

Long term participation outcomes of children and young people with severe acquired brain injuries: A scoping review

Wales, L., Davis, K., Kelly, G. & Lynott, H.





Introduction

- Children and young people (CYP) with acquired brain injuries (ABI) have difficulties participating in activities at home, school and in their communities, which is detrimental to their wellbeing (Anaby et al 2012). However, it is currently unclear which factors support the long term participation of these CYP.
- Scoping reviews search, identify, define and clarify the scope and nature of information gathered through broad range of data sources in order to map and synthesise current evidence and, analyse gaps (Munn et al., 2018).

Aim

To investigate and identify the possible factors supporting CYP to regain participation following severe ABI and inform the development of a long term study research protocol.

Results

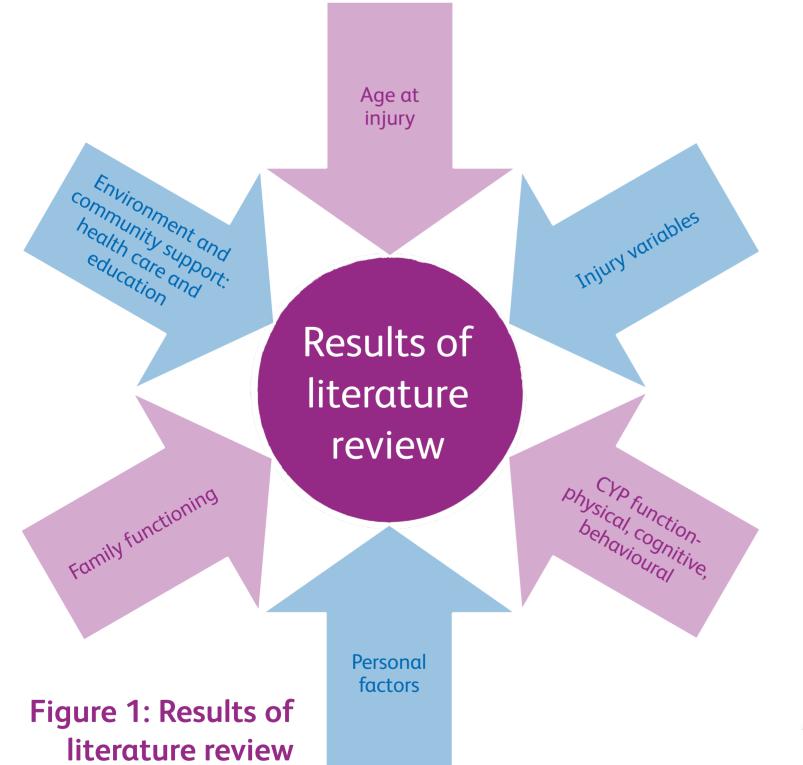
- Literature review: identified theoretical framework for participation (Imms, 2017) and subsequent development of six determinants that have an effect on long term participation (See fig. 1).
- Quality analysis: indicated paucity of studies focussed on severe ABI, gaps in previous study methodologies and the need for a range of different outcome measures.
- CYP and family views: endorsed, explained and confirmed participation as most important long term outcome.
 Identified lived experience of determinants (See fig. 2).
- Expert consultation: recognised uniqueness of population and encouraged further research in this field. Influenced use of an advanced trajectory methodology, and led to an epidemiologist joining the research team.

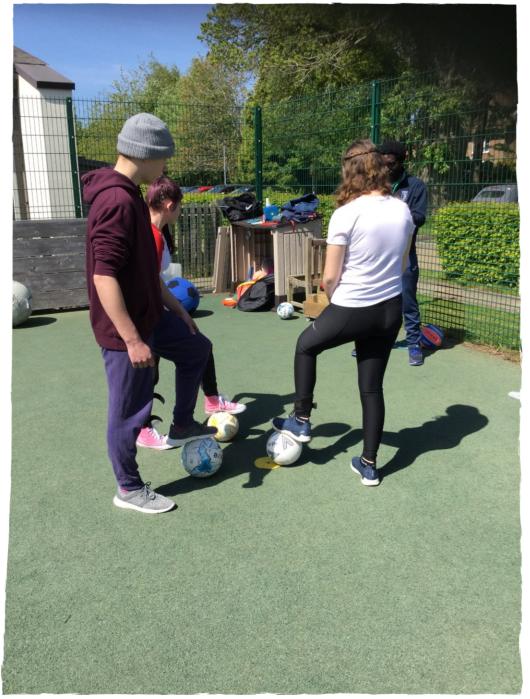
Enhanced scoping methodology

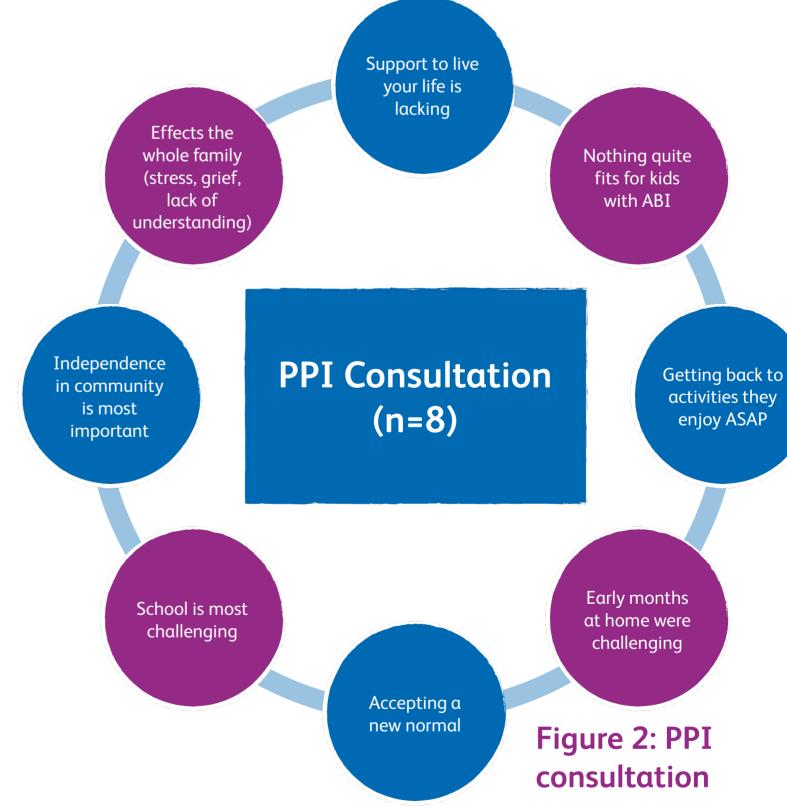
A rigorous & transparent scoping review approach to the collation, analysis and synthesis of evidence was used (Levac et al. 2010).

This included:

- Comprehensive systematic literature review: using search strategy proposed by DeKloet et al (2015) enhanced by broader, iterative investigation of the definition and concept of participation theory.
- Collection of historic data: using routine data from UK Rehabilitation Outcome Collaborative (UKROC) dataset.
- Qualitative interview data gained from CYP and their families: semi structured interviews (n=8).
- Expert consultation discussion notes: with fellows from BACD-Castang fellowship, members of participation network – CountMeIn! and ongoing dialogue with international ABI experts (n=2).







Conclusions and recommendations

- Scoping review methodology provides a valid review approach to synthesis of current knowledge regarding long term participation outcomes follow paediatric ABI.
- A multitude of factors can lead to reduced participation following ABI in childhood, but further research is required to explore how these factors interplay to affect the long term participation outcomes of these CYP.
- Robust trajectory methodology has been identified for a research study exploring CYP emergence of participation over time following severe ABI in the UK.
- Findings from study will influence supportive interventions for practice.

References

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- De Kloet et al 2015 Brain injury, 29(10), pp.1135-1145.
- Imms et al 2017 Developmental Medicine & Child Neurology, 59(1), pp.16-25.

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