studies and guidelines the BCBA clinical quality registry working group will reach agreement on the preliminary set of quality of care indicators that will form the basis of the Delphi process to identify the final set of indicators for the proposed national paediatric and adult clinical quality of care registry.

Achieved: The preliminary set of quality of care indicators assembled through the literature review are being evaluated and refined by the project working group. The ensuing Delphi process will establish the final (consensus) set of indicators for the national paediatric and adult brain cancer clinical registry.

## FAIR

The BCBA national brain cancer clinical registry will focus on making data FAIR when it is established. Please see attached completed FAIR assessment spreadsheet based on what BCBA would like to achieve when the registry is established.

## Collaboration and coverage

BCBA aims to establish a national brain cancer clinical registry. This project is being led by a multi-institutional working group representing, neurosurgery, neuro-oncology, cancer epidemiology, health IT and consumers. The Clinical Lead is A/Prof Lindy Jeffree, Neurosurgeon, Royal Brisbane and Women's Hospital, and collaborators include: the Cooperative Trials Group for Neuro-Oncology (COGNO); NHMRC Clinical Trials Centre, University of Sydney the Australian and New Zealand Children's Haematology/Oncology Group (ANZCHOG); Public Health and Preventive Medicine, Monash University; CSIRO eHealth Research Centre and the Cancer Epidemiology Research Unit, UNSW. BCBA also has support from the Neurosurgical Society of Australasia (NSA) and the Clinical Oncology Society of Australia (COSA).

## Sustainability

Following completion of the current phase in the development of the registry project, BCBA will undertake the Delphi process to identify the consensus set of quality of care indicators, concurrently working to develop the implementation guide for the data capture, while engaging adult and paediatric hospital pilot sites around Australia for the project. In addition to providing funds through its fundraising arm, BCBA is engaging with both State and Federal Health Departments for funding to support the establishment of a registry that we believe will create a model for all cancer groups.

## Learnings

Collaboration is key to establishing the National Paediatric and Adult Brain Cancer Clinical Registry. The BCBA consortium model of multi-disciplinary, multi-institutional collaborators from both the paediatric and adult fields of brain cancer treatment and research has provided the ideal platform to build the engagement necessary to develop such an ambitious project.

Addressing the state-based health funding model and providing funds at a national level to support the establishment of data collections such as this registry would be very helpful. In addition, the development of national guidelines on ethics and consent, as well as procedures such as data exchange agreements, researcher access procedures/protocols, electronic data extraction protocols/procedures and health data linkage protocols.

## Impact

This project will enable the BCBA CQR leadership group to progress to the next phase in developing the clinical quality indicators essential to guiding the collection of data for a national paediatric and adult clinical registry. The literature review undertaken for this project will be the subject of a manuscript developed for publication at a future date. More broadly, the project has created a community of leading brain cancer clinicians, who along with the CSIRO are working nationally with hospital administrators and health department representatives to develop a national brain cancer clinical registry that will provide clinicians, hospitals and governments with previously unavailable data. This data will allow the various stakeholders to make decisions that ultimately will result in the delivery of better quality of care for brain cancer patients at all stages of their treatment journey. As the BCBA registry project moves into the development of Stages 2 and 3, data collected will be used to facilitate registry clinical trials and assist researchers with important clinical information corresponding to biobanked specimens. The impact of the registry project will be ongoing, with the provision of high quality clinical data not only having the potential to optimise quality of life for brain cancer patients, but also improve treatments in a disease where survival rates have barely changed in 30 years.

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