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OUTCOME REPORTING HETEROGENEITY IN HIRSCHSPRUNG'S DISEASE RESEARCH - A SYSTEMATIC REVIEW

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Aim: The aim of this work was to identify which outcomes are currently investigated in Hirschsprung's Disease (HD) research, and make an assessment of their quality of reporting.

Methods: A systematic review was conducted according to a pre-specified protocol (CRD42015024996). Titles were eligible for inclusion if they compared two surgical interventions for HD, and reported at least one outcome following the definitive procedure. Studies were excluded if they only reported outcomes following re-do or non-definitive procedures. Eligibility assessments and data extraction were carried out by two researchers working independently.

Primary outcome:

- Identification of outcomes reported by eligible studies

Secondary outcomes:

- The median number of outcomes investigated per study
- The percentage of studies meeting Harman et al's criteria for transparent outcome reporting
- The percentage of studies fully reporting data for every outcome they investigated

Main Results: 696 unique titles related to HD were identified. 35 were deemed eligible for inclusion in the review. Within these 35 studies, 74 outcomes were investigated. Only four outcome measures were investigated in more than 50% of eligible studies - faecal incontinence (32 studies,91%), enterocolitis (23 studies,66%), constipation (20 studies,57%) and length of stay (18 studies,51%). Thirty-three outcomes(45%) were only investigated once. The median number of outcomes reported per study was 11 (IQR6-13)

Seven studies were only available as abstracts and therefore excluded from data reporting assessments. Seven of the remaining studies(25%) met all criteria for complete data reporting, and seven(25%) fully reported data for every outcome measure they investigated.

Conclusion: The need for a core outcome set in HD is highlighted by the substantial outcome reporting heterogeneity and significant risk of reporting bias demonstrated in this review.

The outcomes identified in this review could be used in a robust Delphi process involving patients, parents and clinicians to develop such a core outcome set.