



# A scoping review of the needs of children and young people with acquired brain injuries and their families

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## Background

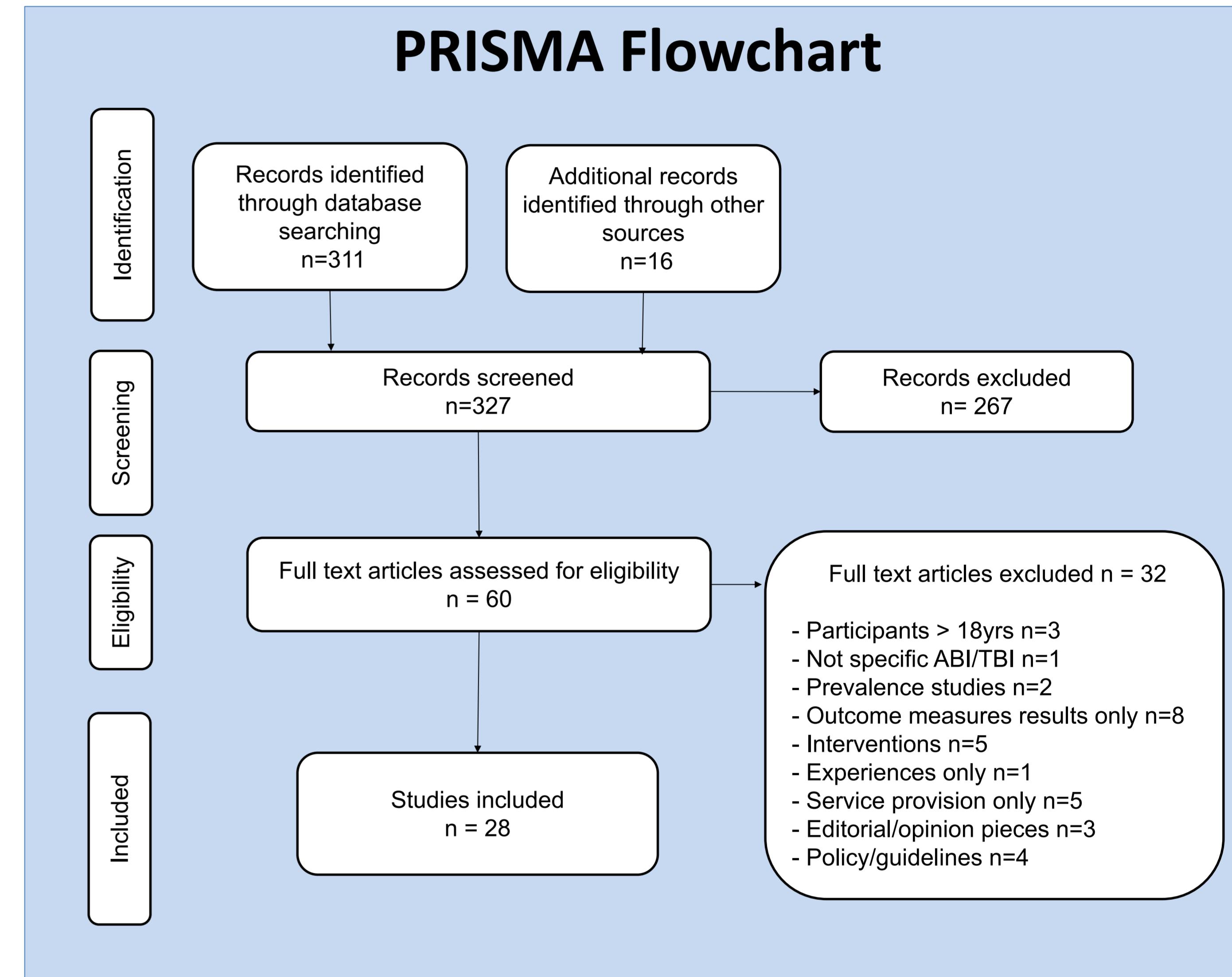
Annually 40,000 children and young people (CYP) sustain acquired brain injury (ABI)<sup>1</sup> resulting in lifelong disabilities which impact on quality of life for CYP and their families<sup>2</sup>. Understanding the needs of CYP with ABI (CYP-ABI) and their families is essential for effective rehabilitation. The aim of this study was to identify studies and key themes describing the nature and extent of CYP-ABI and family needs; met, unmet or unrecognised.

## Method

The Joanna Briggs Institute scoping review methodology was used. Sixteen electronic bibliographic databases were searched between April and July 2018. Papers were screened against eligibility criteria by two independent reviewers. No date limits were applied. Data was extracted regarding CYP-ABI and family needs and thematic analysis conducted to identify the key themes.

## Results

Twenty-eight articles were identified including three systematic reviews, one scoping review, two practice recommendations and 22 original research studies. Extensive needs were reported, many unmet or unrecognised. Key themes identified; CYP-related impairment needs, support needs, return to school and long-term aftercare.



## Key Themes

| CYP-related impairment needs                     | Support needs                              | Return to school                                      | Long-term aftercare                                         |
|--------------------------------------------------|--------------------------------------------|-------------------------------------------------------|-------------------------------------------------------------|
| - Physical                                       | - Caregiver burden                         | - Educational support                                 | - Specialist follow-up                                      |
| - Cognitive                                      | - Information                              | - Effective communication                             | - Identification of long-term sequelae and developing needs |
| - Communication                                  | - Communication                            | - Information sharing                                 | - Holistic family-centred care                              |
| - Psychological                                  | - Accessing services                       | - Training/education                                  | - Support at key transition points                          |
| - Emotional                                      | - Family and siblings                      |                                                       | - Signposting                                               |
| - Behavioural                                    | - Emotional support                        |                                                       | - Referral to services                                      |
| - Social                                         | - Social support                           |                                                       |                                                             |
| - Adolescent-specific                            | - Peer support                             |                                                       |                                                             |
| - Activity/Participation                         |                                            |                                                       |                                                             |
| - Overall well being                             |                                            |                                                       |                                                             |
| Need:<br>Health, social care and education input | Need:<br>Keyworker and family-centred care | Need:<br>Collaboration between professionals involved | Need:<br>Integrated care pathway                            |

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## Discussion

A lack of awareness and understanding of the long-term consequences for CYP-ABI and their families underpins all reported needs. The literature recommends raising awareness, education, specialist follow-up, integrated care pathways and further research to ensure CYP-ABI and their families have appropriate and timely support to optimise recovery and realise potential.

## Conclusion

CYP-ABI and their families report extensive needs, many of which are often unmet or unrecognised by those supporting them. Needs transcend health, social care and education domains across the care pathway.



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