



## **Annual BANS Report**

# **Artificial Nutrition Support in the UK 2005**

**A Report by the British Artificial Nutrition Survey  
(BANS), a committee of BAPEN  
(The British Association for Parenteral and Enteral  
Nutrition)**

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Available from BAPEN website, [www.bapen.org.uk](http://www.bapen.org.uk) . All enquiries to BAPEN Secretariat, The British Association for Parenteral and Enteral Nutrition, Secure Hold Business Centre, Studley Road, Redditch, Worcs, B98 7LG.

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### **Previous BANS reports**

BANS: Trends in Artificial Nutrition Support in the UK During 1996 – 2000.  
ISBN 1 899 467 505 (Published 2001)

BANS: Current Aspects of Artificial Nutrition Support in the UK.  
ISBN 1 899 467 602 (Published 2002)

BANS: Trends in artificial Nutrition Support in the UK Between 1996 and 2002.  
ISBN 1 899467 70 0 (Published 2003)

BANS: Trends in artificial nutrition support in the UK, 2000 – 2003.  
ISBN: 1 899467 95 5 (Published 2005)

Previous BANS reports and other BAPEN publications are available from the BAPEN Office, address above. Executive summaries from previous reports are available on the website.

## BAPEN MISSION STATEMENT

The British Association for Parenteral and Enteral Nutrition (BAPEN) was formed in 1992 as a result of recommendations made by the King's Fund Centre report "A Positive Approach to Nutrition as Treatment". The Association's aim is to improve the nutritional treatment of all sufferers from illness who have become, or are likely to become, malnourished and who are unable to consume or absorb normal food in sufficient quantities to promote recovery.

To achieve this aim BAPEN will:

- Establish a Clinical Governance framework which underpins nutritional management throughout the course of a patient's illness
- Establish a multiprofessional/multidisciplinary research programme which enhances understanding of the pathogenesis of malnutrition, the role of nutrient substrates and evaluates the clinical application of new knowledge and technology.
- Create opportunity for enhancing knowledge and developing skills in clinical nutrition through education and training.
- Communicate the benefits of clinical and cost effective optimal nutritional care to health care professionals, policy makers, and the public.

To foster this aim the Association will

- Set standards of clinical practice in nutritional support.
- Educate and train healthcare workers, patients and policy makers in the prevention and treatment of malnutrition during illness.
- Promote research.

BAPEN disclaims any liability to any healthcare provider, patient or other person affected by this report. Every attempt has been made to ensure the accuracy of the data in this report.

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## Section 1.

### Preface

#### *About BANS - The British Artificial Nutrition Survey.*

BANS was set up as a committee of BAPEN in 1996 to collect and analyse data pertaining to enteral and parenteral nutrition support in adults and children in hospital and the community. The BANS committee reflects the multidisciplinary nature of BAPEN as shown in the list of committee members. An annual report is published each year and copies can be obtained from the BAPEN office. In 2006, for the first time, we are publishing the report based on 2004 and 2005 data electronically on the BAPEN website, [www.bapen.org.uk](http://www.bapen.org.uk)

BANS is registered through BAPEN under the Data Protection Act. To avoid duplication of reported patients, reporters are requested to supply only the initials, date of birth, sex and the first part of their postcode. Without this level of detail, it is not possible to be certain of the accuracy of our data. We are actively pursuing the support of Section 60 of the Health and Social Care Act, 2001 through the Patients Information Advisory Group (PIAG). This is a government agency tasked with implementing Section 60 of the Health and Social Care Act, 2001 which is designed to protect patients from inappropriate use of medical records. It goes further than the Data Protection Act 1998 and seeks to ensure that data collection is either anonymous, pseudonymised or obtained with full consent of the patient or parent. BANS and its reporters are legally obliged to comply with this legislation. We will inform reporters and BAPEN members of the outcome through "In Touch" and the BAPEN website.

The chair of BANS would like to express on behalf of the committee his gratitude to all those reporters who make this unique venture possible. We hope that all centres in the UK will report to BANS so that as complete a picture as possible of artificial nutritional support can be obtained each year.

We have obtained encouraging data through our links with parenteral and enteral homecare companies. They have kindly contributed anonymous data which we have aggregated to compare with our own data from our 400 reporters nationwide. Shortfalls in coverage of Home Artificial Nutrition have been calculated and provide evidence of variable shortfalls as indicated in Section 8 of this report. This is particularly important because we recognise the reality of a shortfall in data collection for a number of reasons. The BANS committee is striving to maximise the potential of BANS data but will continue to depend on the goodwill of almost 400 reporters across the UK. We look forward to the introduction of electronic reporting (*e-BANS*) in 2007.

Dr Barry Jones  
Chair of the BANS committee, August, 2006

## Section 2

### Executive summary of BANS data, 2005

- Once again, reporters have been busy providing evidence of ever more activity across the UK. This brief document gives an overview of the latest information from data collected from 2005. We are not planning to produce a full printed report this year, but instead will place this year's analysis of the data on the BAPEN website. This will allow us more time to concentrate on developing and introducing electronic reporting (e-BANS) which is taking longer than we hoped. It will also permit quicker and easier access for all to BANS data.
- We are repeating the catheter sepsis data questionnaire in a revised form in conjunction with NNNG and will present this at a later date.
- With regard to the coverage of the UK, we have obtained independent data from the major commercial enteral and parenteral homecare companies to whom we are very grateful. This has allowed us to estimate the total number of HETF and HPN adults and children in the UK. There is clearly a variable shortfall in the accrual of complete data by BANS.
- We hope that the introduction of e-BANS in 2007 will make it easier for reporters both to report new and follow up data, but also to access their own data at any time. It is essential for this aspect of BANS activity that BANS obtains the support of Section 60 of the Health and Social Care Act, 2001 via PIAG, the Patients' Information Advisory Group. At the time of writing our application for Section 60 support is being considered by PIAG. We will publicise the result of this consultation on the BAPEN website and through "In Touch".

### Adult HETF

- New registrations (5978, up 5.7% from 2004) show a reversal of the downward trend from 2001 (7187 in 280 centres) compared to 5656 in 252 centres in 2004. Centres have stabilised at 257.
- However, point prevalence is up from 16890 in 2003 to 18260 in 2004 and 18686 in 2005 with period prevalence up from 21028 to 21677 to 23095.

Centres reporting point prevalence data were up from 311 in 2000 to 333 in 2005 and for period prevalence from 319 to 340. This would suggest that there has been no attrition of reporting centres and that the decline in new registrations since 2001 has stopped whilst established patients are surviving long enough to contribute to a rise in point prevalence of 2.3% and period prevalence of 6.5%.

- Period prevalence per million population continues to rise (England 384; Scotland 371; N Ireland 465; Wales 386/million). These are minimum estimates – see [Independent data](#) below
- In the youngest age group of 16 – 20 years, there were 131(2.2%) new registrations, and 866 (4.6%) established patients.
- CNS diagnoses account for 52.8%, GI for 24.1% and Respiratory for only 1.6% of new cases. Cerebrovascular accident was the single most common diagnosis (26% of patients) followed by neoplasia of all types at 33% (31.3% in 2004), with head and neck cancers accounting for 14% of all new HETF patients.
- The reason given for HETF was “swallowing disorders” in 68% and “to improve nutritional status” in 23.7%.
- Full activity was noted in 26.8% and limited activity in 32.8% new cases whereas 26.7% were bedbound and 13.2% housebound. 33(0.6%) new cases and 138(0.7%) established cases were unconscious which raises ethical questions as to the futility of their treatment.
- Total help was required in 50.6% of new cases but 29.3% were fully independent. 63.4% live in their own home with 34.2% in a nursing or residential home. There was little change in established patients.
- The route of enteral access was gastrostomy in 81.2% and nasogastric tube in 13% of new cases with 84.6% and 12% for established patients.
- There has been no change in new case involvement with a homecare company (new 81.2%; point prevalence 75.2%).
- The contribution of dementia to HETF figures is discussed in Section 10 and below.

## Paediatric HETF

- New registrations (950) have remained static, but point prevalence (4861) and period prevalence (5644) have increased by 4.3 & 4.4% respectively.
- Numbers of reporting centres are similar to those in 2004 (new: 136 to 143; point prevalence 229 to 230; period prevalence 236 to 241). This would suggest a continuing rise in overall numbers of patients and numbers per centre.
- CNS conditions account for 36.3% of new cases, GI for 14.6% and Respiratory for 4.9%.

- New registrations <1 year old have risen progressively from 220 in 2000 to 367 in 2005. The predominant age group in point prevalence remains 6 – 9 years.
- At the upper end of the age range, 8.7% of new registrations and 14% of point prevalence were aged 13 – 15 years and many of these are likely to transfer to adult care. Although 38.6% of new registrations were under 1 year of age, only 3.9% of point prevalence is accounted for by this age group.
- Full activity was achieved for 44% new cases and 50.4 % had limited activity.
- Children were cared for in their own homes in 97.5% of new cases and 93.5% of point prevalence cases.
- The route of enteral access was by gastrostomy in 34.3% of new cases compared to 53.9% of established ones (point prevalence) whereas nasogastric feeding accounted for 64.6% of new cases versus 45.5% established.
- A homecare company was involved in 84.7% of new cases but only 71.6% of established patients. There has been a gradual increase since 2002 when 81.4% new and 63.7% of established children received support from homecare companies.

## Adult HPN

- New registrations, at 112, have recovered from the low of 79 recorded in 2004. Point (636) and period prevalence (667) have continued to follow the rising trend noted in previous years.
- Reporting centres for new cases have fallen from 34 in 2002 to 25 but those for point and period prevalence have remained constant at 55 and 63.
- Overall UK period prevalence per million population continues to rise (11.1/million) as a result of rising period prevalence in England but not the remaining 3 countries. (England 11.1; Scotland 14.6; N Ireland 5.4; Wales 5.4. These are minimum estimates – see [Independent data](#) below.
- The age distribution of new cases has not changed significantly. In the age group of 16 -20 years, there has been no increase at 4.5%. It is not known how many of these have transferred from paediatric to adult care (see below Transition from childhood to adult HANS).
- GI diagnoses account for 80.4% new cases and CNS only 3.8%. New cancer cases fell from 14% in 2004 to 11.7% in 2005. For the first time, Crohn's disease is no longer the most common diagnosis in new registrants although absolute numbers grow. Small bowel infarction accounts for 21.4% compared to Crohn's at 17%, motility disorders (6.3%), scleroderma (6.3%) and radiation (1.8%).



- Indications for HPN were fistula (8.9%), obstruction (13.4%), malabsorption (16%) and short bowel syndrome (44%).
- Full activity was noted in 54% and limited activity in 38%. New patients were independent in 56% cases but totally dependent cases rose from 18% in 2004 to 33%.
- Almost all live in their own home (93%) but 2.7% resided in a nursing home.
- An external section catheter was used in 96%.
- A homecare company was involved in 97% of new cases and 84% of established cases.

## Paediatric HPN

- New registrations (25), point prevalence (96) and period prevalence (111) have continued to rise. Those for point (96) and period prevalence (111) are the highest recorded.
- Reporting centres for new cases which had have fallen from 12 in 2001 to 7 in 2004 have stabilised at 10.
- Age distribution demonstrates some dramatic changes. From 2001 to 2005, new cases age 0-1 year rose from 15.4 to 60%; 1-2 years fell from 89 to 12%; 3-5 years fell from 15.4 to 12%; 6-9 years fell from 23 to 8%; 10-12 years no registrations; 13-15 years fell from 15.4 to 8%.
- The majority of new cases had GI diagnoses (76%) but a lower proportion than in 2004 (89%). A slight increase in other diagnostic groups accounts for this but there is no clear trend.
- Short bowel syndrome accounted for 40% of new cases, malabsorption 28%, failure to thrive 12% and improvement in nutrition 16%.
- No children were bed bound or house bound with 81% having normal activity or 19% limited activity. In established children this changed to 69% full normal activity and 25% with limited activity.
- Only 12% of new cases had a subcutaneous port, the remaining all having an external section.
- A homecare company was involved in 92% of new cases but as in previous years, we have noted an inexplicable fall to 60.4% in established patients.

## Independent data

- Anonymised data from the major commercial homecare companies indicates that BANS data falls short of complete capture of all patients on HAN in the UK.
- The shortfall varies for point prevalence of each modality (Adult HPN 18%; Paediatric HPN 39%; Adult HETF 29%; Paediatric HETF 65%).
- Using correction factors calculated from this data, we estimate that total point prevalences in the UK (point prevalence /million population in brackets) are: Adult HPN 735 (12.3); Paediatric HPN 134 (2.2); Adult HETF 24129 (403); Paediatric HETF 11753 (196).
- Thus there are an estimated 36751(614/million) adults and children receiving artificial nutritional support in the community.

## Dementia and HETF

- Artificial nutritional support of patients with dementia is controversial and the ethical deliberations required before offering such support continue to exercise the minds of all those involved in decision making on a daily basis.
- Recent publications have cautioned against feeding those with advanced dementia but BANS data indicates a continuing rise in numbers being fed by PEG and NG tube from 2000 – 2004. In 2005, there was a decline in numbers for the first time. Nevertheless, there were still 571 patients being fed at the end of 2005.
- These were characterised by total dependency and nursing home placement in the majority of cases.
- We do not have any information on cognitive function or the ability to give informed consent in this group of patients but by inference from the dependency data, it seems likely that cognitive decline was advanced. Clinicians are therefore providing HETF to many patients with advanced dementia (who lack the capacity to provide informed consent) “in the patient’s best interests”. It is difficult to discern what outcomes justify such decisions. The quality of life experienced by these patients must call into question such decisions to treat. Further studies are required.

## Transition from childhood to adult HANS

- The transition from care in a children's centre to an adult centre can be traumatic and difficult for all concerned. BANS has attempted to estimate the number of children moving from age group 13 – 15 (i.e. up to 16<sup>th</sup> birthday) to 16 – 19 (i.e. up to 20<sup>th</sup> birthday) years of age on the adult registers for HETF and HPN.

### *HETF*

- In the 13-15 group there were 866 children and in the 16-19 group there were 679.
- Cerebral palsy was the most common diagnosis (13-15 years: 26.2%; 16-20 years: 32.3%).
- The average duration of HETF in children aged 16-19 years exceeded 4 years. Most of this group had therefore transferred from the younger age group.

### *HPN*

- For HPN, there were 17 children aged 13-15 years and 16 aged 16-20years.
- In the older group, the average duration of HPN exceeded 4 years for most diagnoses.
- The numbers involved are therefore small, even allowing for a shortfall in reporting of 39% (see above). Nevertheless, this group of children represent an enormous investment of time and effort by their paediatric centres.
- Many of these children may require small bowel transplantation in the future and they require the highest standards of care possible. To achieve this requires formal arrangements for transition to late juvenile and adult care in selected centres.

Dr Barry JM Jones  
Chair of BANS, August, 2006

## Section 3

### Abbreviations and Definitions of Terms

#### *Abbreviations*

BANS	British Artificial Nutrition Survey
BAPEN	British Association for Parenteral and Enteral Nutrition
CHC	Commercial Homecare Company
ETF	Enteral Tube Feeding
GI	Gastrointestinal
HANS	Home Artificial Nutrition Support
HETF	Home Enteral Tube Feeding
HPN	Home Parenteral Nutrition
NNNG	National Nurse Nutrition Group
NST	Nutrition Support Team
PN	Parenteral Nutrition
Pt Prev	Point prevalence
Prd prev	Period prevalence

#### *Definitions*

New registrations:

This is the number of new registrations in the given period of 1 year.

Point prevalence (pt prev):

This is the number of patients registered with BANS who were on artificial nutritional support at the specified census point in time (i.e. last day of year).

Period prevalence (prd prev):

This is the total number of patients registered with BANS who were on artificial nutritional support over the specified period of time (i.e. over a year).

Outcome

This is the status of the patient 1 year after commencing nutritional support.

Children

Data is presented on children up to 16 years of age.

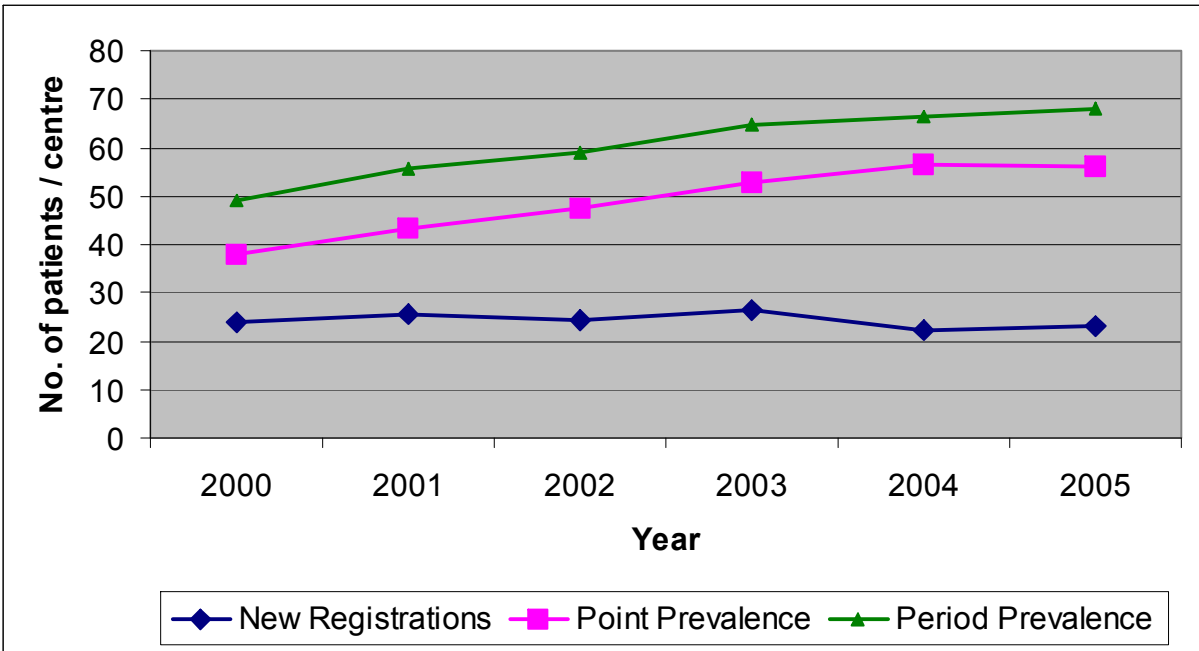
## Section 4

### Home Enteral Tube Feeding (HETF) in Adults

#### *New registrations, point and period prevalence*

There continues to be steady growth in the number of registered adult patients on HETF. In 2005, the number of patients that received HETF during the year was 28095 (period prevalence) and the number receiving it at the end of the year was 18686 (point prevalence). This represents 2.3% growth in point prevalence and 6.5% growth in period prevalence since 2004 (Table 4.1). The number of new patients registered with BANS in 2005 increased by 5.7% to 5978, but the numbers of new patients registered per reporting centre has remained fairly constant since 2000, while both point and period prevalence per centre continue to increase (Figure 4.1).

**Figure 4.1: Adult HETF - Number of new registrations, point prevalence and period prevalence per centre, 2000 to 2005**



**Table 4.1: Adult HETF – New registrations, point and period prevalence of adults receiving HETF (number of reporting centres in brackets)**

	2000	2001	2002	2003	2004	2005
<b>New registrations</b>	6629 (275)	7187 (280)	6428 (264)	6585 (251)	5656 (252)	5978 (257)
<b>Point prevalence</b>	11817 (311)	13742 (318)	15148 (319)	16890 (319)	18260 (323)	18686 (333)
<b>Period prevalence</b>	15652 (319)	18376 (331)	19474 (331)	21028 (325)	21677 (327)	23095 (340)

**Home enteral tube feeding according to country within UK**

More than 80% of new patients registered with BANS in 2005 lived in England (5978 [83%])(Table 4.2). The proportion of patients from each constituent country (England, Scotland, N. Ireland, Wales) has remained similar since 2000 (figures for point prevalence 83%, 8%, 4% and 5% of the total respectively). There are considerable variations in new, point and period prevalence expressed per million of the population between the home countries of the UK (Table 4.3).

**Table 4.2: Adult HETF patients registered with BANS according to country in 2005**

Country	New registrations n (% of total)	Point prevalence n (% of total)	Period prevalence n (% of total)
<b>England</b>	4970 (83.1)	15552 (83.2)	19240 (83.3)
<b>Scotland</b>	485 (8.1)	1563 (8.4)	1888 (8.2)
<b>N. Ireland</b>	233 (4.0)	687 (3.7)	795 (3.4)
<b>Wales</b>	281 (4.7)	862 (4.6)	1141 (5.0)
<b>Isle of Man</b>	9 (0.1)	22 (0.1)	31 (0.1)

**Table 4.3: HETF cases /million population total population of constituent nations of UK for adults\***

	New	Point prevalence	Period prevalence
<b>England</b>	99	310	384
<b>Scotland</b>	96	308	371
<b>N. Ireland</b>	136	402	465
<b>Wales</b>	95	291	386

\* using population statistics from mid-year population estimates, 2004: Office for National Statistics, General Register Office for Scotland and Northern Ireland Statistics and Research Agency.

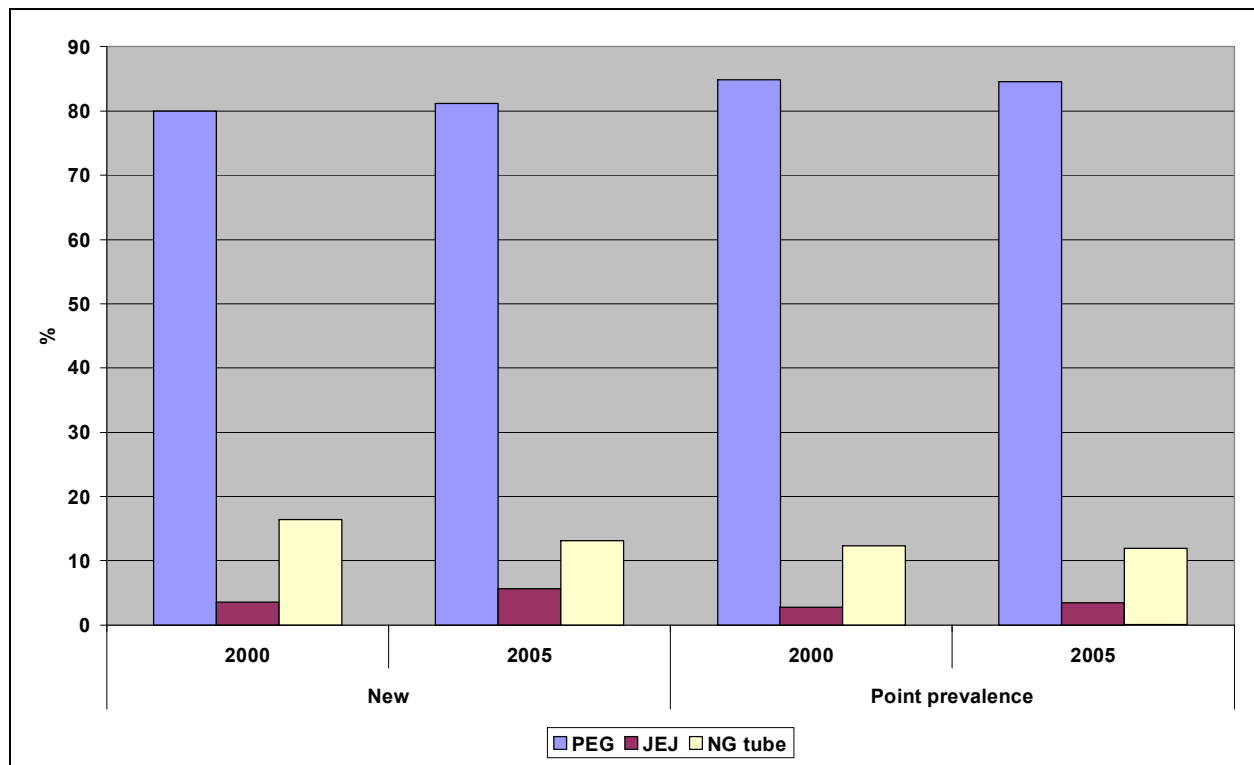
### **Diagnoses and indications for adult HETF**

For adults on HETF registered with BANS at the end of 2005 (point prevalence), as in previous years, the main reason for feeding was a swallowing disorder (68% of patients, n 12666). Diseases of the nervous system accounted for 53% of new registrations with disorders of the gut, 24%. Cerebrovascular accident was the single most common diagnosis (26% of patients) followed by neoplasia of all types at 33%, with head and neck cancers accounting for 14% of all new HETF patients.

### **Enteral access route for adult HETF**

Gastrostomy feeding continues to be the most common route of access in adult patients (85%; n 15803) with only 12% fed via nasogastric tube (n 2221) and 3% by jejunostomy (n 662). Table 4.2 shows the trend from 2000 to 2005.

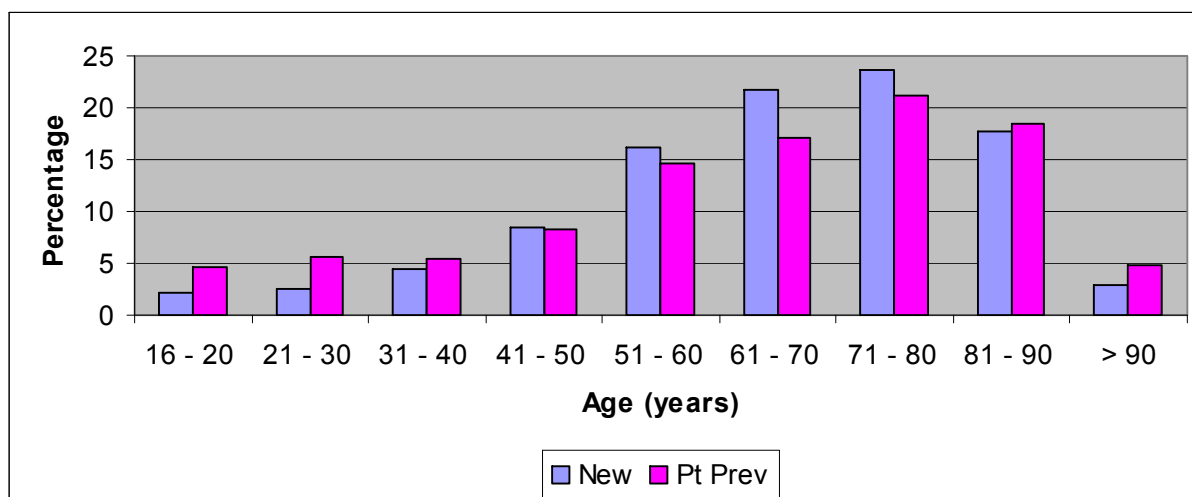
**Figure 4.2 Access routes for HETF, 2000 and 2005**



### **Age, activity levels and quality of life in adults receiving HETF**

As reported previously, the adults receiving HETF continue to be an increasingly elderly and disabled patient group. In 2005, of the patients registered with BANS (new and point prevalence), >65% were aged 60 years and over, and around 45% were aged 70 years and over as can be seen in Figure 4.3.

**Figure 4.3: Adult HETF: Age distribution of new registrations and adults receiving HETF at the end of 2005**



Activity also continued to be limited in this patient group with 27% of new patients being bedbound, 46% housebound or have limited activity, and only 27% of patients have full normal activity (Table 4.4).

**Table 4.4 Level of activity of HETF patients on HETF, 2000 and 2005**

	New		Point prevalence	
	2000	2005	2000	2005
<b>Normal activity</b>	17.2	26.8	16	21.2
<b>Limited activity</b>	30.1	32.8	31.4	32.7
<b>Housebound</b>	19.4	13.2	22	16.5
<b>Bedbound</b>	30.4	26.7	28.5	28.7
<b>Unconscious</b>	0.6	0.6	1	0.7

Similarly the ability to manage HETF continued to be limited for the majority of patients as in previous years, with 74% of patients requiring total help or some help to manage (total help n 10488 (56% of total), some help n 3258 (17% of total)). Despite this level of disability, most patients (58%) live at home and ~35% in nursing or residential homes. It remains unclear who provides the support that many of these patients need in the home setting.

#### **Outcome of adults one year after commencing HETF**

The status after 1 year of 33568 patients registered with BANS who had been discharged home on enteral tube feeding was as follows: 47% continued with HETF, 37% had died, 15% had returned to oral feeding, 0.6% were in hospital and feeding had been withdrawn or refused in 0.8%.



### ***Use of commercial home delivery companies for adult HETF***

Most new registrants in 2005 (82%) received the services of a commercial home care delivery company, although fewer established patients received such support (point prevalence 75%). The trend towards commercial homecare supply for new patients from 2000 to 2005 (74 v 82%) will take time to affect the lower figures for established patients (60 v 75%).

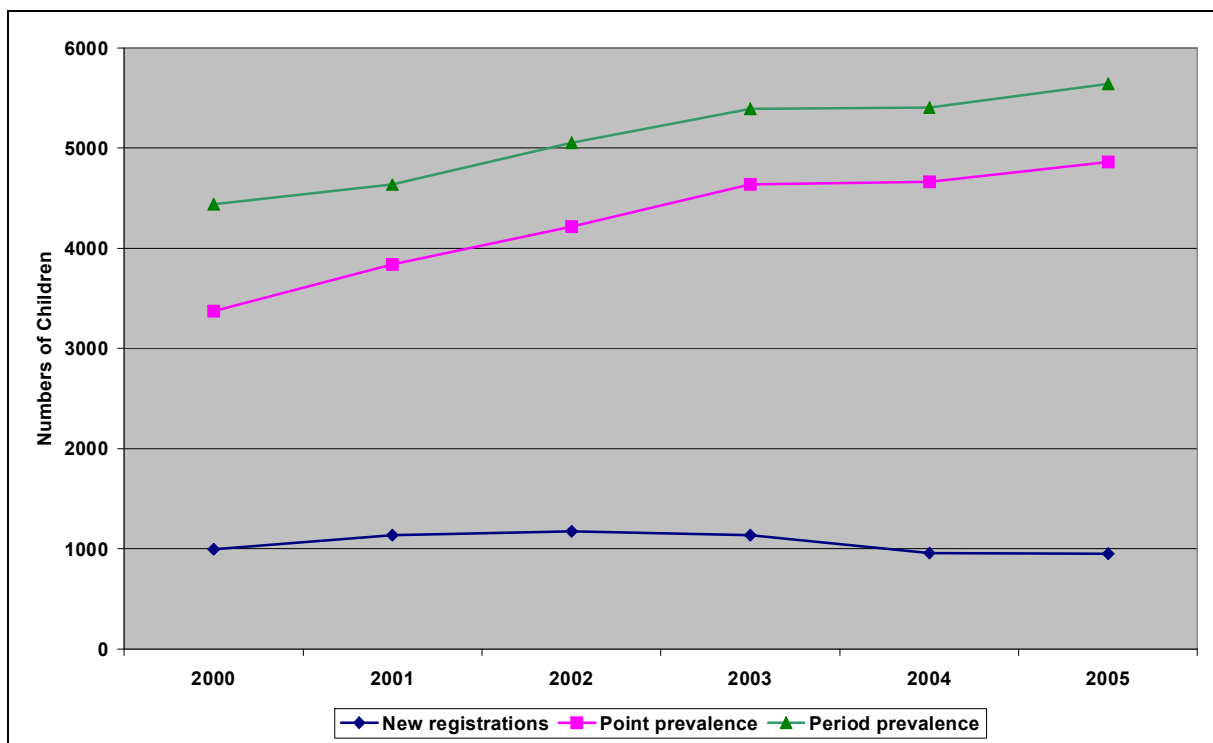
## Section 5

### Home enteral tube feeding (HETF) in children

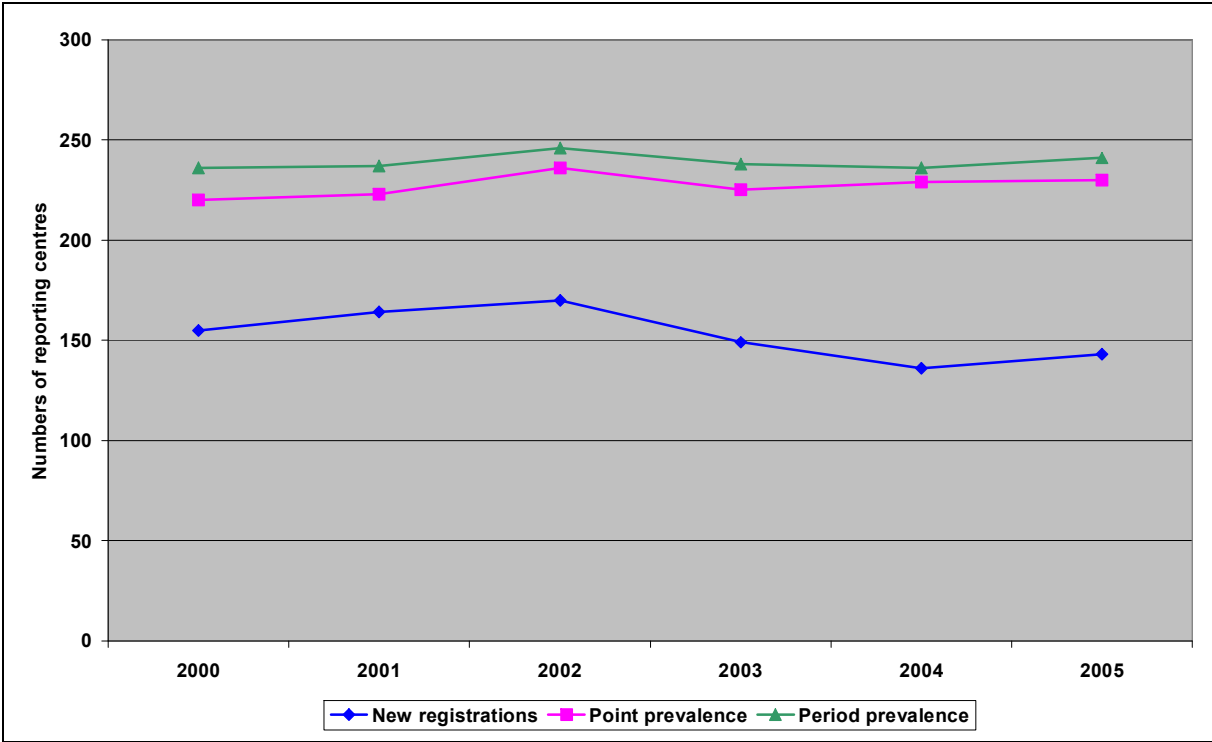
#### *New registrations, point and period prevalences of HETF in children*

New registrations (950) have remained static, but point prevalence (4861) and period prevalence (5644) have increased by 4.3 & 4.4% respectively (Figure 5.1). Numbers of reporting centres since are similar to those in 2004 (new 136 to 143; point prevalence 229 to 230; period prevalence 236 to 241) (Figure 5.2). This would suggest a continuing rise in overall numbers of patients and numbers per centre.

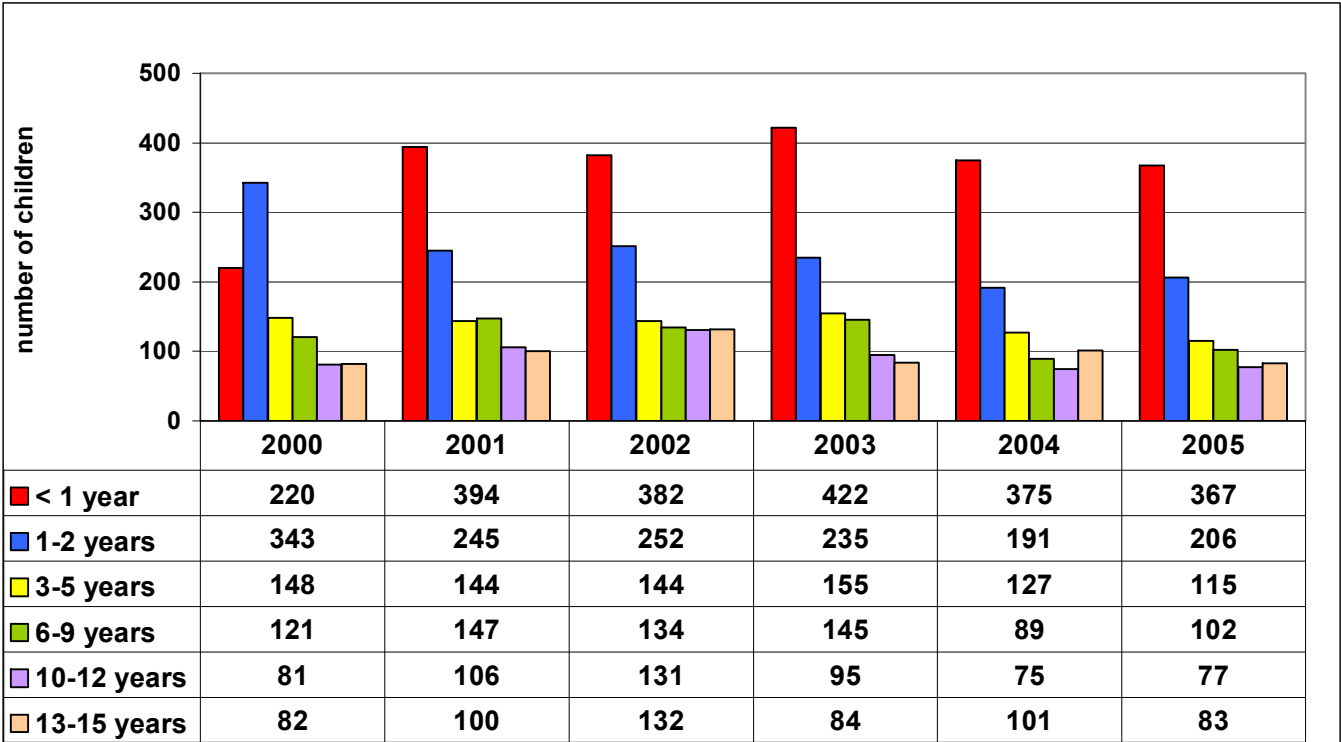
**Figure 5.1** *New registrations, point and period prevalences of children receiving HETF, 2000 – 2005*



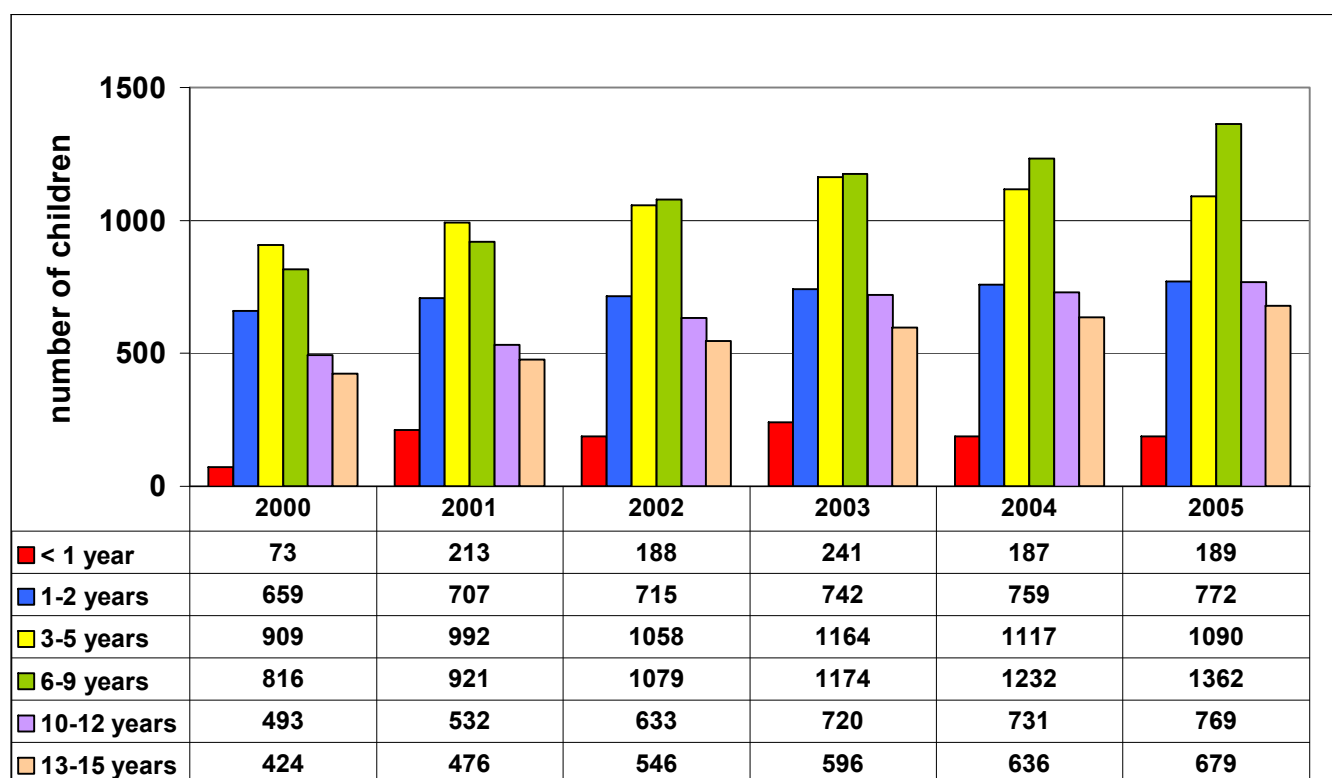
**Figure 5.2 Numbers of reporting centres for children receiving HETF, 2000 – 2005**



**Figure 5.3 Age bands of newly registered children on HETF**



**Figure 5.4 Age bands of children on HETF – point prevalence**



**Diagnoses, age, location, activity levels and commercial homecare company support**

CNS conditions account for 36.3% of new cases, GI for 14.6% and Respiratory for 4.9%. Age distribution has not changed significantly but 8.7% of new registrations and 14% of point prevalence are aged 13 – 15 years and many of these are likely to transfer to adult care. Although 38.6% of new registrations were under 1 year of age, only 3.9% of point prevalence is accounted for by this age group (Figures 5.3 & 5.4).

Full activity was reported in 44% new cases and 50.4 % had limited activity. Children were cared for in their own homes in 97.5% of new cases and 93.5% of point prevalence cases.

The route of enteral access was by gastrostomy in 34.3% of new cases compared to 53.9% of established ones (point prevalence) whereas nasogastric feeding accounted for 64.6% of new cases versus 45.5% established.

A homecare company was involved in 84.7% of new cases but only 71.6% of established patients. There has been a gradual increase since 2002 when 81.4% new and 63.7% of established children received support from homecare companies.

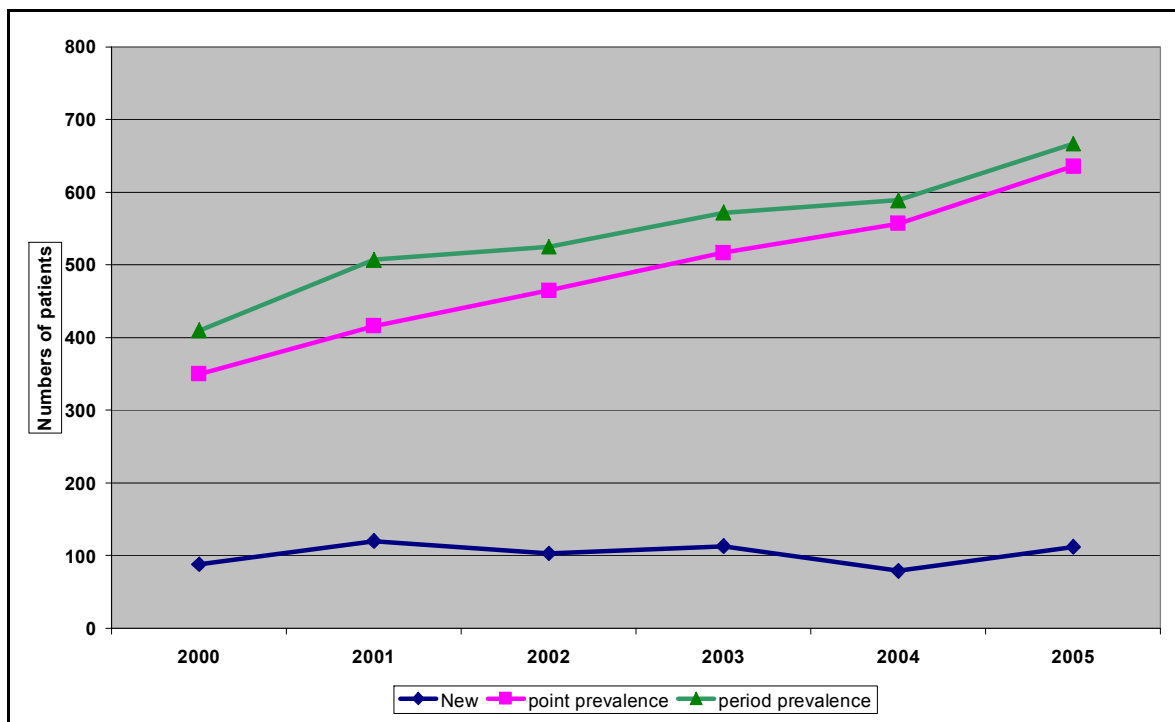
## Section 6

### Adult Home Parenteral Nutrition (HPN)

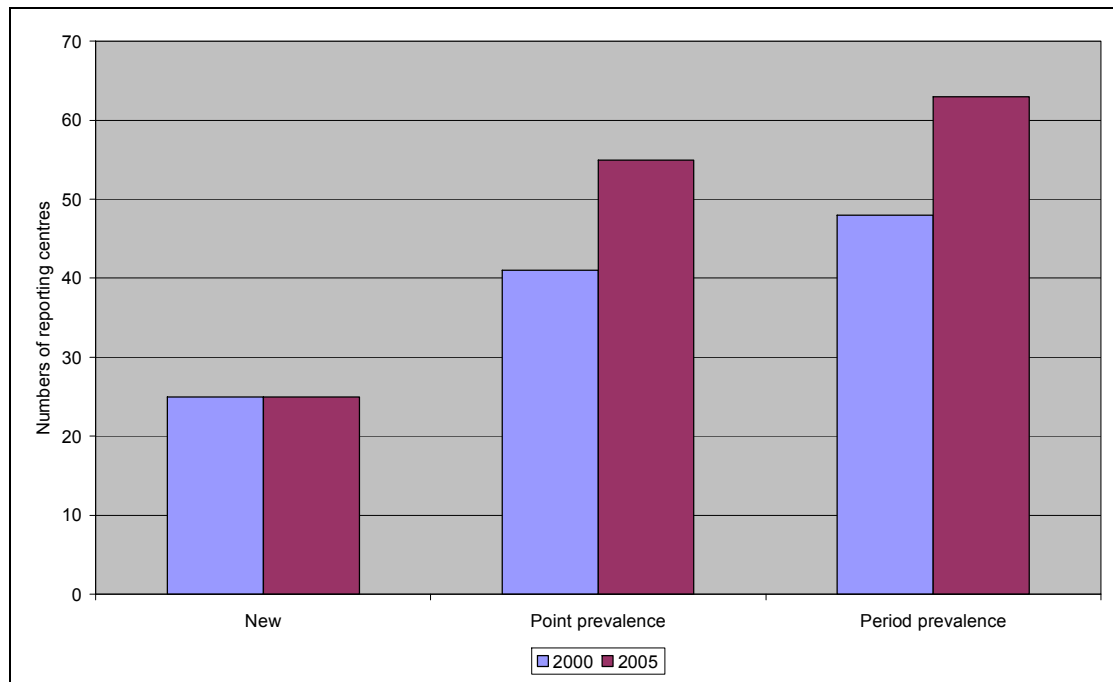
#### *New registrations, point and period prevalence*

In the UK as a whole, new registrations(112) increased from the low recorded in 2004 (79). Point (636) and period prevalence (667) have continued to follow the rising trend noted in previous years (Figure 6.1). Reporting centres for new cases have fallen from 34 in 2002 to 25 but those for point and period prevalence have remained constant at 55 and 63 (Figure 6.2).

**Figure 6.1** Number of new registrations, point prevalence and period prevalence of HPN, 2000 – 2005



**Figure 6.2 Numbers of adult HPN reporting centres in UK for new registrations, point prevalence and period prevalence, 2000 and 2005.**



### ***Distribution and trends of HPN patients according to country within the UK***

Period prevalence in England continues to rise but in the remaining 3 countries, no significant changes are noted over the last 6 years. The delivery of HPN in Scotland is provided through a managed clinical network founded in 2000. In Wales, a similar network is being implemented. In Northern Ireland, most HPN patients are primarily cared for in 1 major centre. In England, there were 22 centres registering new patients but 50 reporting established patients.

Prevalence per million population is shown in Table 6.1 and should be compared with figures from the 2003 data report. Overall, there has been an increase in the prevalence of HPN throughout the UK. The steady figures in Scotland suggest that a steady state has been reached there but not in the rest of the UK which still has some way to go before attaining the same level of service as Scotland. Under reporting in Scotland is unlikely as the Managed Clinical Network collects data on all HPN patients but in remainder of UK, particularly England, there remain some concerns regarding the completeness of reporting. This point is discussed further in Section 8.

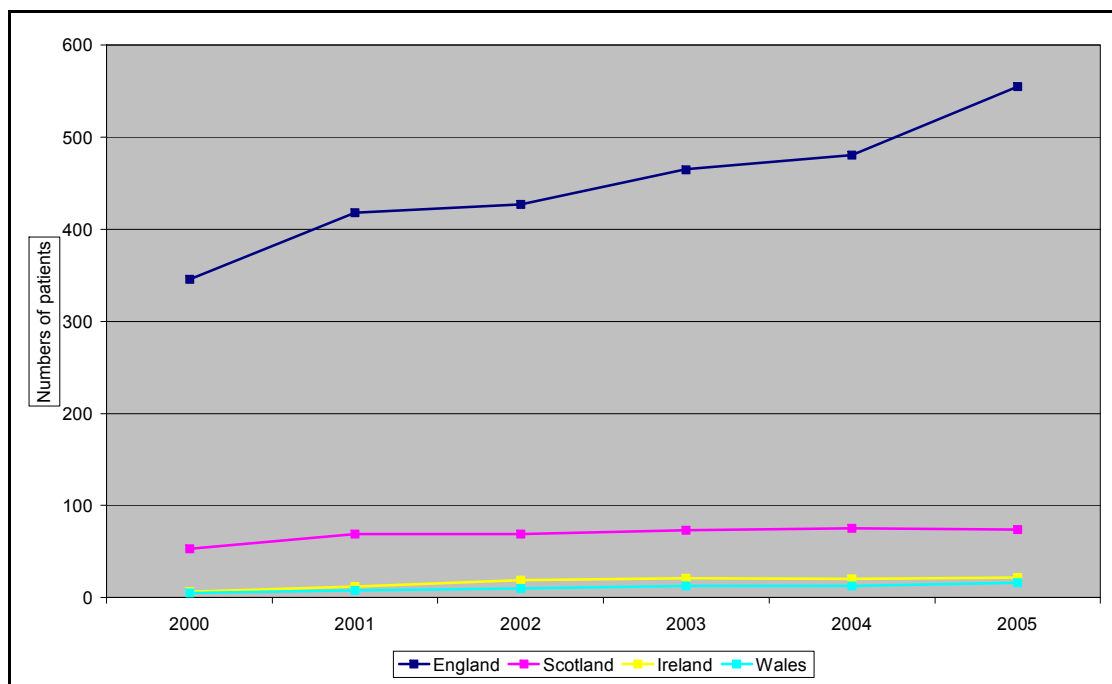
**Table 6.1 Prevalence per million population\* in UK and home countries (2003 data in brackets\*\*)**

	New	Point prevalence	Period prevalence
England	2.0 (2)	10.6 (8.6)	11.1 (9.5)
Scotland	2.0 (2.3)	14.2 (12.9)	14.6 (14.3)
N. Ireland	0.6 (1.2)	12.3 (9.5)	12.9 (12.5)
Wales	1.0 (1.4)	4.4 (4.5)	5.4 (4.5)

\*Sources: Mid-year population estimates, 2004: Office for National Statistics, General Register Office for Scotland and Northern Ireland Statistics and Research Agency.

\*\* 2001 census data

**Figure 6.3 Period prevalence of Adult HPN in constituent countries of UK, 2000 – 2005**

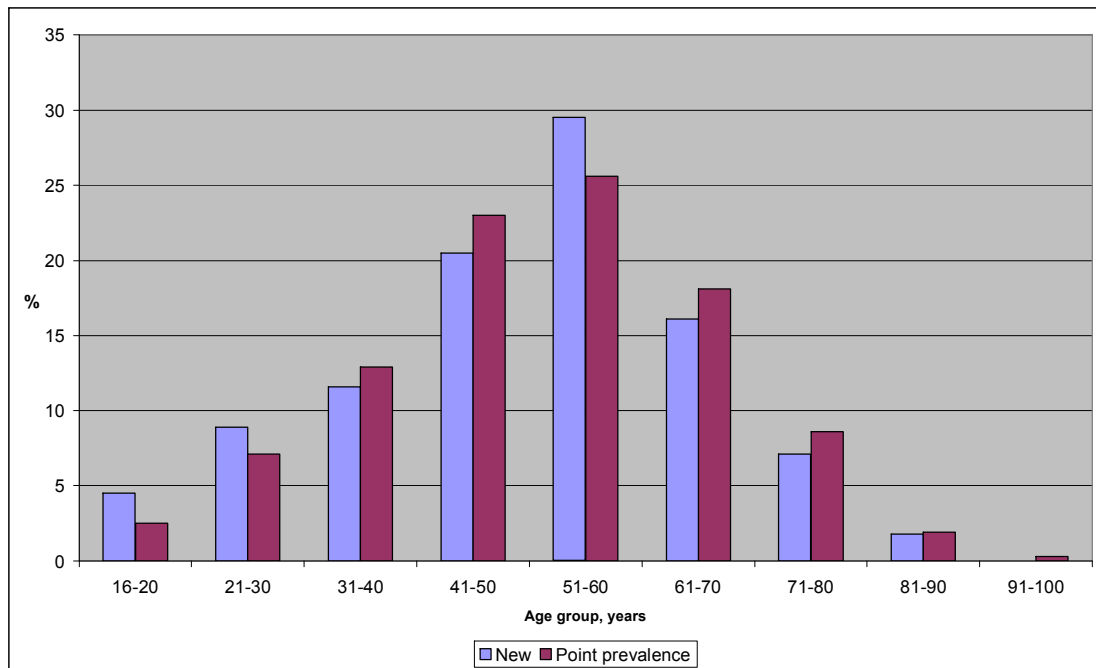


### **Characteristics of Adult HPN patients in UK, 2005**

#### **Age distribution**

The age distribution of new cases and established patients is shown in Figure 6.4. There has been little change in age distribution over last 5 years. In the age group of 16 -20 years, there has been no increase at 4.5%. It is not known how many of these have transferred from paediatric to adult care. At the other end of the spectrum, there are a surprising number of over seventies. It is not known how many of these die from their underlying disease, or an unrelated disease or how many are unable to continue their HPN due to old age. As HPN patients survive into old age, difficult ethical questions may arise although these have not yet been widely discussed.

**Figure 6.4 Age distribution of Adult HPN in UK for new registrations and point prevalence, 2005**



### **Diagnoses and Reasons for feeding**

As shown in Figure 6.2, GI diagnoses account for 80.4% new cases and CNS only 3.8%. New cancer cases fell from 14% in 2004 to 11.7% in 2005. New registrations for small bowel infarction account for 21.4% compared to Crohn's at 17%, motility disorders (6.3%), scleroderma (6.3%) and radiation (1.8%). Crohn's disease is no longer the most common diagnosis in new registrants but remains the most common indication in established patients (27.5% in 2005). However, Absolute numbers of Crohn's patients on HPN continue to rise (Figure 6.5 and Table 6.3). Indications for HPN (new registrations) were fistula (8.9%), obstruction (13.4%), malabsorption (16%) and short bowel syndrome (44%).

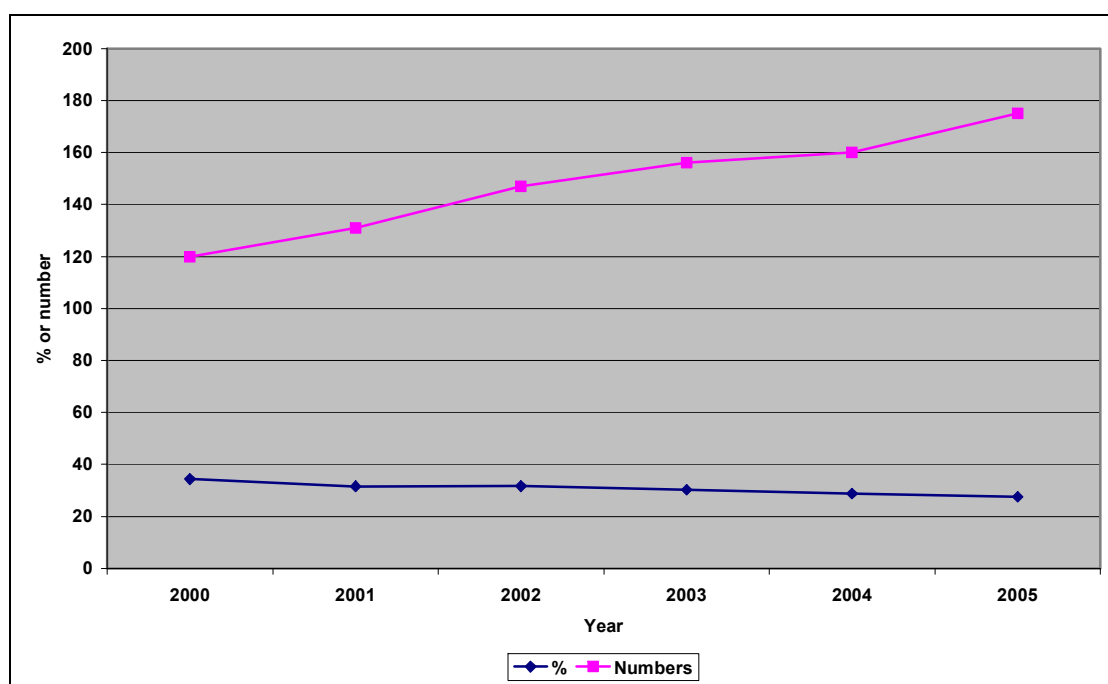
**Table 6.2 Diagnostic categories of Adult HPN, 2000 and 2005**

	New registrations		Point prevalence	
	2000	2005	2000	2005
Crohn's	25	17	34.3	27.5
Ulcerative colitis	3.4	0.9	2.3	2.8
Ischaemia*	14.8	21.4	17.7	19.2
Radiation enteritis	5.7	1.8	5.1	3.5
Pseudo-obstruction	4.5	6.3	9.1	10.4
Systemic Sclerosis	3.4	6.3	2.9	3.3
Cancer**	16.8	11.7	5.8	6.7

\*Small bowel infarction due to arterial or venous thrombosis or volvulus. \*\*Includes cancer of oesophagus, stomach, small bowel, pancreas, colon, head and neck, lymphoma and leukaemia



**Figure 6.5 Crohn's disease trend in percentage contribution to total HPN point prevalence and absolute numbers, 2000 – 2005**



**Table 6.3 Crohn's disease 2000 – 2005**

Year	2000	2001	2002	2003	2004	2005
%	34.3	31.5	31.6	30.2	28.7	27.5
Numbers	120	131	147	156	160	175

### **Location, Ability to Manage and Activity level**

Full activity was noted in 54% and limited activity in 38%. New patients were independent in 56% cases but totally dependent cases rose from 18% in 2004 to 33%. Almost all live in their own home (93%) but 2.7% resided in a nursing home.

### **Access route and Administration of HPN**

An external section catheter was used in 96% and a homecare company was involved in 97% of new cases and 84% of established cases.

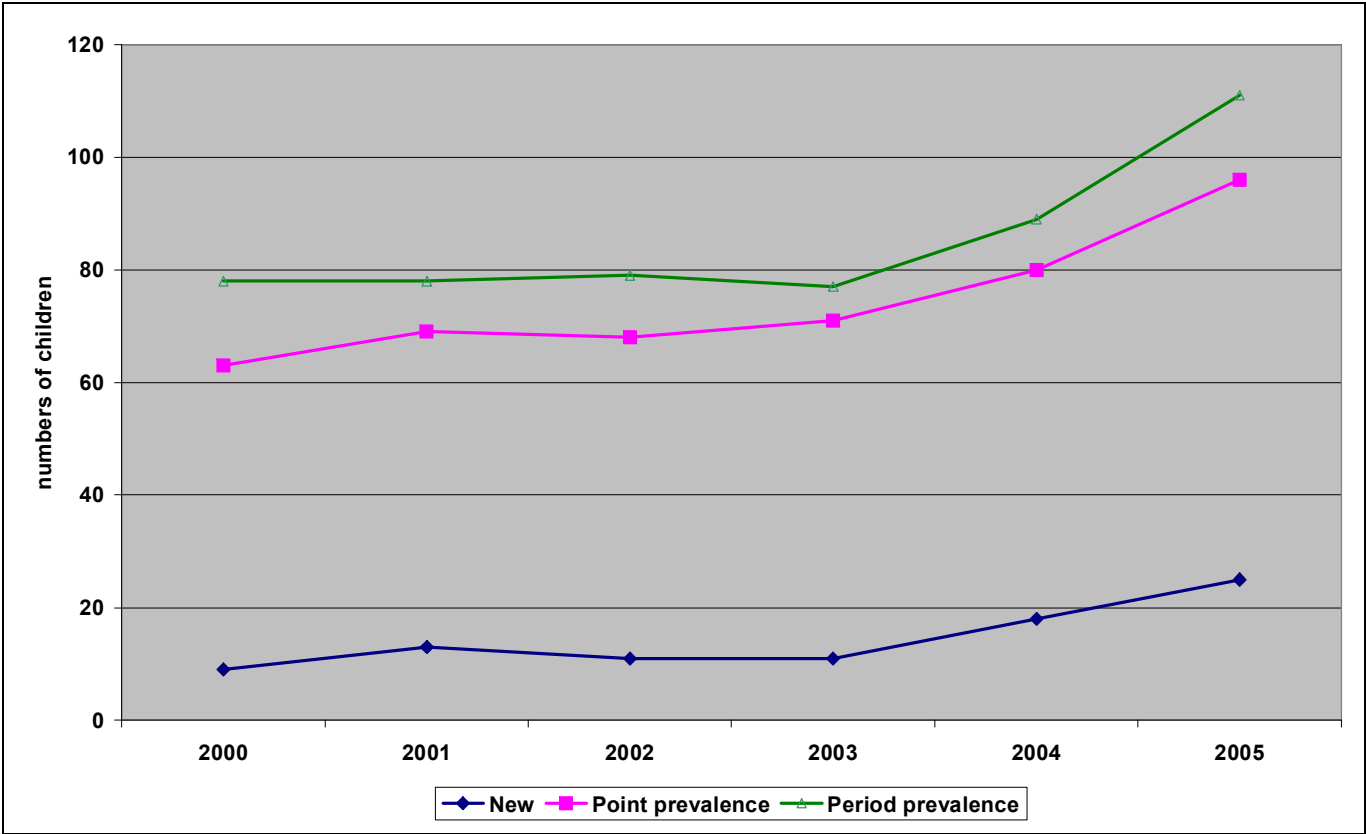
# Section 7

## Home parenteral nutrition (HPN) in children

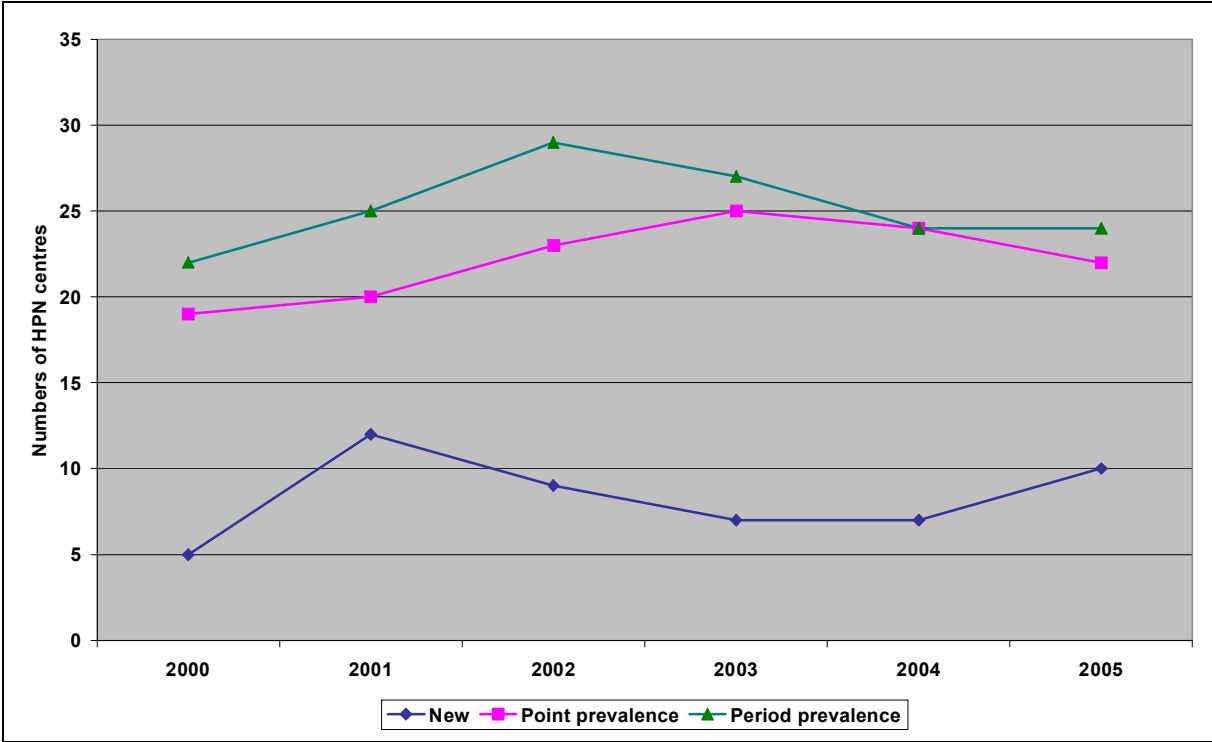
### *New registrations, point and period prevalences of HPN in children*

New registrations (25), point prevalence (96) and period prevalence (111) have continued to rise (Figure 7.1). Those for point (96) and period prevalence(111) are the highest recorded. Reporting centres for new cases which had have fallen from 12 in 2001 to 7 in 2004 have stabilised at 10 (Figure 7.2).

**Figure 7.1** *New registrations, point and period prevalences of children receiving HPN, 2000 - 2005*



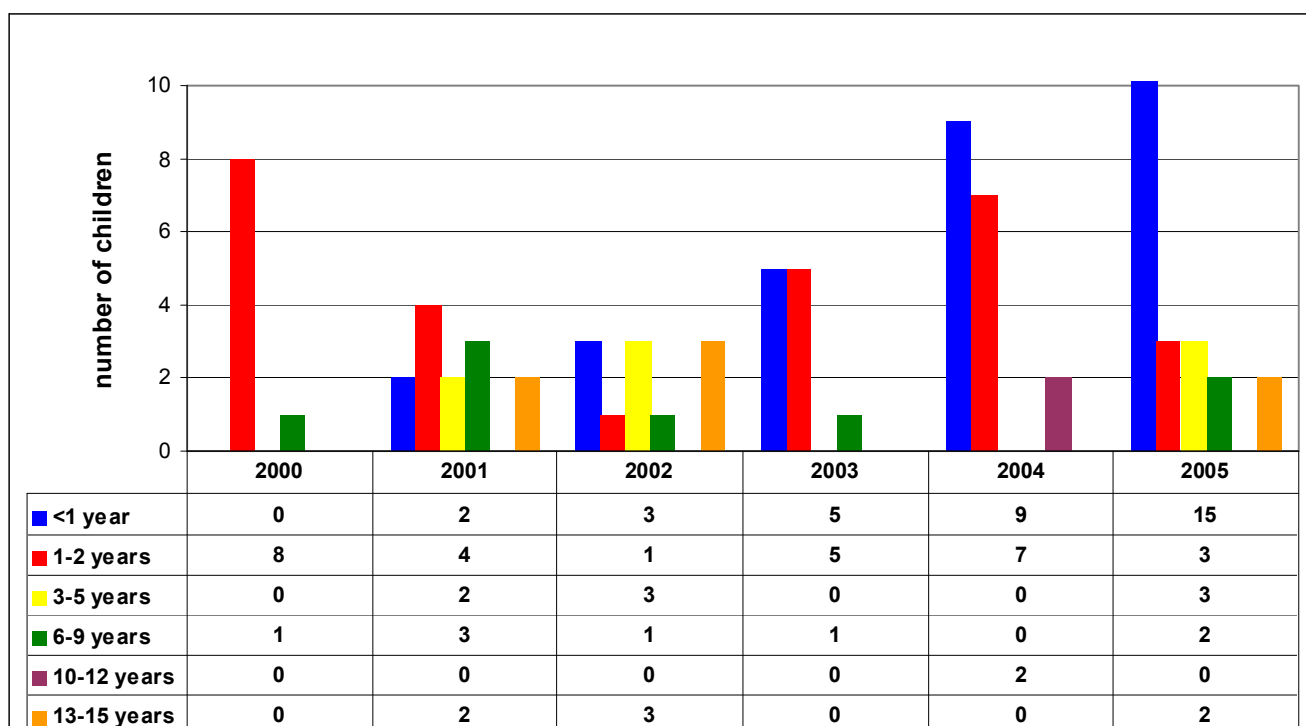
**Figure 7.2 Numbers of reporting centres for HPN for children, 2000 – 2005**



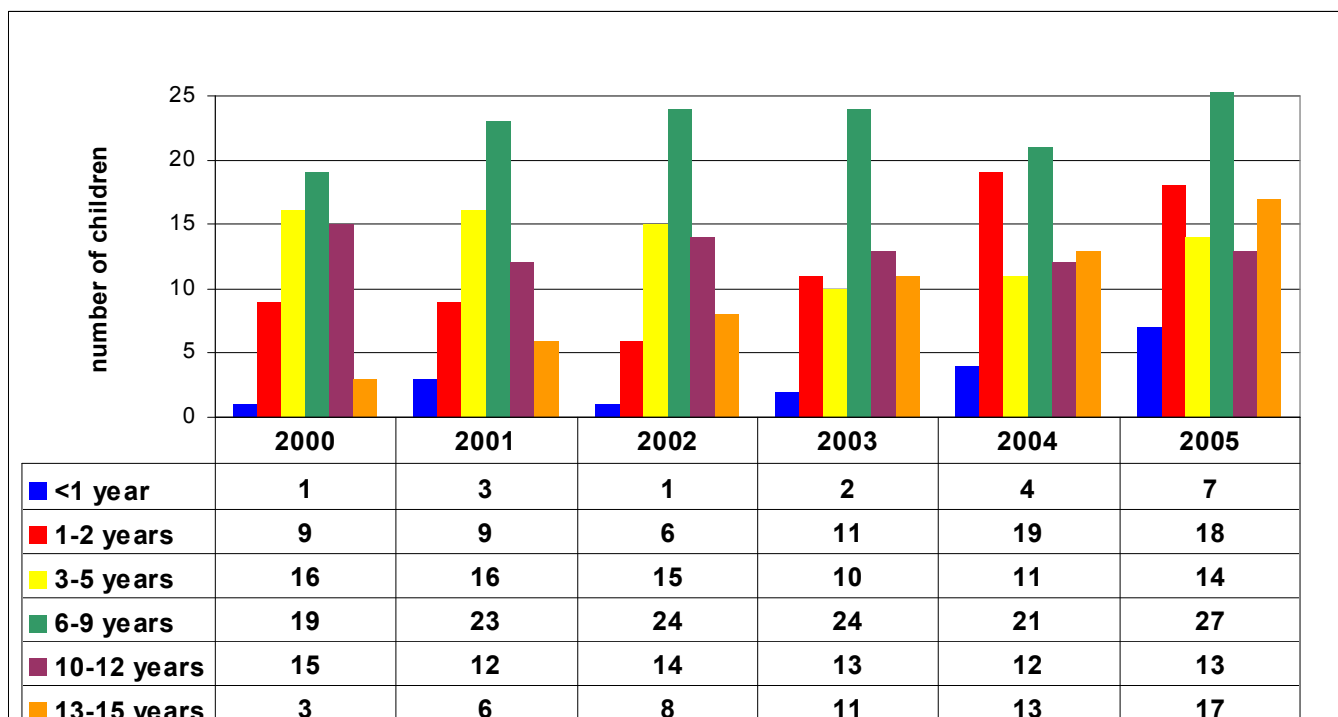
**Age distribution**

Age distribution demonstrates some dramatic changes. From 2001 to 2005, new cases age 0-1 year rose from 15.4 to 60%; 1-2 years fell from 89 to 12%; 3 -5 years fell from 15.4 to 12%; 6 -9 years fell from 23 to 8%; 10 – 12 years no registrations; 13 -15 years fell from 15.4 to 8% (Figures 7.3 & 7.4).

**Figure 7.3 Age bands – New registrations of HPN in children, 2000 - 2005**



**Figure 7.4 Age bands - Point prevalence of HPN in children, 2000 – 2005**



***Diagnoses, indications for HPN, location, activity levels and commercial homecare company support***

The majority of new cases had GI diagnoses (76%) but a lower proportion than in 2004 (89%). Slight increase in other diagnostic groups account for this but there is no clear trend.

Short bowel syndrome accounted for 40% of new cases, malabsorption 28%, failure to thrive 12% and improvement in nutrition 16%.

No children were bed bound or house bound with 81% having normal activity or 19% limited activity. In established children this changed to 69% full normal activity and 25% with limited activity.

Only 12% of new cases had a subcutaneous port, the remaining all having an external section.

A homecare company was involved in 92% of new cases but as in previous years, we have noted an inexplicable fall to 60.4% in established patients.

## Section 8

### Independently acquired data from Commercial Homecare Companies (CHCs)

In 2005, the BANS committee asked all major commercial homecare companies to provide their own data on children and adults receiving HETF or HPN on a particular day, i.e. point prevalence. The data was pooled and provided to BANS in an aggregated form (Table 8.1) to ensure company confidentiality was maintained.

BANS routinely collects data on the proportion of HETF and HPN patients receiving their nutritional supplies from a commercial homecare company (Table 8.2). We have therefore been able to compare our own data with that of the CHCs to corroborate the degree to which BANS coverage of home nutritional support applies across the UK (Table 8.1). BANS has always striven to achieve 100% coverage but we have acknowledged that this has become increasingly difficult in recent years for a variety of reasons.

It can be seen from Table 8.1 (rows 1 and 4) that there is a shortfall in reporting to BANS which is in the region of 29% for adult HETF, 65% for paediatric HETF, 18% for adult HETF and 39% for paediatric HPN. This represents a major challenge for BANS. However by using the CHC data, the total number of patients receiving Home Artificial Nutritional Support (HANS) can be estimated (row 5 v row 2).

Despite the shortfalls identified in row 6, BANS remains the only comprehensive source of audit data on HANS in the UK. The shortfall for HPN identified with the aid of the commercial homecare companies is less than that in 1999 when Pharmaceutical Advisers to Health Authorities were asked to provide similar data (BANS annual report, 1999). Although a population of only 17 million was represented by the advisers, a 33% shortfall in reporting was identified in 1999, compared to only 18% in the present study.

It is hoped that the introduction of “e-BANS”, an electronic reporting system, and Section 60 support for BANS through PIAG (Patients’ Information Advisory Group) will encourage more reporters to contribute in future.

**Table 8.1 Point prevalence of UK patients receiving nutritional supplies from Home care companies (CHC) – Data from CHCs February 2006 compared to BANS data for 31<sup>st</sup> December 2005\***

	HETF (adjusted for CHC coverage)		HPN(adjusted for CHC coverage)	
	ADULT	PAED	ADULT	PAED
<b>1. Totals supplied by CHC companies</b>	18145	7 099	621	96
<b>2. BANS 2005 total Pt prevalence</b>	18686	4861	636	96
<b>3. % CHC – BANS Pt prevalence, 2005</b>	75.2%	60.4%	84.4%	71.6%
<b>4. CHC numbers known to BANS, 2005</b>	14052	2936	537	69
<b>5. Estimated point prevalence, 2005</b>	24129	11753	735	134
<b>6. Estimated % shortfall</b>	29%	65%	18%	39%

\* The data shown in Table 8.1 does not include any from Northern Ireland where HAN is provided from NHS sources.

**Table 8.2 Use of Commercial Homecare Companies - BANS data, 2005**

	<b>New %</b>	<b>Point prevalence %</b>
<b>Adult HETF</b>	81.8	75.2
<b>Paed HETF</b>	92	60.4
<b>Adult HPN</b>	97.3	84.4
<b>Paed HPN</b>	84.7	71.6

## Section 9

### Transition from childhood to adult care

#### *Introduction*

The transition from care in a children's centre to an adult centre can be traumatic and difficult for all concerned. Children with chronic illnesses requiring nutritional support are surviving long enough to reach adulthood and require transfer to adult care which is best organised by an interdisciplinary team.

There are few formal arrangements for such transition. BANS has attempted to estimate the number of children moving from age group 13 – 15 to 16 – 19 years on the adult register for both HETF and HPN. All data relates to point prevalence in 2005. BANS has not yet analysed the data to determine the exact numbers transferring from the 13-15 group to the 16-20 year old group but deductions can be made from the average length of feeding in the 16-20 year old group.

#### *Enteral Feeding*

BANS reviewed data of children aged 13-15 and adult patients aged 16 – 20 years old. There were 866 children in the 13-15 year age group and 679 in the 16-20 year group. The age distribution of children has not changed significantly, but 8.7% of new registrations and 14% of point prevalence are aged 13 – 15 years. Figures detailed below represent the percentage of patients receiving home enteral nutrition by diagnosis, and the average days on tube feeding. (Figures 9.1 & 9.2).

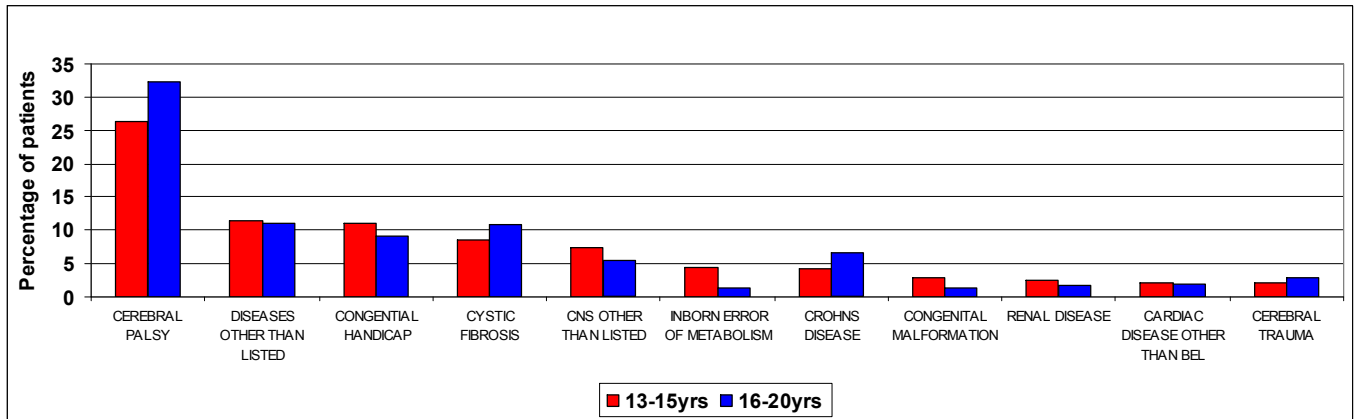
The main diagnostic categories that feature in both children (13-15 years) and adults (16-20 years) are detailed in Figure 9.1. They include patients with chronic illnesses who will require long term feeding, for example, disease of inborn errors of metabolism, renal disease, diseases of central nervous system and cystic fibrosis. Most of these children have complex needs requiring the expertise of interdisciplinary teams in both the paediatric and adult centres. Cerebral palsy features as the commonest diagnosis for both 13-15 year olds (26.2%) and 16-20 year olds (32.3%).

The average duration of feeding for 13-15 year olds is compared to 16 – 20 year olds in Figure 9.2. The average duration of feeding days for renal disease (13-15yrs) is 7.9 years and (16-20 yrs) 5.8 years; inborn errors of metabolism (13-15yrs) 8 years and (16-20yrs) 6.9 yrs; central nervous system, cerebral palsy (13 – 15yrs) 6 years and (16-20 yrs) 5.5 years; cerebral trauma (13-15 yrs) 5.3 years and (16-20yrs) 4.6 years. The average duration of HETF in the 16-20 group exceeds the 4 year span in this group thereby indicating that many had transferred from the 13 -15 group.

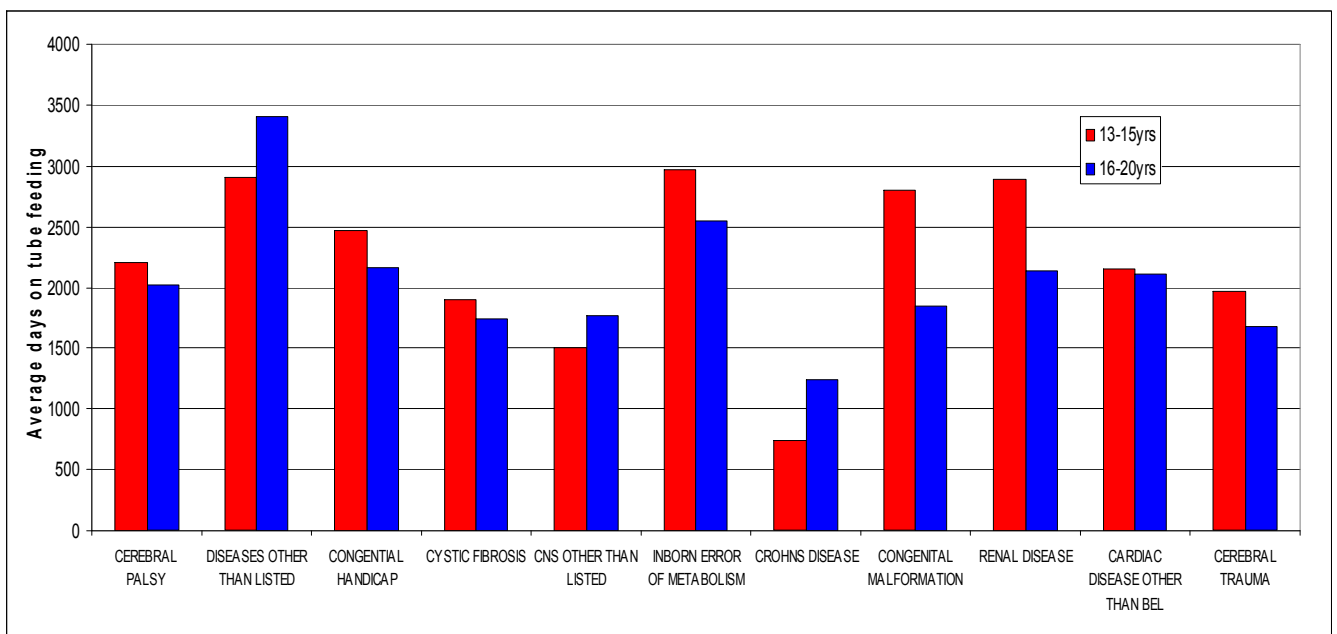
The life expectancy for children with chronic illnesses continues to increase, thus their need for ongoing nutritional therapy into adulthood is deemed essential. Considering what the patients and parents want from transitional service and how this provision can be made remains a challenge for both children and adult centres. Adequate resources for the management of transfer to adult care are essential to ensure quality of care.



**Figure 9.1 Percentage of patients receiving home enteral nutrition by age group (13-15yrs & 16-20yrs) and diagnosis**



**Figure 9.2 Average days on feeding by age group for patients receiving home enteral nutrition**

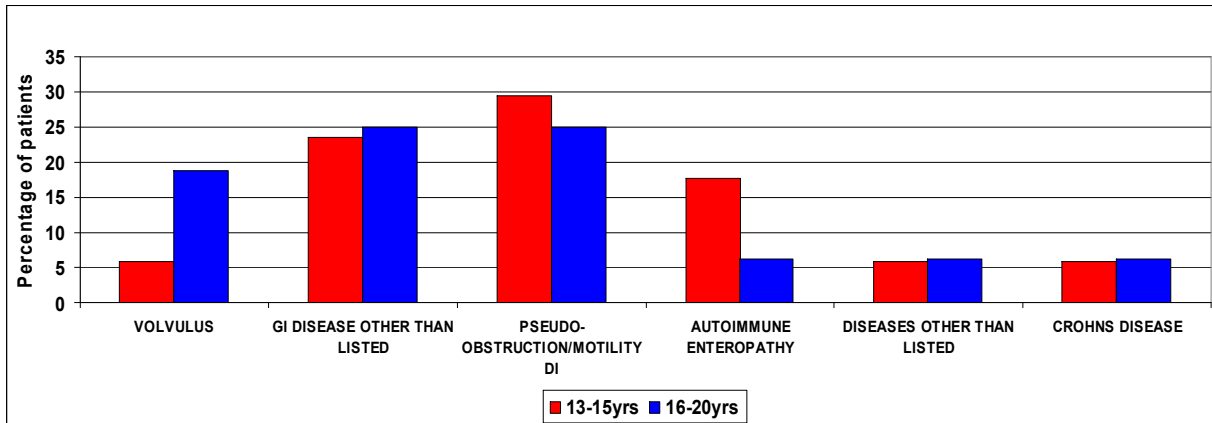


### Home Parenteral Nutrition

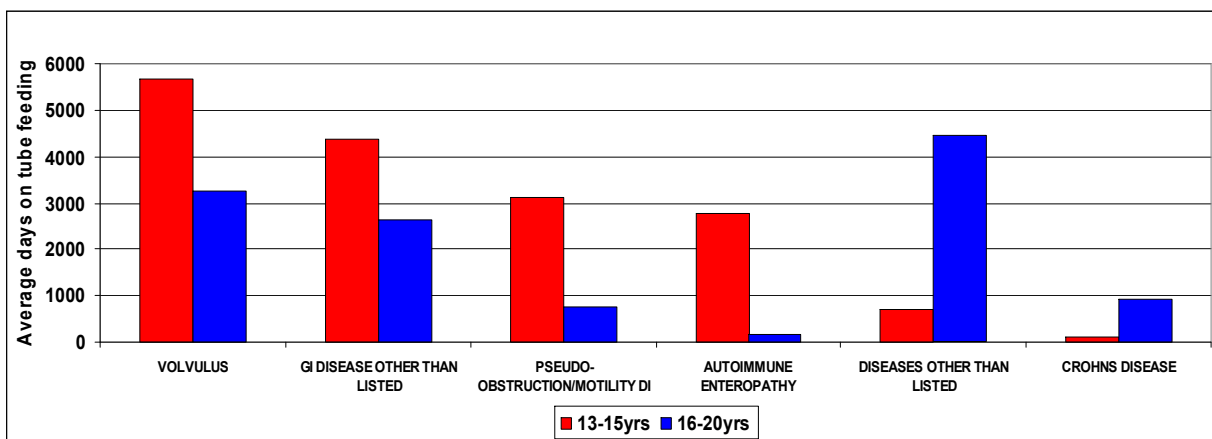
Seventeen 13-15 year olds, (seven females and ten males) and sixteen 16-20 year olds (nine females and seven males) were identified when reviewing the transitional data. Over 25% had a diagnosis of intermittent pseudo obstruction (Figure 9.3). The duration of feeding is indicated in Figure 9.4 and shows that most diagnoses in the 16-20 group were associated with greater than 4 years duration on HPN. It can therefore be deduced that most in the older group had received HPN before the age of 16.

Although the number of children surviving longer increases, there are few arrangements for transitional care. It is vital that clinics are geared to support the vulnerable age group of 13 – 16 year olds who will require transfer of services from the paediatric to adult care. A gradual transition rather than abrupt transfer is considered good practice.

**Figure 9.3 Percentage of patients receiving home parenteral nutrition by age group (13-15yrs & 16-20yrs) and diagnosis**



**Figure 9.4 Average days on feeding by age group for patients receiving home parenteral nutrition**



## Section 10

### HETF and dementia

#### Introduction

In the UK, chronic neurological diseases are the commonest indications for home enteral tube feeding (HETF). The majority receive HETF via a gastrostomy (PEG). Dementia is the most controversial indication for HETF. Consent for PEG insertion in dementia is often difficult or impossible and subject to ethical debate. Recent publications suggest that dementia is a poor indication for enteral nutrition, with no improvements in quality of life, aspiration pneumonia or survival (Finucane *et al*, 1999; Sanders *et al*, 2000 & 2004).

Using BANS data, we have looked at the incidence and prevalence of dementia as an indication for HETF in the UK. BANS does not collect data on the precise type of dementia, nor the cognitive functional level of such patients when starting HETF. BANS 2004 data on dementia with HETF was presented at the British Society of Gastroenterology meeting in Birmingham March 2006 (Jones BJM, 2006)

#### New registrations and prevalence of HETF and dementia

In 2005, of 5978 new HETF cases, 183(3.1%) had dementia and received HETF in 92 centres. In 2004, new registrations of patients with dementia on HETF were made by 107 centres and numbered 221/5656 (4%) of new HETF registrations. Point prevalence in 2005 was reported to be 571/1868 (3.1%) by 160 centres and period prevalence was 726/23095 (3.1%) in 178 centres.

In 2004, point prevalence was 592/18260 (3.2%) in 167 centres and period prevalence was 735/21677 (3.4%) in 181 centres (Table 10.1). Table 10.1 indicates that overall numbers of new patients have fallen in the last 2 years. The number of established patients was rising year on year from 341 in 2000 to 592 in 2004 but fell to 571 in 2005. The upward trend from 2000 has halted or reversed in 2005 which may indicate that clinicians are beginning to heed current advice to avoid HETF in dementia.

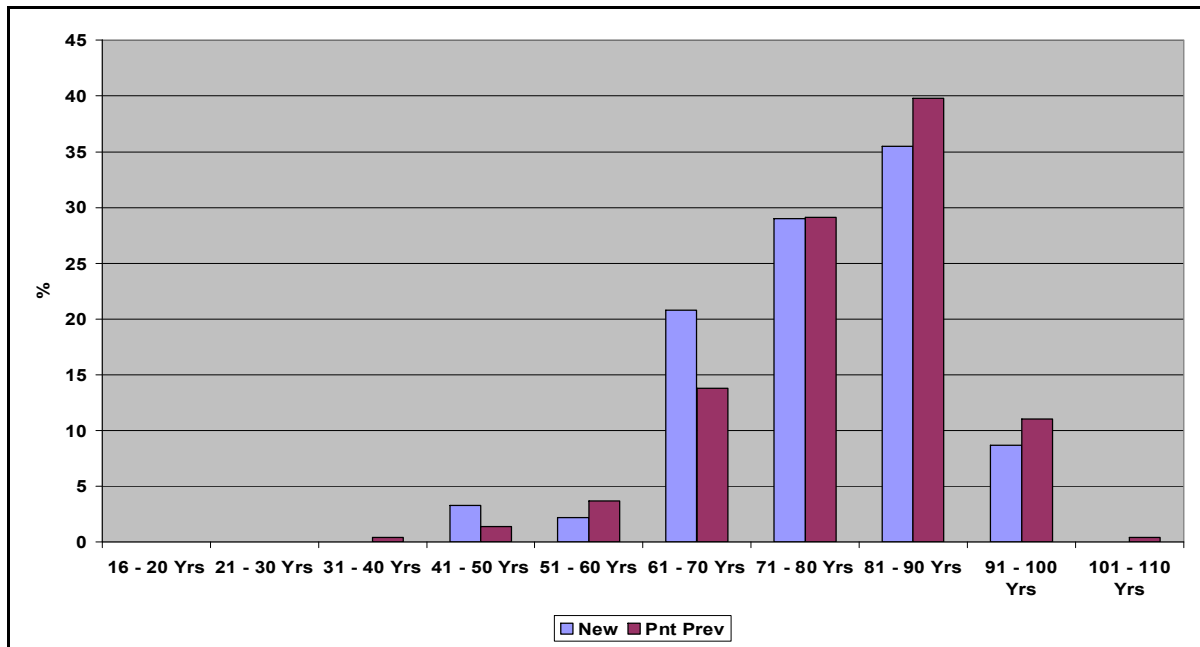
**Table 10.1 Numbers of new registrations and point prevalence of dementia and HETF, 2000 – 2005**

	2000	2001	2002	2003	2004	2005
New	260	280	254	254	221	183
Point prevalence	341	426	483	547	592	571
Period prevalence	No data?	No data?	No data?	No data?	735	726

### **Age distribution of dementia and HETF**

The predominant age of new patients was 71 – 90 years (74% of total with dementia) (Figure 10.1). There is no significant difference between new and established cases in any age band. This is in keeping with the short survival of patients with dementia on HETF.

**Figure 10.1 HETF and dementia in 2005 – age band distribution,**



### **Indications for HETF in dementia**

The main indications for HETF in dementia were "swallowing difficulty" in 63% and "to improve nutritional status" in 33% (Figure 10.2) yet current opinion suggests that nutritional status is not improved by HETF in dementia. We have no data to indicate what cognitive function remains at the time the decision is made to implement HETF but it is possible that there is dislocation between the decline of deglutition and cognitive function, particularly in multi infarct dementia. In such cases, some improvement in quality of life might be expected and some degree of patient autonomy may still exist. In this situation, some patients may still be able to give informed consent to insertion of a PEG or other access route.

### **Access route for HETF in dementia and commercial homecare company involvement**

In 2004, HETF was by gastrostomy (87%), nasogastric tube (12.5%) and jejunostomy (0.5%). Commercial homecare companies supplied equipment and feeds in 84% new cases.

### ***Location, dependency level and functional capacity***

Residence in a nursing home was recorded in 81% of cases in 2004 and 77% in 2005. with 15 % in their own home in 2004 and 20% in 2005. Only a few were able to maintain “normal activity” according to reporters, whereas 61% were bed bound and 19% housebound.

The ability to self care was very limited with almost all patients requiring total care and support, (98% in 2004 and 91% in 2005).

### ***Outcome of HETF and dementia***

Mortality one year after commencing HETF was at least 48% although under-reporting at follow up may have led to over recording of survival. From 2000 – 2005, BANS has records of 1078 dementia patients and 1 year mortality was at least 47.8%.

### ***Conclusions***

A substantial number of patients with dementia receive HETF in the UK, mostly by PEG. They are characterised by total dependency and nursing home placement in the majority of cases. There is little change in functional status following discharge and almost all require total support in the community whether in a nursing home or their own home. It is therefore possible that many of these patients should not have been offered enteral nutritional support but BANS can not provide objective data on this point except through the surrogates of poor functional capacity evidenced by dependency levels. We have also no data on quality of life but would presume that being bedbound and totally dependent does not represent good quality of life. It is possible that the advice to avoid HETF in dementia is now being heeded since BANS data for 2005 indicates a downturn in new and established cases.

Alternatively, it is also possible that HETF is being offered to earlier cases of dementia with some residual cognitive function and that the decision to provide HETF can not be avoided in these patients. Further research on this topic is clearly required in case the blanket advice in the recent literature prevents appropriate treatment in individual cases. We also have no data on whether nutritional status or clinical outcomes are improved by HETF.

Mortality has been recorded as extremely high in many studies of demented patients on HETF but BANS data may have underestimated mortality. If our data is correct, 50% of patients with dementia being fed in nursing homes may be suffering prolongation of their lives with no benefit to quality of life discernable by patient, family, carers or doctors.

BANS data provides no evidence in favour of HETF in dementia but the decision to offer HETF to individual patients should still be undertaken on an individual basis, particularly when patient autonomy can not be expressed. Good practice guidance is available from the BMA and GMC websites.

## Section 11

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