

How many children are on home parenteral nutrition in the UK?

S. V. Beath¹, H. Gowen² and J. W. L. Puntis³

¹The Liver Unit, Birmingham Children's Hospital, ²British Intestinal Failure Registry, Institute of Child Health, Birmingham Children's Hospital B4 6NH, UK and ³The General Infirmary at Leeds Paediatric Offices, A Floor Old Main Site, Great George Street Leeds LS1 3EX, UK

There has been a rising demand for home parenteral nutrition (HPN) services for children over the past 20 years. In order to help plan a strategy for delivery of care at the regional level, our aim was to carry out a national point prevalence survey of HPN during February 2010.

An Excel spreadsheet was sent to paediatric gastroenterologists currently participating in the British Intestinal Failure Survey (BIFS) requesting information on children currently receiving or about to be discharged on HPN. Point prevalence of HPN was calculated using population statistics available for children aged 16 years and below. Comparison was made with a similar study carried out by the British Paediatric Surveillance Unit in 1993⁽¹⁾. Trends in underlying diagnosis were explored by comparing the BPSU data with the current BIFS database for 2006–2009⁽²⁾.

Diagnostic group	1993 BPSU survey	2006–2009 BIFS survey
Short-bowel syndrome	18 (27%)	194 (63%)
Disorder of motility	12 (18%)	43 (14%)
Enteropathy	12 (18%)	32 (10.4%)
Other	24 (37%)	39 (12.6%)
Total	66	308

Paediatric gastroenterologists from 27 out of 32 BIFS participating Trusts responded indicating that there were 137 children receiving HPN, four times as many as in 1993; six of these were older than 16 years but remained under paediatric care. The regional point prevalence of HPN varied from 1.76 to 41.4 per million, with a mean of 13.6 patients per million. The relative frequency of short-bowel syndrome had increased from 27% in 1993 to 63%.

HPN services for children in the past 20 years have expanded at different rates across the UK; a national consensus on standards of care for children with intestinal failure may represent an important step towards optimising outcomes.

1. Candy D, Ross E & Devane S (1993) Survey of children on long term parenteral nutrition, UK and Eire 1992. BPSU 8th Annual Report 1993.
2. Personal communication Mr H Gowen BIFS administrator Henry.Gowen@bch.nhs.uk