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Child health and education outcomes in children with Hirschsprung disease: a population-based data linkage study in England

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Hirschsprung disease (HSCR) is a rare congenital intestinal condition that, despite lifesaving surgery, can result in a lower quality of life throughout childhood and into adulthood. There is a lack of population-level research on the reasons why children with HSCR are frequently hospitalised throughout childhood, or on school experiences. We used linked administrative data from health and education services (ECHILD) to create a cohort of births from 2002–2020. We evaluated admission and mortality rates, number of surgical procedures, and reasons for admissions for children with and without HSCR at ages 0-14. We assessed how many children had recorded Special Educational Needs by Year 1 of primary school (age 6). Of the 11,261,227 children in our cohort, 3227 (0.03%) had HSCR. 95.0% of children with HSCR were readmitted by age 4 compared with 40.2% of those without. Across ages and sexes, children with HSCR were frequently admitted for constipation, gastroenteritis, intestinal infections, abdominal pain, and nausea and vomiting. 44.0% of children with HSCR had recorded Special Educational Needs by age 6 compared with 17.9% of those without HSCR. Improvements to treatment success, including novel or complementary approaches, are required in order to improve quality of life for children with HSCR. Further research is needed to understand the impact of HSCR and its treatment at the transition from paediatric to adult services, and on child development, progress in school, and other psychosocial factors including mental health.

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