

Developing a National Brain Cancer Registry: A Clinical Feasibility Study

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Key Points

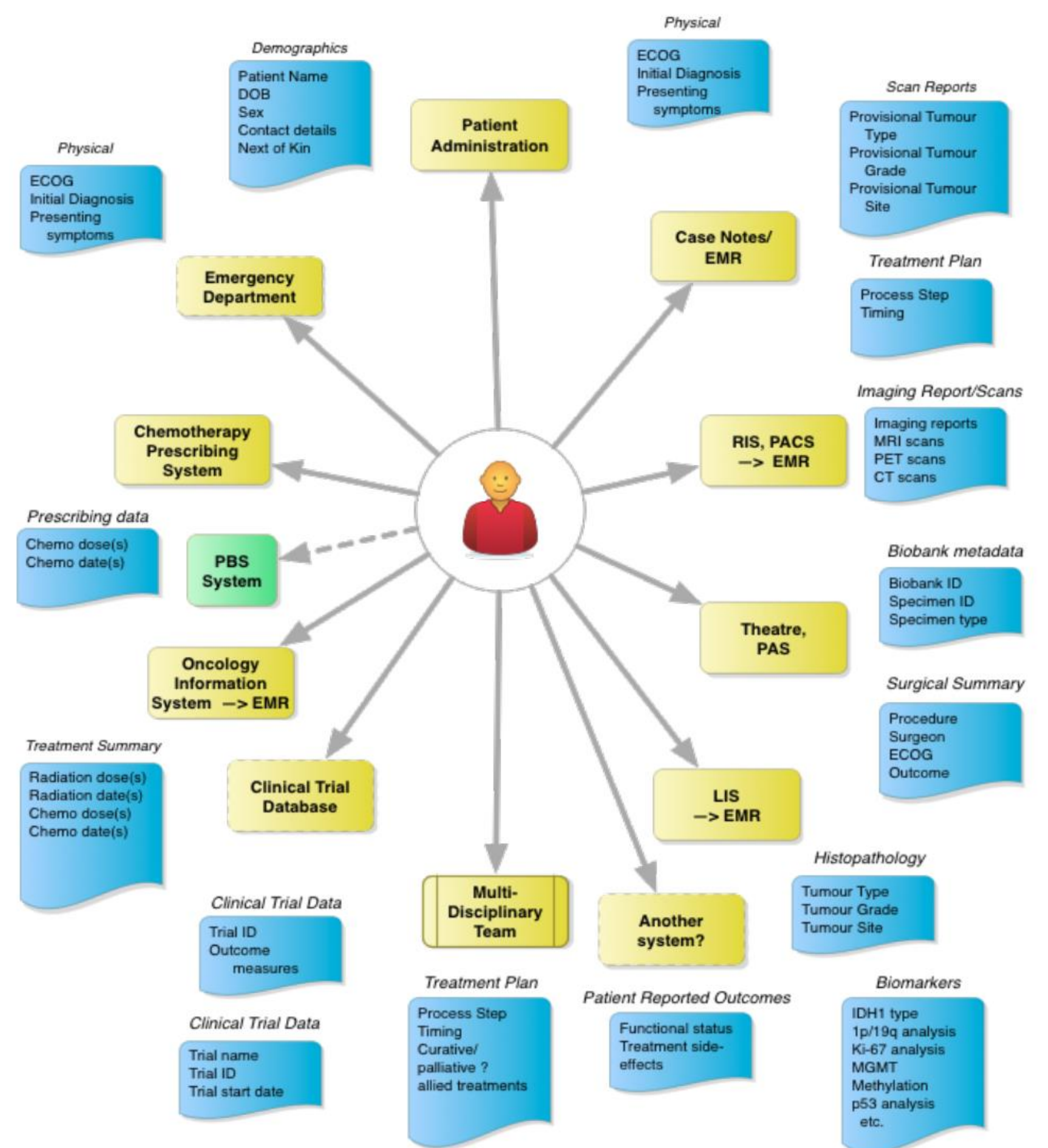
- Pathways for the treatment of brain cancer are complex, iterative and involve multiple providers and locations.
- Administrative, diagnostic, treatment and outcomes data are scattered (and duplicated) across a range of paper and electronic systems.
- Discussions are underway between Brain Cancer Biobanking Australia (BCBA) and other key stakeholders to implement a National Adult and Paediatric Brain Cancer Clinical Registry.

Aims & Methods

An Australian National Paediatric and Adult Brain Cancer Clinical Registry would benefit patients by collecting and reporting clinical quality metrics, providing feedback to clinicians and clinical information to researchers, and informing the community and government about brain cancer incidence and outcomes.

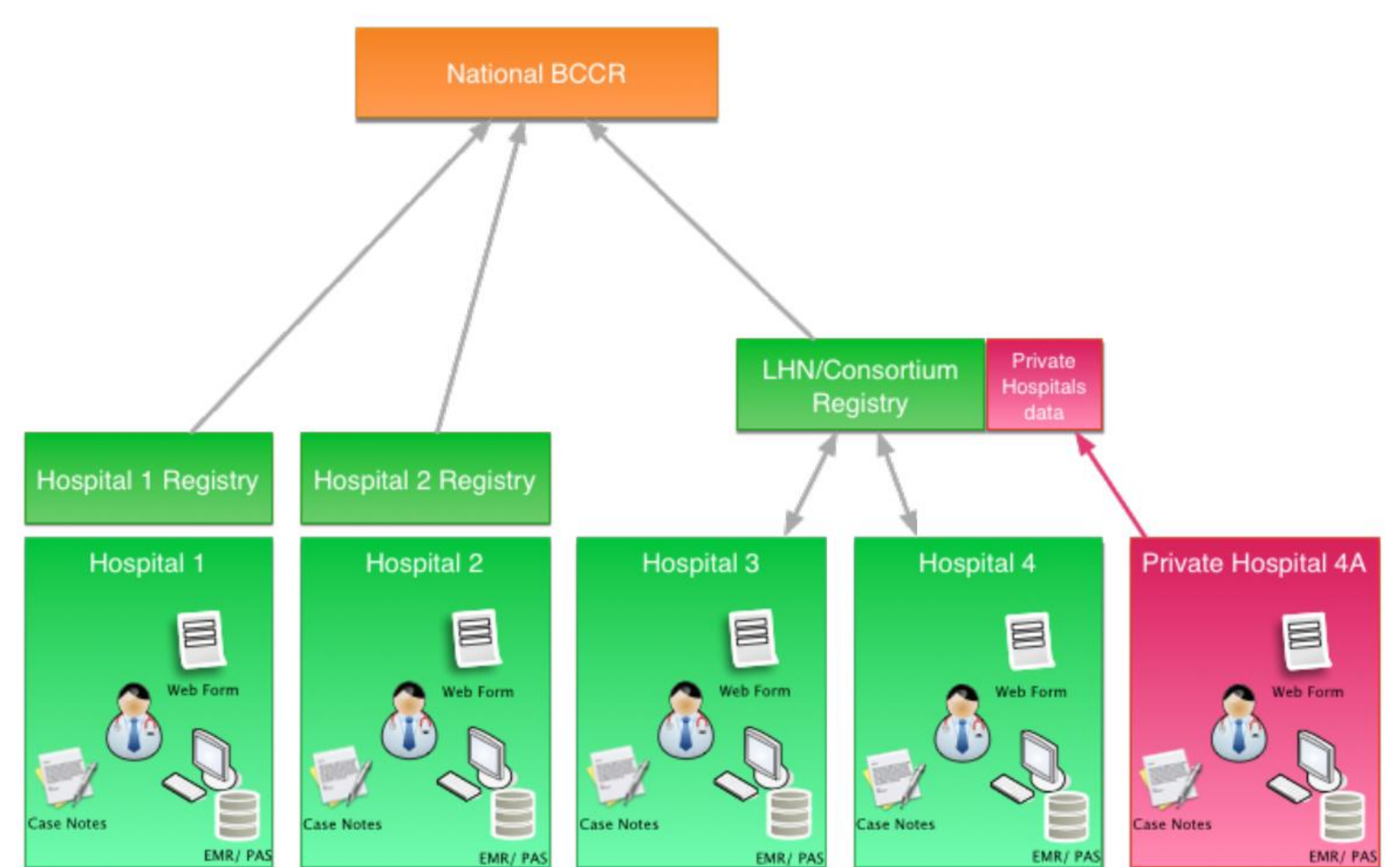
To identify the possible scope and mechanisms for development of a registry, information was collated from a literature review, clinician consultations, review of existing information systems at different institutions across Australia, and case studies of local and international clinical registries.

Typical hospital systems holding relevant data



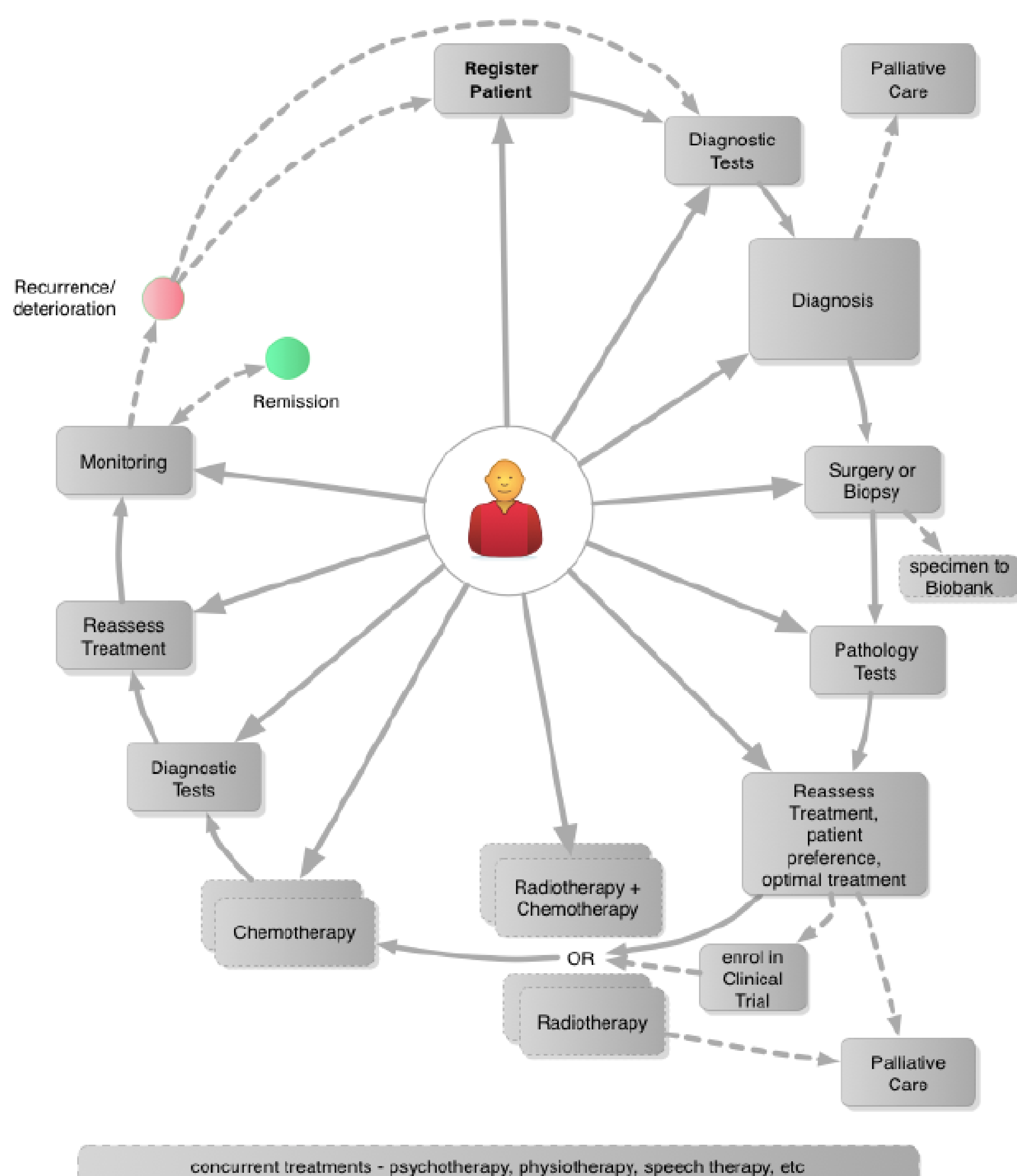
(Browne 2019, Figure 2)

Proposed Hybrid Two Tier Model for the Australian National Paediatric and Adult Brain Cancer Clinical Registry



(Browne 2019, Figure 5)

Generalised and simplified hospital process flow



(Browne 2019, Figure 1)

Conclusions:

Of the different repository models considered, the hybrid model has been chosen for development.

Brain Cancer Biobanking Australia (BCBA) is now developing a preliminary set of clinical quality indicators to inform stage one – the quality of care component – of the registry and inviting pilot sites to implement data collection.