72278 - Defining excellence: the first core set of quality indicators for Hirschsprung’s disease care

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Introduction: This study aimed to establish a core set of quality indicators to benchmark Hirschsprung’s disease (HSCR) care across hospitals within a European clinical audit framework (EPSA; European Pediatric Surgical Audit), focusing on short- and long-term outcomes, and care quality improvement.

Method: An online Delphi method gathered inputs from health care professionals (HCPs) belonging to both ERNICA-recognized and non-recognized expert centers, and from patient representatives (PRs) in the field of HSCR. They evaluated baseline characteristics and potential outcome-, structure- and process indicators for HSCR care, identified through a systematic literature and guideline review, on a nine-point Likert-scale over three Delphi questionnaire rounds. The items selection criteria were predefined, with participants selecting the five to ten most essential indicators for the core set in the second and third rounds.

Result: An international panel of 8 PRs and 96 multidisciplinary HCPs from 59 hospitals in 17 countries completed all three Delphi rounds (response rate 73%), eventually including 11 baseline characteristics and 36 indicators. Six indicators were universally prioritized. Each group (HCPs and PRs) proposed four exclusive indicators. A mutual agreement was subsequently reached, with HCPs endorsing the indicators proposed by PRs and vice versa.

Discussion: This study established a core indicator set of 11 baseline characteristics, 5 outcome indicators, 2 structure indicators, and 7 process indicators for evaluating (quality of) HSCR care. These indicators, to be implemented in the EPSA, aim to highlight practice variations and guide HSCR care quality improvement, laying the groundwork for new guideline development after three years of data collection.