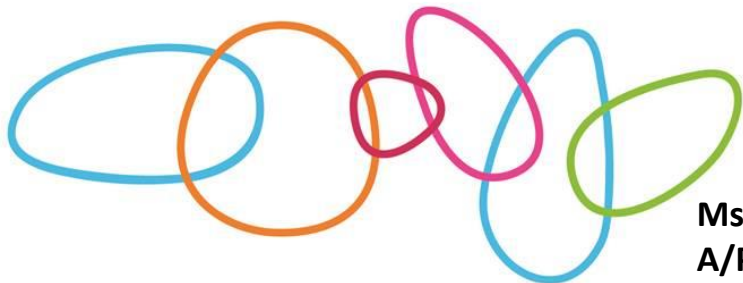


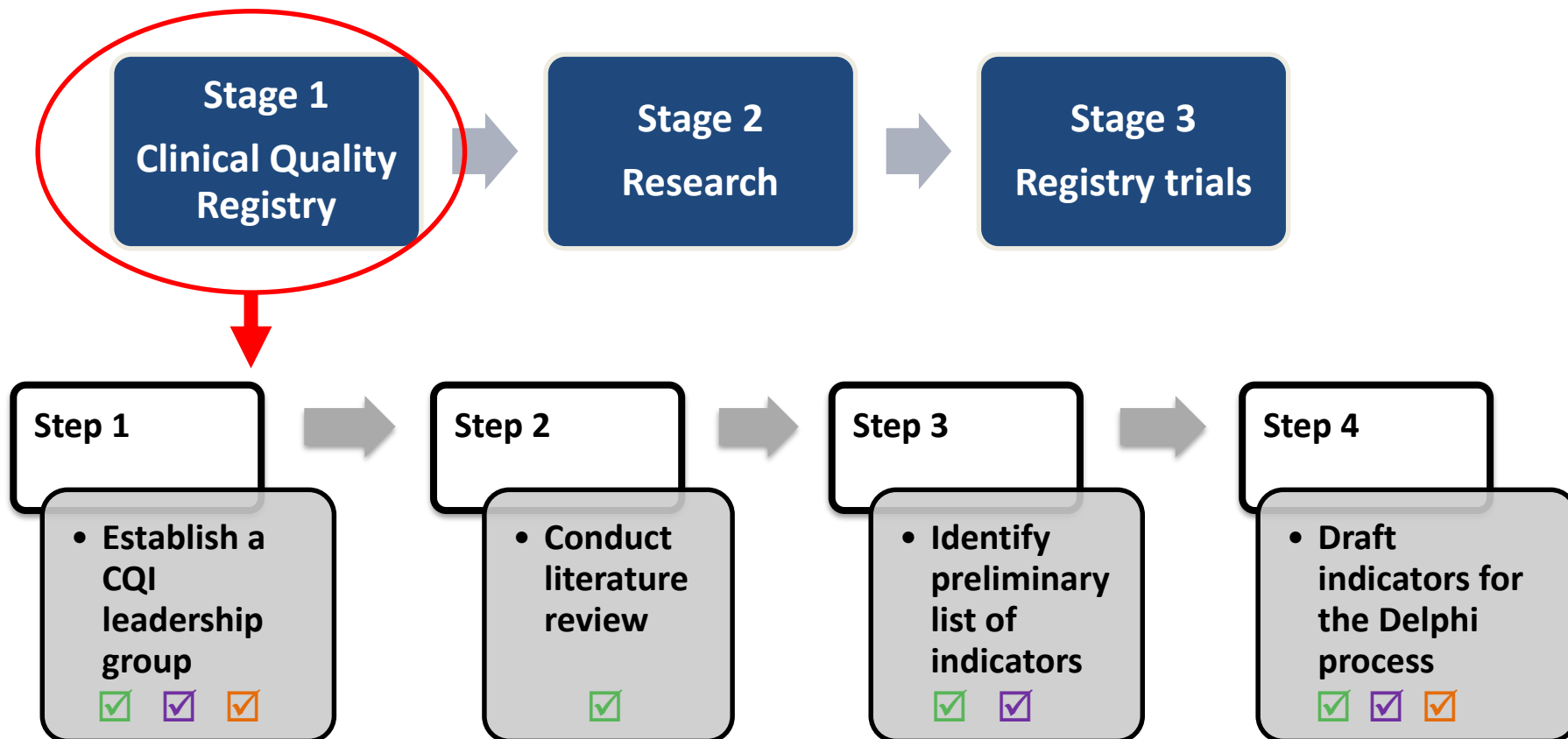
# Towards the Development of Clinical Quality Indicators for a National Paediatric and Adult Brain Cancer Clinical Registry

*Brain Cancer Biobanking Australia (BCBA)*



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# National Brain Cancer Clinical Registry development



The Data will be made **FAIR**

Achieved:

1. **Consensus**

2. **Collaboration**

3. **Good governance**

Planned:

4. Efficient & sustainably resourced

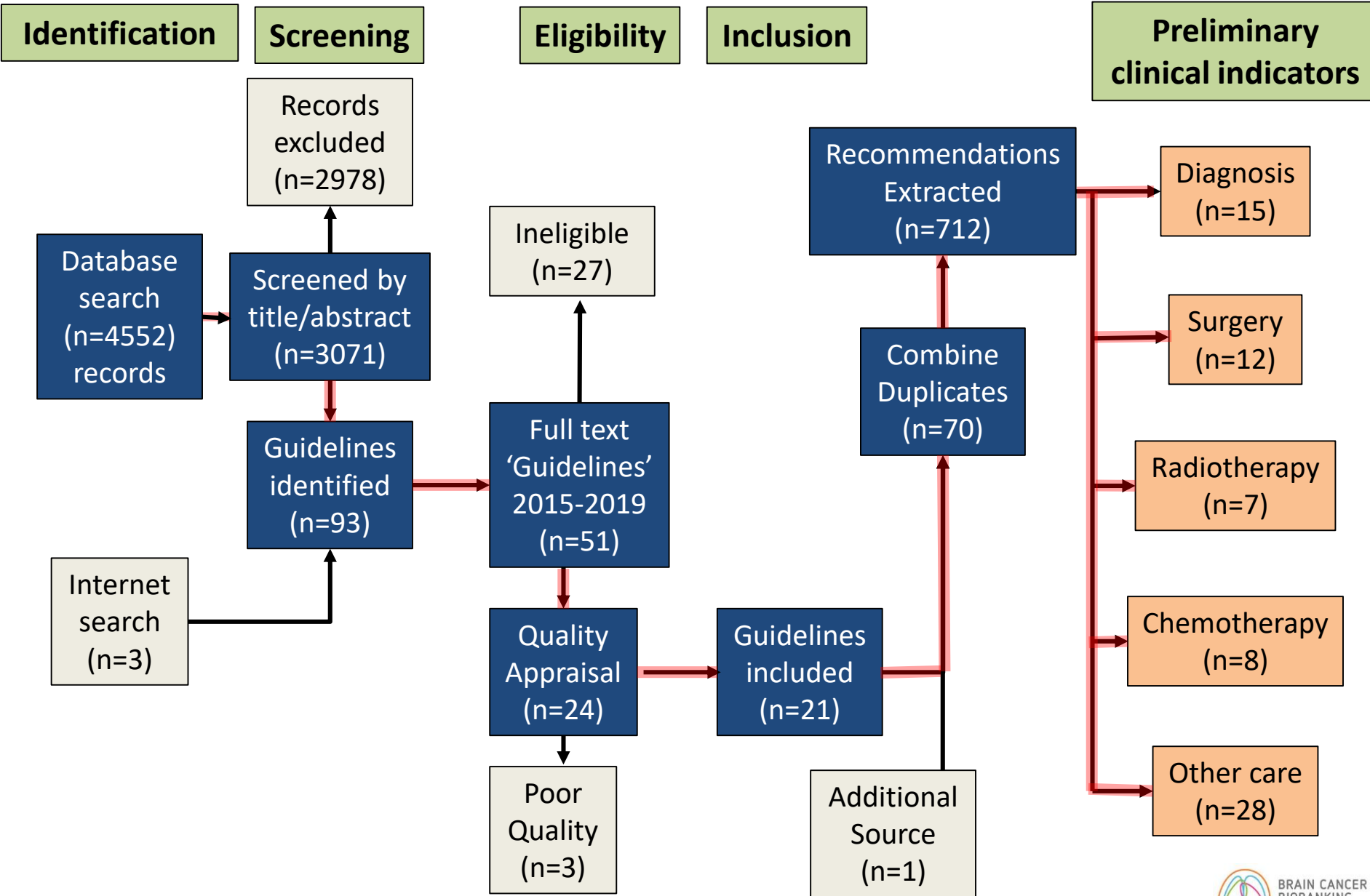
5. Web based public registry

6. Fully accessible to authorised persons

7. Interoperable, standardised data

8. Standard usage rights

# Search Results



# Lessons Learnt

## Collaboration and coverage

- Build on existing work (extensive existing literature)
- Expert guidance essential for interpretation

## Sustainability

- Specific content is evolving; work with principles
- Technical solutions (existing databases) reduce administrative burden
- *Patient care* motivates clinicians, organizations & funders

## Learnings

- Translation from clinical ideas to technical datapoints is onerous
- Iterative cycles of funding, clinical & technical progress are necessary

## Impact

- The National Registry will provide previously unavailable data to reduce unwarranted variation in care and improve outcomes for brain cancer patients.

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