



B A P E N
Advancing Clinical Nutrition

Annual BANS Report, 2007[©]

**Artificial Nutrition Support in the UK
2000 - 2006**

**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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Previous BANS reports

BANS: Artificial nutrition support in the UK, 2005. (Published on BAPEN website in 2006): www.bapen.org.uk
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BANS: Trends in artificial nutrition support in the UK, 2000 – 2003.
ISBN: 1 899467 95 5 (Published 2005)

BANS: Trends in artificial Nutrition Support in the UK Between 1996 and 2002.
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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 During 1996 – 2000.
ISBN 1 899 467 505 (Published 2001)

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BAPEN STRATEGY – 2005 – 2015

Selected items relevant to BANS

THE VISION:

- To help ensure that those suffering from malnutrition or other nutritional problems are appropriately recognised and managed.
- That the recognition of BAPEN as a champion of excellence in nutritional care should greatly assist in this process.

AIMS:

- To encourage the development of an integrated approach to managed nutritional care.
- To improve the nutritional care of people at risk of malnutrition whether in hospitals or in the community.

OBJECTIVES:

1. To support individual patients and groups needing nutritional intervention

- 1.1 BAPEN will listen to patients' / carers' nutritional concerns and will act appropriately
- 1.2 BAPEN will lobby for patient centred policies relating to nutritional care
- 1.3 BAPEN will promote equity of access to nutritional care for all patients

2. To establish a sound basis to enable realisation of the above objectives.

- 2.1 BAPEN will initiate and maintain regular meetings with the relevant government departments, Royal Colleges, specialist societies, and other key stakeholders at national level

4. To develop a robust and cohesive approach to information gathering about nutrition provision at national level and to identify / redress any gaps

- 4.1 BAPEN will develop and seek sponsorship for the British Artificial Nutrition Survey (BANS)
- 4.2 BAPEN will support FOCUS initiatives targeted at identified areas of practice so that information can be collected and disseminated
- 4.3 BAPEN will produce regular reports and promote national standards of practice

6. To provide support for multi-professional / disciplinary groups wishing to develop a clinical Nutrition Support Team (NST)

- 6.2 BAPEN will report NST activity on an ad hoc basis through the BANS initiative
- 6.3 BAPEN will develop standards through which NSTs can identify good practice and benchmark their own activity
- 6.4 BAPEN will lead other clinical governance initiatives related to nutritional intervention

The full strategy document can be found on BAPEN website:
www.bapen.org.uk

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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 of previous reports can be obtained from the BAPEN office. In 2006, for the first time, we published the report based on 2004 & 2005 data electronically on the BAPEN website www.bapen.org.uk from which it can be downloaded without charge. This year, we have again published our annual report on the BAPEN website. We have also conducted 2 audits of in patient central venous catheter related sepsis. These will be reported elsewhere and in BAPEN's journal, In Touch.

BANS is registered through BAPEN under the Data Protection Act. To avoid duplication of reported patients, reporters are requested to supply only the patients' 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. In 2006, we actively sought 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 anonymised, pseudonymised or obtained with full consent of the patient or parent. BANS and its reporters are legally obliged to comply with this legislation. Following a hearing of our case by PIAG in September, 2006, we gained temporary support for continuation of data collection for 1 year. This was subject to BANS developing an alternative strategy which is centred around gaining informed consent from patients or parents, and assent from those able to represent those lacking mental capacity. The latter reflects the introduction of the Mental Capacity Act in 2007 in England and Wales. Following our resubmission to PIAG in September 2007, we have had a meeting in October 2007 with PIAG to discuss progress. We are now optimistic that we will be given further Section 60 support subject to resubmission to PIAG in December. The specially developed consent and information forms will be available on BAPEN website shortly.

The PIAG submission has run in parallel with our efforts to introduce electronic reporting through "e-BANS". This has been delayed but has undergone pilot studies in England and Scotland throughout the summer with a view to going "live" in January, 2008. BANS hopes that this development will make it easier for reporters to not only enter data, but to access their own data as and when they wish.

We have also obtained encouraging data through our links with parenteral and enteral homecare companies. They have again 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 9 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.

.....Which brings me to our reporters. 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 hope you agree that BANS has been a worthwhile endeavour. A job worth doing is worth doing well. I hope we can continue to count on you for continued support as we look forward to the introduction of electronic reporting (*e-BANS*) in early 2008.

Dr Barry Jones
Chair of the BANS committee, November, 2007

Section 2

Executive Summary, 2006 data

HETF –Adults

- Point prevalence rose by 4% to 19583 despite a fall in new registrations of 15%. The number of centres reporting new cases fell from 257 in 2005 to 216 in 2006, whereas period and point prevalence reporters were maintained (340 & 347). This disparity would not be explained by a general fall off in reporting numbers due to problems mentioned in the Preface.
- Patients/centre have stabilised with an average of 24 new per centre and 58 for point prevalence. The demand for HETF appears to be levelling off after many years of progressive growth except for the 11% rise in point prevalence in Northern Ireland.
- New registrations were 86/million population in UK as a whole with point prevalence 327/million and period prevalence 385/million. These represent the minimum numbers in the UK. For estimates allowing for non reporting, see Section 9.
- As in previous years, the majority of HETF patients are older people (60% >60 years of age, 20% >80) but 60% live in their own homes with ~40% in nursing homes. In the eldest patients (aged > 75 years), ~90% were bedbound, housebound or had limited activity. Total help with HETF was required by 72%. These figures indicate a very high dependency level which has implications for the provision of such care.
- Neurological disorders account for 50% of adult HETF with cerebrovascular disease the commonest diagnosis. Substantial numbers of patients with cerebral palsy or congenital conditions receive HETF as adults(see transition data below).
- Neurodegenerative disorders such as Huntingdon's chorea, multiple sclerosis, motor neurone disease, muscular dystrophy and Parkinson's disease represent 14.8% of point prevalence (2879).
- Dementia still accounted for 143 new cases and 573 established cases despite concerns over the appropriateness of HETF in such patients.
- Cancer diagnoses were present in 35% of new cases and 23% established patients. Both figures have been rising steadily since 2000 (26 & 15% respectively). Head and neck cancer is the commonest type of cancer receiving HETF.
- Outcomes 1 year after starting HETF reveal a high overall mortality of 36% with 15% returning to oral nutrition. For cancers, the figures are 40% and 28% respectively.
- Route of enteral access was gastrostomy in 84%, nasogastric tube in 12% and jejunostomy in 4%. Commercial homecare companies were involved in 80% of new cases and 76% of established patients as in previous years.

HETF – children

- Number of new registrations have fallen to their lowest ever at 772 compared to 1175 in 2002. Surprisingly, period and point prevalence figures are comparable to those in 2005.
- Reporting centres fell dramatically for new cases to 116 compared to 170 in 2002 but numbers reporting point and period prevalence remained stable.
- Respiratory and gastrointestinal diagnoses predominate but greater clarity of diagnosis will be achieved with restructuring of diagnostic lists with e-BANS.
- In the oldest age group of children, numbers continue to rise which has implications for transition to adult care. There were 710 established children in this age group.
- Outcome 1 year after starting HETF showed 71% continuing with HETF, 21% had returned to oral feeding and 6% had died due to underlying disease.

HPN – Adult

- The number of new registrations fell slightly to 100 but point and period prevalence continue to rise. There were 716 established patients on the census day and 746 in the whole year.
- The number of reporting centres fell for new cases but remained stable for established cases. We feel this indicates that new referrals for HPN are being discharged from fewer centres which accords with BAPEN's strategy of concentrating HPN in centres with adequate experience. However, the position of established patients still gives cause for concern as there are no less than 63 centres reporting during the year. Of these, 48 are in England.
- All 4 home countries recorded larger numbers of established patients in 2006.
- New cases occur with a frequency of 0.6 – 2.2 per million
- Established patients (point prevalence) varied from 6.1 in Wales to 16 in Scotland with a national UK average of 12 per million.
- Average UK period prevalence was 12.5 per million.
- The most dramatic increases have occurred in Wales and N Ireland.
- The proportion of new cases between 16 and 40 years is steady (2000: 27.2%; 2006: 27.8%). Patients in this age group may be the most appropriate to consider for small bowel transplantation.
- Crohns disease has re-established itself as the most frequent indication for HPN having been displaced in 2005 by bowel ischaemia. Absolute numbers of Crohns patients continue to rise (point prevalence 196)
- HPN patients were discharged to their own homes in 97% of cases. No help was required with their HPN on discharge in 57% rising to 70% in established cases.

- Parenteral access was via an external catheter in 97% on discharge but only 85% of established cases with subcutaneous ports becoming more popular.
- Commercial homecare companies were involved in 95% of new discharges but only 85% of established cases.
- Outcome 1 year after starting HPN was 64% still on HPN and 19% returned to oral nutrition. Mortality was 13%.

Postcode distribution of Adult HPN

- With the aid of NSCAG, variations in point prevalence per million population in England were calculated. The variation in point prevalence per million was 3.7 – 22.5 for old SHAs. This variation was only slightly less at 6.2 – 16.2 for the new larger SHAs. These figures greatly exceed the regional variations in the prevalence of the diagnoses of patients requiring HPN.
- BANS regards these figures as indicative of “post code treatment” and evidence of inequity of access to HPN.

HPN – children

- The number of new registrations is the lowest recorded since 2001. However, period and point prevalence figures remain stable.
- Reporting centres for new cases numbered only 3 whereas those for period and point prevalence remain steady at 22 & 23.
- These figures give cause for concern about the number of non-reporting paediatric centres in England whereas we believe data from Scotland is complete due to the activity of the Scottish Managed Clinical HPN Network.
- Amongst established children, the age group of 6 - 9 years was most prevalent but the contribution of 13 -15 year olds has increased over the period 2000 – 2006. There were 17 established children on HPN in this age group. This observation is relevant to planning for facilities for transition from childhood to adult HPN.
- Normal activity levels were recorded for 76% of new discharges with only 1 child bed bound.
- Parenteral access route was via an external catheter in 100% of new discharges but 92 % of established cases in whom 8% had a subcutaneous port.
- Commercial homecare companies were involved in 90% of new cases and 62% of established children.
- Outcome 1 year after starting HPN was 65% still requiring HPN, 19% returned to oral nutrition. Mortality was 15%.

Transition from childhood to adult HAN

- HETF - There were 671 children identified as having moved from the oldest paediatric age group to the youngest adult group. There were 321 girls and 350 boys. Cerebral palsy (32.4%); congenital handicap (10.13%); cystic fibrosis (9.68%) were the main diagnostic groupings. Crohns was the main gastrointestinal diagnosis.
- HPN – Only 14 children were identified to have transitioned to adult care. All had gastrointestinal causes. This group is associated with long term HPN support and some will become candidates for small bowel transplantation or bowel elongation procedures.

Independent data and BANS

- Once again, we have obtained confidential commercial information regarding total commercial homecare company experience in 2006. As in 2005; this data indicates significant shortfalls in the reporting of Home Artificial Nutrition in the UK with the exception of Scottish adult and paediatric HPN. The most significant shortfalls relate to paediatric reporting of HETF (55% shortfall) and HPN (33% shortfall).
- By comparison, adult HETF shortfall is estimated at 20% but HPN is only 5%. BANS data for adult HPN should therefore be regarded as almost complete. This is of vital importance in England where there is ongoing discussion of the provision of HPN services with the Department of Health.
- Using this data, we have estimated that the point prevalence of patients was as follows: Adult HETF 24551, Paediatric HETF 10978, Adult HPN 757 and Paediatric HPN 141. Thus a total of 35529 patients were receiving HETF at the end of 2006 and 898 were receiving HPN.

“e- BANS” – the future

- An electronic version of BANS is now almost ready to roll out to reporters after much hard work by the committee. The diagnostic categories have been changed to provide more precision and “granularity”. We will be distributing e-BANs with a new written version to start simultaneously to avoid collecting 2 differing sets of data. We hope all reporters will rapidly switch over to e-BANS.
- Each reporter will be able to see their own data and will receive email reminders of those patients requiring follow up data.

Dr Barry JM Jones, Chair BANS
October 2007

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
NSCAG	National Specialised Services Advisory Group
NST	Nutrition Support Team
PN	Parenteral Nutrition
Pt Prev	Point prevalence
Prd prev	Period prevalence
SHA	Strategic Health Authority

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 (2000-2006)

Dr Rebecca Stratton

New registrations, point and period prevalence

The number of adults receiving HETF and registered with BANS at the end of 2006 (point prevalence) was 19,583. This represents a growth of 4% since 2005. The period prevalence remains unchanged since last year (Table 4.1). The numbers of new registrations and centres reporting new registrations have dropped by around 15% (Table 4.1).

Table 4.1: Adult HETF in the UK - New registrations, point and period prevalence of adults receiving HETF (number of reporting centres in brackets) in 2006

	2000	2001	2002	2003	2004	2005	2006
New registrations	6629 (275)	7187 (280)	6428 (264)	6585 (251)	5656 (252)	5978 (257)	5145 (216)
Point prevalence	11817 (311)	13742 (318)	15148 (319)	16890 (319)	18260 (323)	18686 (333)	19583 (340)
Period prevalence	15652 (319)	18376 (331)	19474 (331)	21028 (325)	21677 (327)	23095 (340)	23088 (347)

Figure 4.1 highlights the slowing in growth of BANS registrations of home enteral tube feeding in adults over the past couple of years, with the data shown per reporting centre. Whilst the absolute numbers of registered patients and centres has fallen, perhaps due to reporting difficulties, the numbers per centre remains a valid assessment of average workload for those centres which have reported. This would suggest that the demand for HETF is levelling off after many years of progressive increases.

Home enteral tube feeding according to country within UK

As in previous years, more than 80% of patients registered with BANS (both new registrations and point prevalence) were from England in 2006 (see Figure 4.2a (new registrations) and Figure 4.2b (point prevalence)), with ~8% from Scotland, ~5% from N. Ireland, ~5% from Wales and ~0.2% from the Isle of Man.

Figure 4.1: Adult HETF in the UK - Number of new registrations, point prevalence and period prevalence per centre, 2000 to 2006

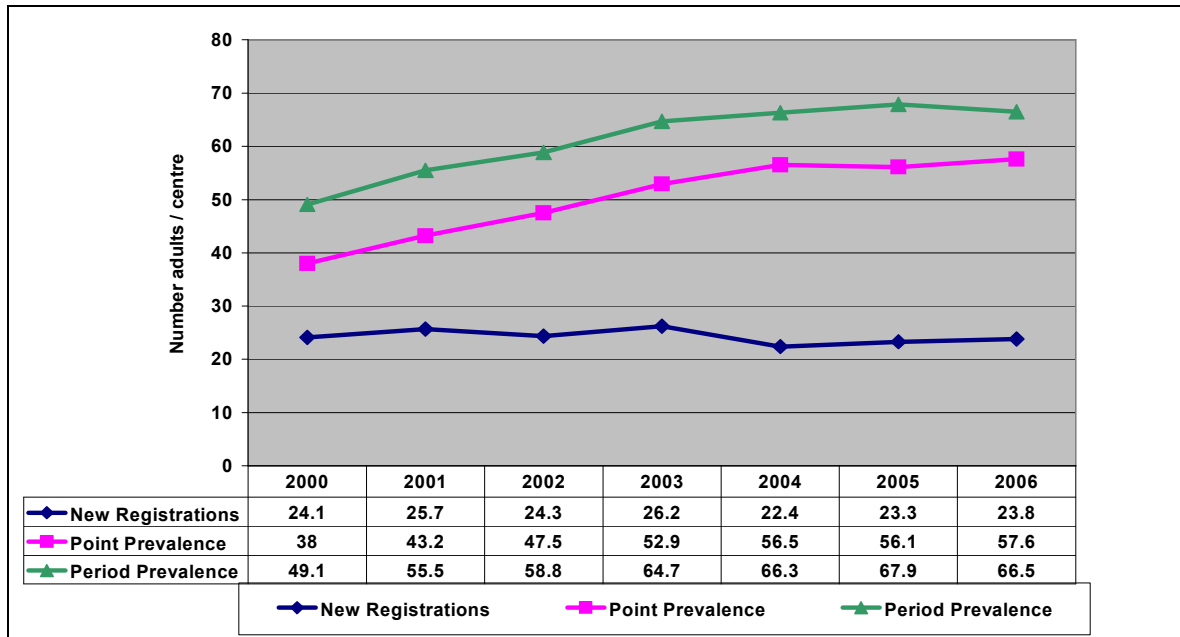
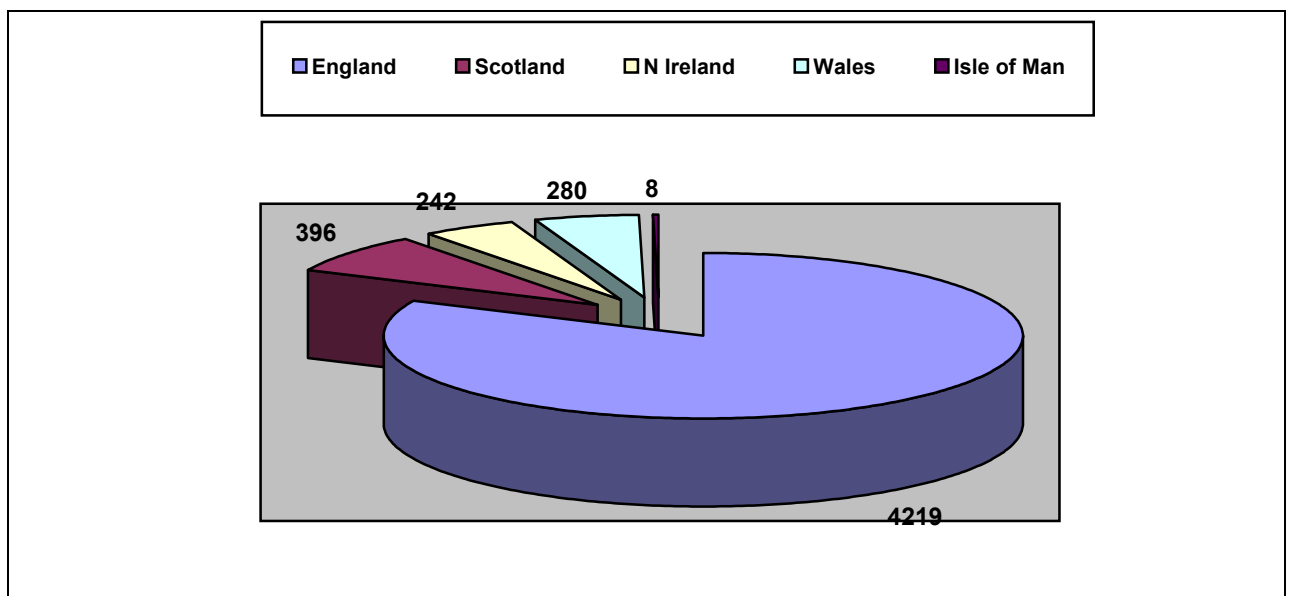
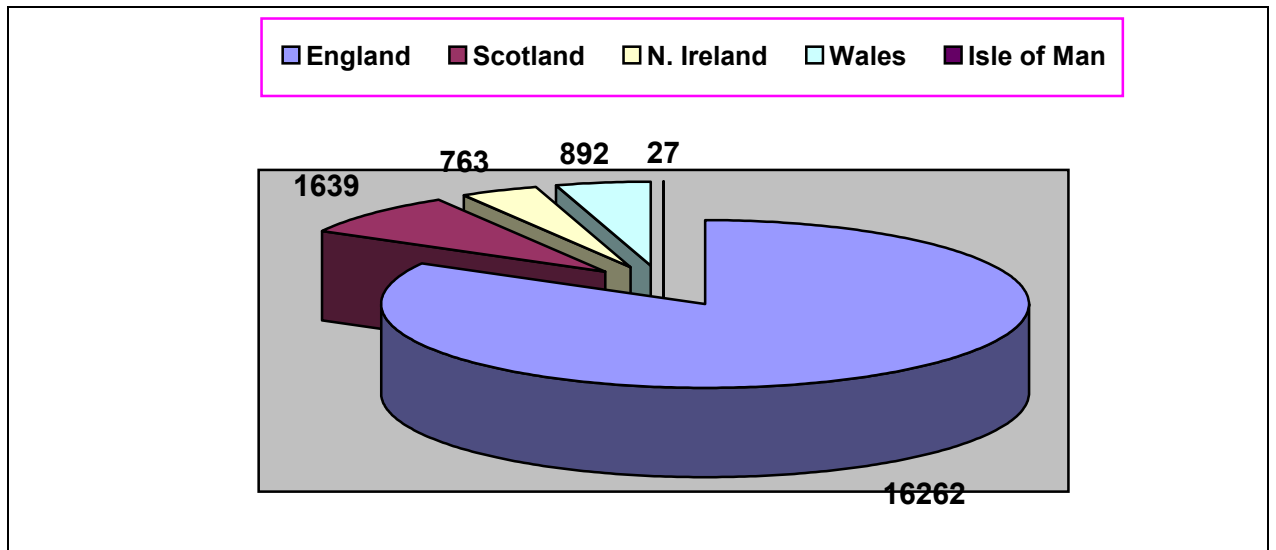


Figure 4.2a+b: Adult HETF patients registered with BANS according to country in 2006

4.2a: New registrations



4.2b: Point prevalence



The growth in point prevalence since last year is around 5% for England and Scotland (Figure 4.3), but in both countries there has been a fall in the number of new registrations. In Wales, the number of new registrations remains static since 2005 but the point prevalence has increased by 3.5%. Larger growth in the point prevalence of adults receiving HETF has been seen in Northern Ireland (11% since 2005), whilst in the Isle of Man, the number of patients at the end of 2006 (n 27) represented an increase of 23% since 2005 (see Figure 4.3). We did not collect specific data on Isle of Man until 2004.

New registrations were 86/million population in UK as a whole with point prevalence 327/million and period prevalence 385/million (Table 4.2). These represent the minimum numbers in the UK. For estimates allowing for non reporting, see Section 9.

Figure 4.3: Growth in point prevalence of adult HETF according to country (2000-2006)

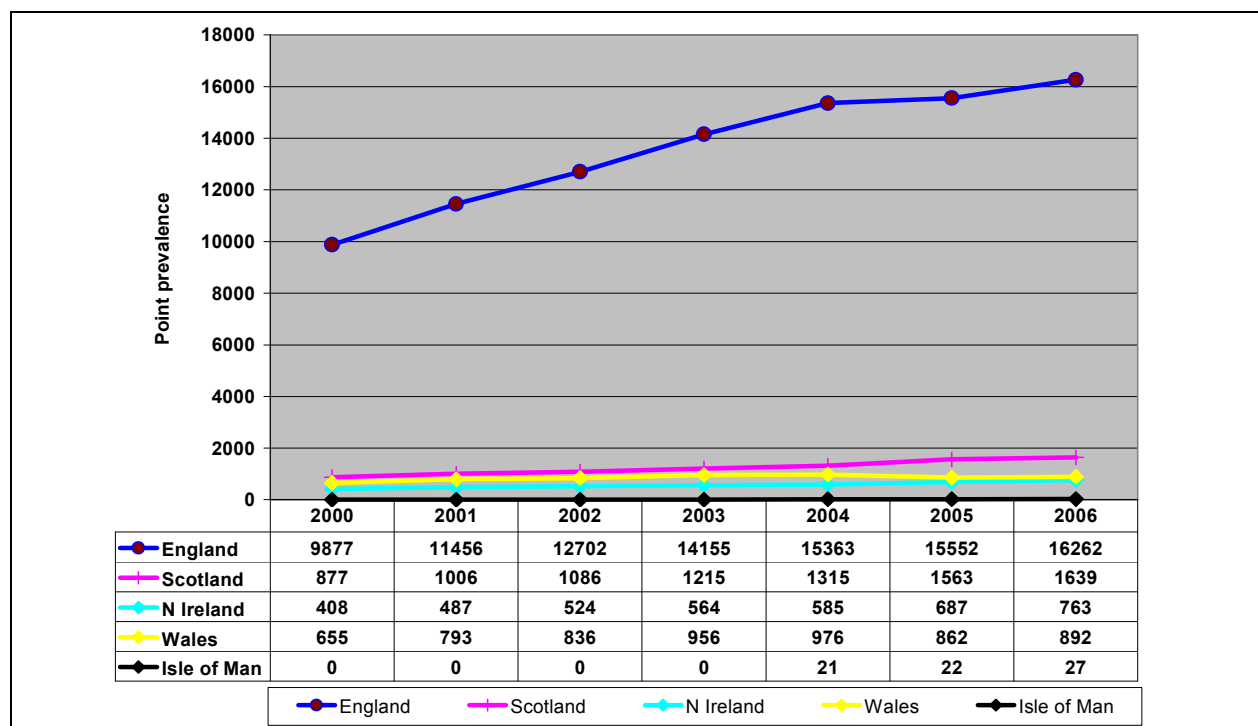


Table 4.2: Adult HETF in home countries / million population (BANS data)

	<i>New registrations/million</i>	<i>Point prevalence/million</i>	<i>Period prevalence/million</i>
England	85	326	381
Scotland	78	323	396
N Ireland	136	425	508
Wales	98	302	377
Isle of Man	107	354	419
United Kingdom	86	327	385

Age and location of patients receiving home enteral tube feeding

As in previous years, most adults on HETF registered with BANS were older people (both new registrations and patients registered with BANS at the end of 2006). Most (>60%) were aged over 60y (62%), with ~40% over 70y and ~20% over 80y (point prevalence). Despite being a relatively elderly population, most patients (~60%) live in their own home, with about one third resident in nursing homes.

Diagnoses and indications for adult HETF

As in previous years, diseases of the central nervous system accounted for 50% of new registrations and 60% of established patients (Table 4.3), with the most common single condition being cerebrovascular disease (27% of all patients, n 5298). However, it should be noted that there are substantial numbers of adults with cerebral palsy and congenital handicap receiving HETF. Those with Huntington's Chorea, motor neurone disease, muscular dystrophy, multiple sclerosis and Parkinson's disease also represent large numbers which may be of interest to planners and charitable bodies. 573 patients with dementia received HETF in 2006. The ability of such patients to consent is usually poor due to diminished mental capacity. Anecdotes suggest few have "advanced directives" or have yet taken advantage of the new Mental Capacity Act in England and Wales. Such patients pose considerable problems for reporters who must now obtain informed assent from those able to represent the interests of such patients.

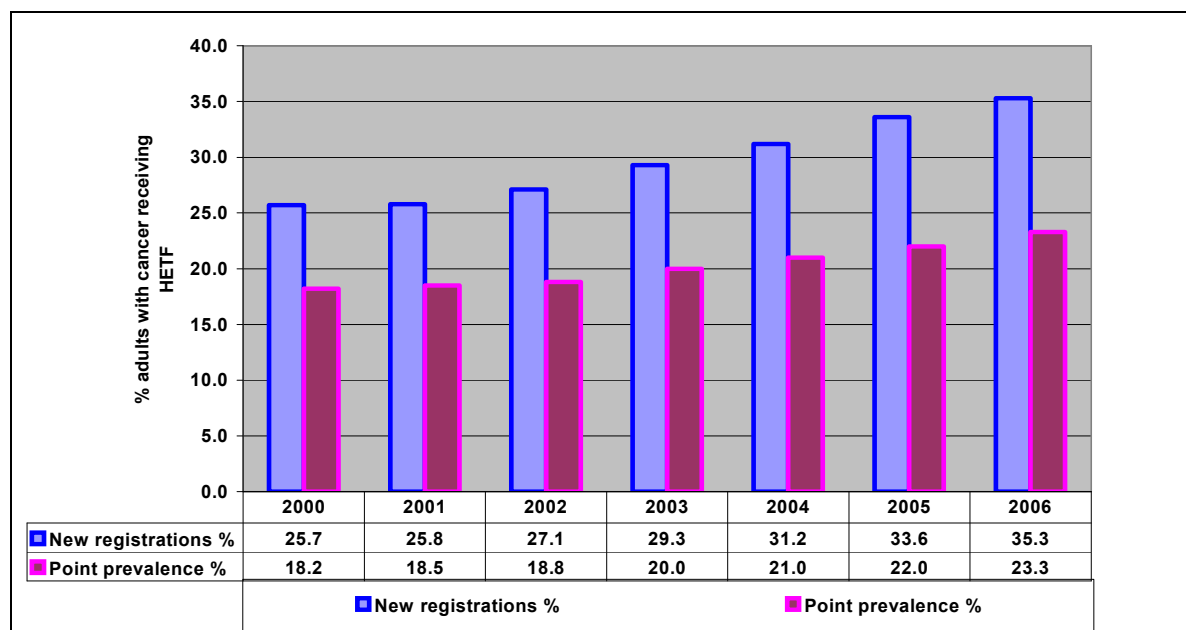
GI diseases were the second most common diagnostic group (point prevalence 19%), which includes cancers of the gastrointestinal tract. The third largest group was 'other' (16% of point prevalence), which includes patients with head and neck cancer, an indication that is consistently increasing year by year (4% (n 472) in 2000 vs. 9.6% (n 1889) in 2006). Overall 23% of patients (n 4564) (point prevalence) had a diagnosis of cancer, a proportion that is slowly rising (Figure 4.4). For new registrations of adults on HETF, the proportion with head and neck cancer has steadily increased over the years (6.5% (n 429) in 2000 vs. 15.6% (n 801) in 2006) and patients with cancer of any kind now account for 35% of new registrations (Figure 4.4). During this period the proportion with a CVA has decreased (from 34.8% (n 2308) in 2000 to 24.5% (n 1260) in 2006).

As in previous years, the two main reasons for feeding were a swallowing disorder (68% of patients, point prevalence) and improving nutritional status (22%, point prevalence). The reasons for feeding were similar in new registrations.

Table 4.3: Adults with neurological conditions receiving HETF in UK, 2006

	<i>New Registrations</i>		<i>Point prevalence</i>	
	n	%	n	%
Cerebral palsy	77	1.5	979	5.0
Congenital handicap	25	0.5	328	1.7
Cerebral trauma	132	2.6	747	3.8
Cerebral tumour	16	0.3	80	0.4
Cerebrovascular disease	1260	24.5	5298	27.1
Dementia	143	2.8	573	2.9
Huntingdon's chorea	45	0.9	256	1.3
Motor neurone disease	258	5.0	696	3.6
Multiple sclerosis	202	3.9	1265	6.5
Muscular dystrophy	28	0.5	119	0.6
Parkinson's disease	172	3.3	543	2.8
Unspecified CNS condition	237	4.6	891	4.5
Total	2595	50.4	11775	60.1

Figure 4.4: Increasing proportion of patients receiving HETF with cancer (2000-2006)



Enteral access route for adult HETF

Gastrostomy feeding continued to be the most common route of access in adult patients (84% (n 16464) of patients at the end of 2006), with only 12% fed via nasogastric tube and 4% by jejunostomy. This has changed very little over the previous 5 years.

Activity levels and ability to manage HETF

Although many patients receiving HETF (~60%) live at home, patients' activity levels and their ability to manage is mostly very limited. As in previous years, nearly 80% of adult patients had limited activity (33%) or were housebound (15%) or bedbound (28%) - based on point prevalence data of 19,583 patients at the end of 2006. In the eldest patients (aged > 75 years), ~90% were bedbound, housebound or had limited activity.

Similarly the ability to manage HETF continued to be limited for the majority of patients. As in previous years, 72% of patients required total help (n 10699) or some help (n 3412) to manage.

Outcome of adults one year after commencing HETF

The status of 33,955 BANS registered patients after 1 year of home enteral tube feeding was as follows : 47.1% continued with HETF, 36.3% had died, 15.3% had returned to oral feeding, <1% were in hospital and <1% were withdrawn or had refused feeding. The 1-year outcome of all patients with cancer (n 8661) including those with head and neck (n 2394) and oesophageal (n 2406) cancers are summarised in Table 4.4.

Table 4.4: Outcome of adults with cancer one year after commencing HETF

<i>Outcome (% of patients)</i>	<i>All cancers (n 8661)</i>	<i>Head and neck cancers (including oropharyngeal) (n 5102)</i>	<i>Oesophageal cancer (n 2406)</i>
Continuing	29.8%	34.2%	23.8%
Died	40.2%	33.7%	49%
Return to oral feeding	28.2%	30.9%	24.9%
In hospital	<1%	<1%	1%
Withdrawn or refused	1.1%	<1%	1.3%

Use of commercial home delivery companies for adult HETF

More than 80% of adults newly registered with BANS on HETF and 76% of all patients (point prevalence) have a commercial home care delivery company. This has remained similar in recent years.

Adults and children receiving HETF

The combined total number of adult and paediatric patients receiving HETF and registered with BANS at the end of 2006 (point prevalence) was 24479 (19583 adults and 4896 children). The period prevalence for 2006 was 28754 (23088 adults and 5666 children). There was a total of 5917 new registrations (5145 adults and 772 children).

The point prevalence figure for 2006 suggested that at least 409 patients were receiving HETF at any one time per million of population in the UK (estimated UK population 59.9 million).

Since not all patients receiving HETF in the UK are registered with BANS, it is estimated that there were in the region of 25000-27000 patients receiving HETF at the end of 2006, allowing for probable under reporting. (See Section 9)

Section 5

Home enteral tube feeding (HETF) in children

Christine Holden

New registrations, point and period prevalences of HETF in children

New registrations (772) have decreased and are the lowest since recorded from 2000 and point prevalence (4896) but period prevalence (5666) has increased marginally (Figure 5.1). Figure 5.2 shows the number of reporting centres for children.

Figure 5.1: New registrations, point and period prevalence of children receiving HETF in UK, 2000 – 2006

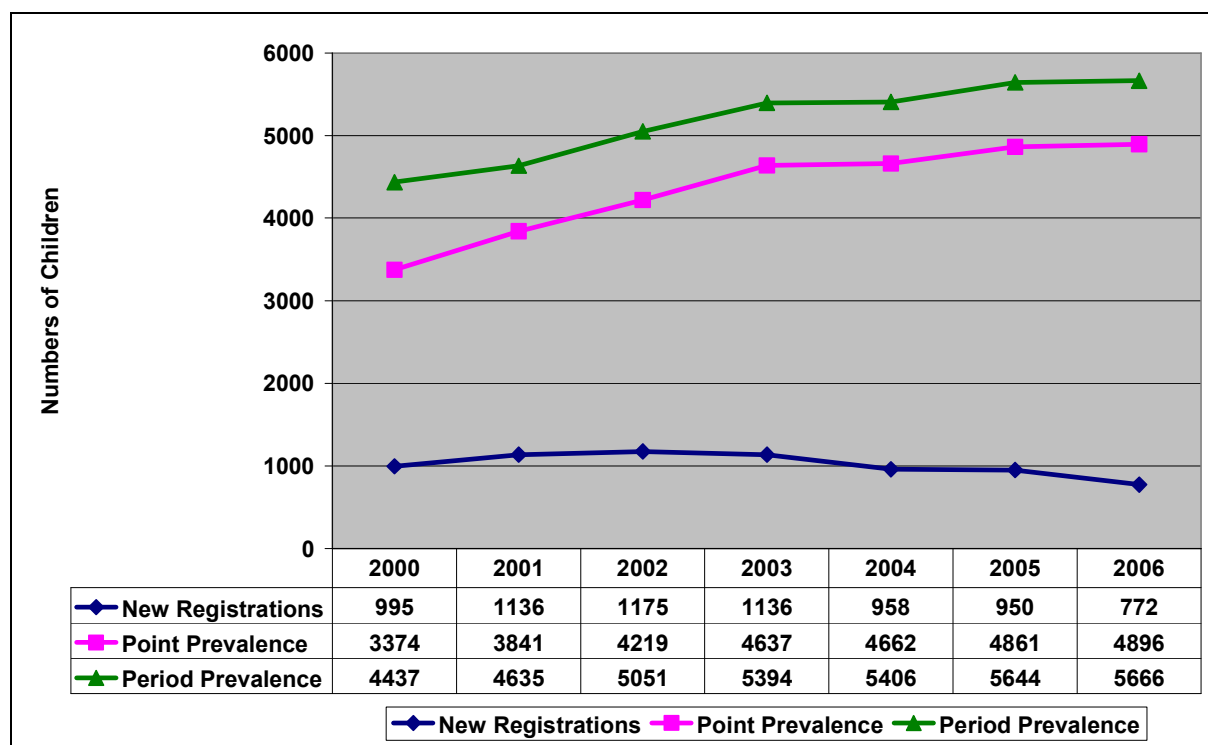
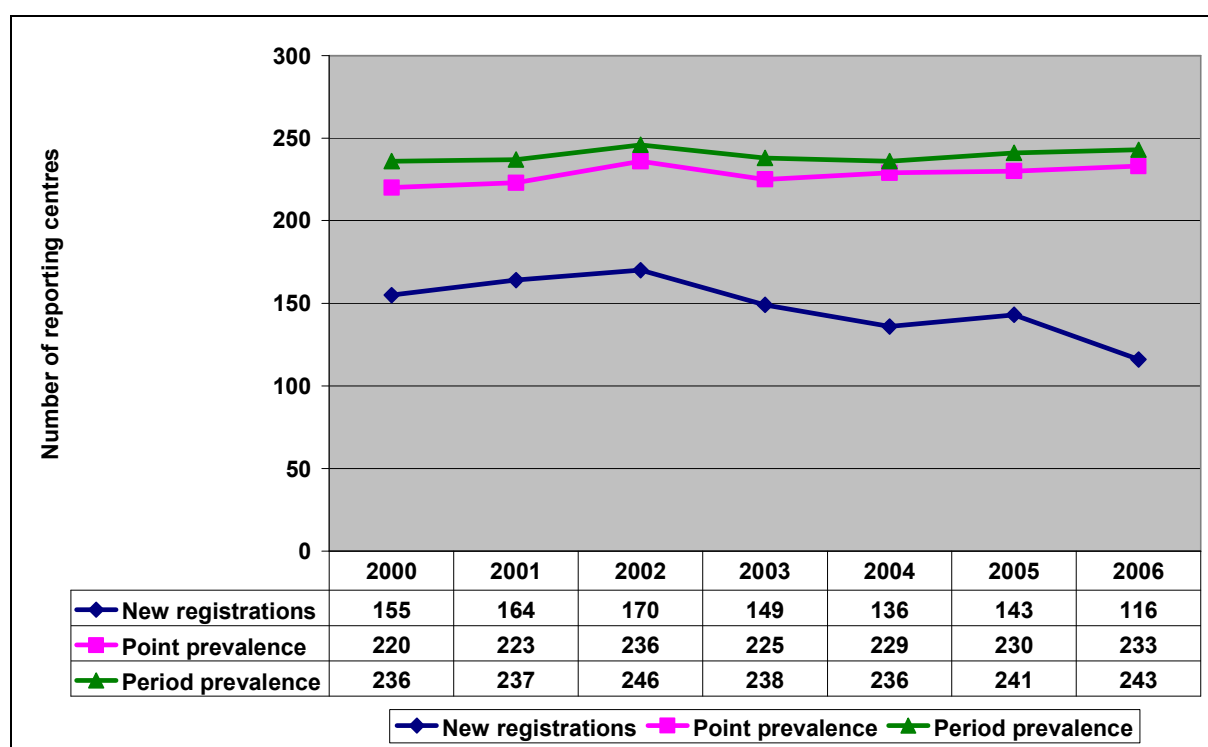


Figure 5.2: Numbers of UK reporting centres for children receiving HETF, 2000 – 2006



New registrations has reduced from 170 (highest recorded) in 2002 to 116 in 2006. This is extremely disappointing (Figure 5.2).

Diagnoses and indications for HETF

Main diagnostic categories registered are detailed in Figures 5.3 and 5.4. Gastrointestinal, renal, respiratory diseases, cerebral palsy and inborn errors of metabolism feature predominantly.

Main diagnostic categories point prevalence patients registered for 2006 are other diseases 41.1%; central nervous system disorders 33.2%; gastrointestinal disease 11.2%; respiratory disorders 6.8%. Review of other diseases was undertaken. Additional diagnostic categories included children with cancer, non-organic failure to thrive, tracheomalacia, etc. BANS has actively improved diagnostic categories for forthcoming launch of e-Bans. We hope that improvements in standardisation of coding will be able reporters to clarify diagnostic categories appropriately.

Figure 5.3 (A): Main diagnostic categories –HETF new registrations

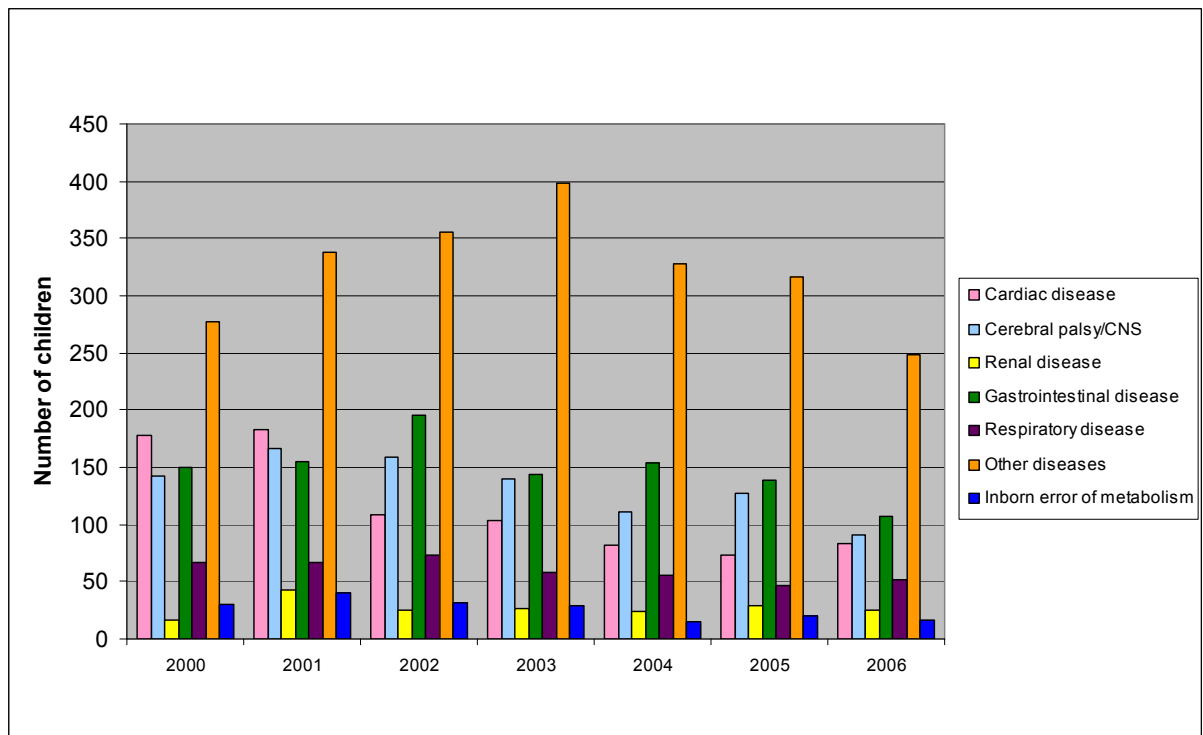
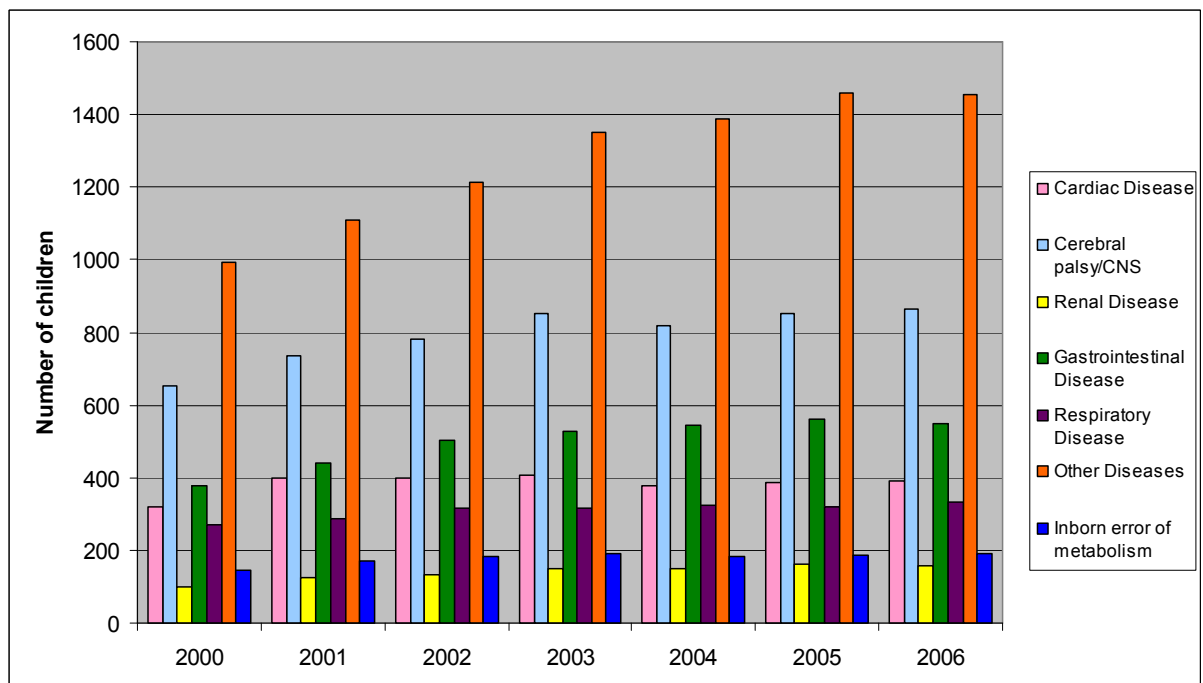


Figure 5.3 (B): Main HETF diagnostic categories –point prevalence



Main reasons for feeding for new patients in 2006 were failure to thrive (24.8%); swallowing disorder (24.2%) and 48.6% requiring support to improve/maintain nutritional status.

Age distribution

Age distribution has not changed significantly with the previous 2005 report. However, 43.9% of new registrations were under 1 year of age and 3.8% of point prevalence is accounted for by this age group (Figures 5.4A and 5.4B). 8.9% new registrations and 14.5% of point prevalence are aged 13 – 15, many of whom are likely to be transferred to adult services.

Figure 5.4 (A): Age bands of newly registered children on HETF

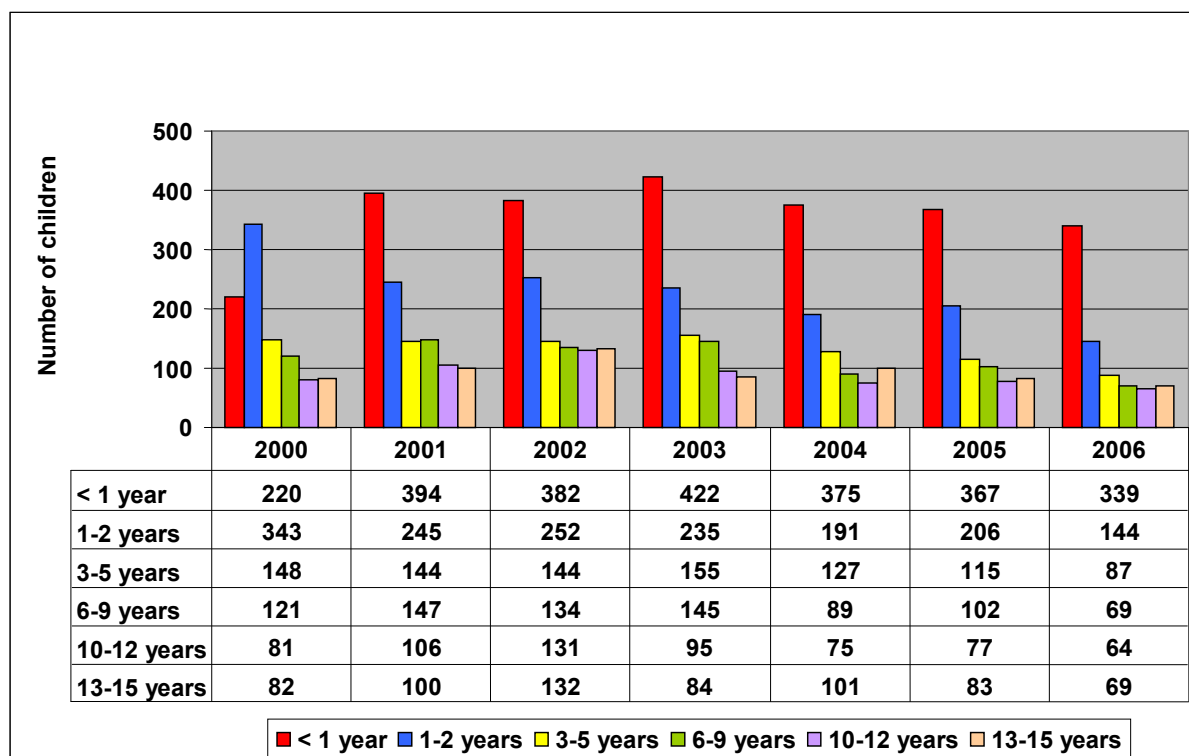
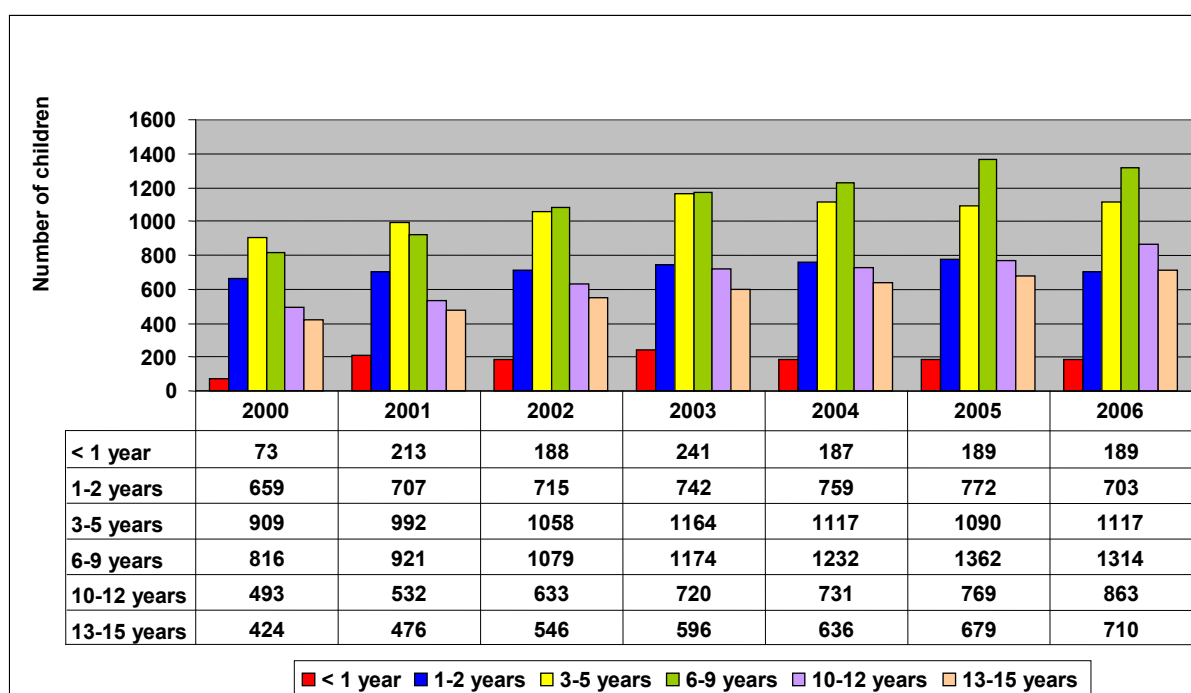


Figure 5.4 (B): Age bands of children on HETF – point prevalence



Activity levels and location

Full activity was reported in 50.4% of new cases and 38.7% point prevalence. Children were cared for in their own homes in 97.7% of new cases and 94.4% of point prevalence cases. This figure is consistent with previous reports.

Route of enteral access and nutrient delivery

The route for enteral access was by gastrostomy in 30.4% of new cases, compared with 53.3% of established ones (point prevalence). By contrast, nasogastric feeding accounted for 68.5% of new cases and 45.45% established. These figures are consistent with the previous 2005 report.

Homecare company involvement

Homecare companies were involved with families in 79.9% of new cases but only in 73% of established patients.

Outcome of children 1 year after discharge on HETF

The status after 1 year of 6942 children registered with BANS who had been discharged home on enteral feeding were as follows: 71% continued with HETF, 6% died due to underlying disease, 21% had returned to oral feeding, 1% were in hospital and feeding had been withdrawn or refused in 1%.

Section 6

Adult Home Parenteral Nutrition (HPN)

Dr Barry JM Jones

New registrations, point and period prevalence

New registrations remain static at about 100 per year whereas point and period prevalence continue to rise linearly (Figure 6.1). 746 patients were registered as having received HPN in 2006 in the UK as whole.

The number of centres registering new cases to BANS has fallen but point and period prevalence have risen (Figure 6.2). This suggests there has been no fall off of available reporters but that new cases are becoming concentrated in larger centres. The surprisingly large number of centres reporting point and period prevalence accords with previous data (BANS report, 2005) suggesting that some centres are caring for very few patients still. We can not exclude the possibility that some centres do not report to BANS (see 2006 report)

The number of centres reporting new cases in England has also reduced but reporting centres for prevalence data have shown no major changes since 2004.

Figure 6.1: Number of new registrations, point prevalence and period prevalence of HPN in UK, 2000 – 2006

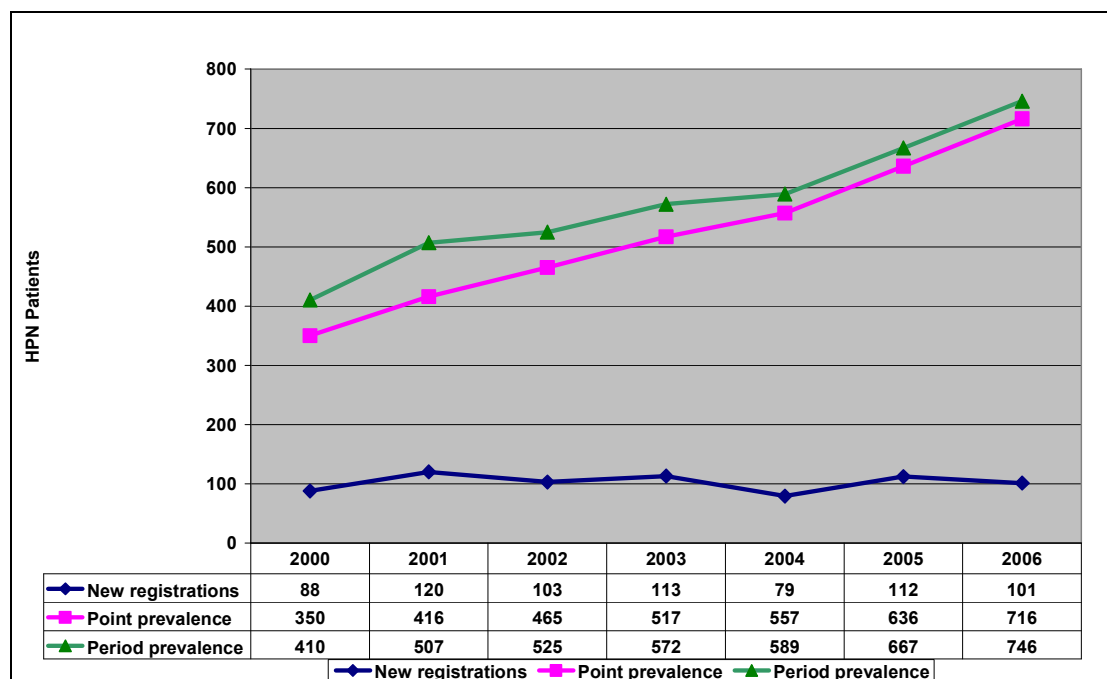
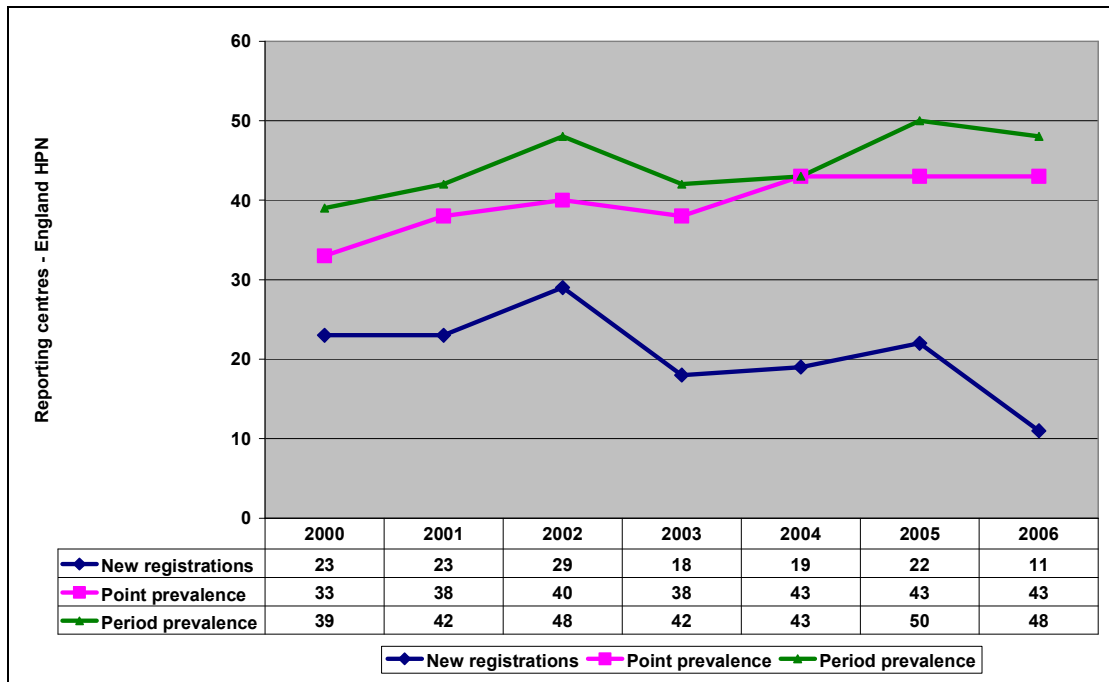


Figure 6.2: Numbers of adult HPN reporting centres in UK for new registrations, point prevalence and period prevalence, 2000 to 2006.



Figure 6.3: Numbers of adult HPN reporting centres in England for new registrations, point prevalence and period prevalence, 2000 and 2006.



New registrations, point and period prevalence in constituent countries of UK

In Figure 6.4, point prevalence for the 4 constituent countries in the United Kingdom shows large increases over the period 2000 to 2006 (England 177%; Scotland 160%; Wales 400%; N Ireland 433%). Translated into prevalence per million, new registrations in 2006 fell compared to 2003 and 2005 but point and period prevalence have increased. In the UK as a whole, new registrations were 1.7/million, point prevalence was 12/million and period prevalence 12.5/million (Table 6.1).

Figure 6.4: Period prevalence of Adult HPN in constituent countries of UK, 2000 – 2006

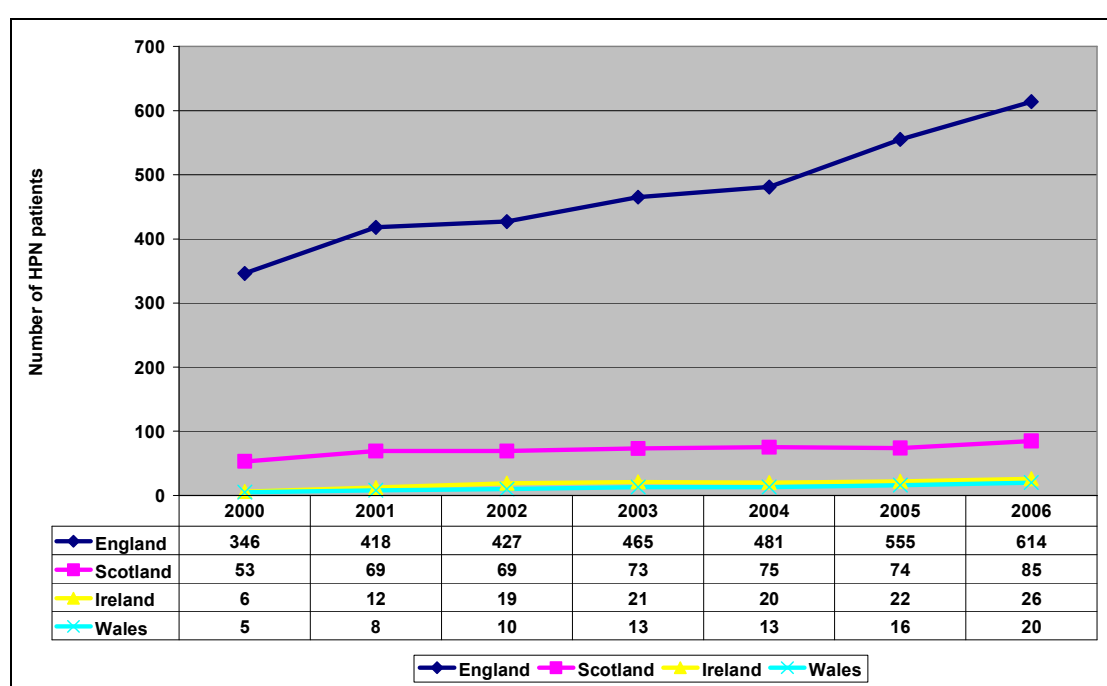


Table 6.1: Prevalence per million population* in UK and home countries in 2006 (2003 data in brackets)**

	New	Point prevalence	Period prevalence
England	1.7 (2)	11.8 (8.6)	12.3 (9.5)
Scotland	2.2 (2.3)	16 (12.9)	16.7 (14.3)
N. Ireland	0.6 (1.2)	15.2 (9.5)	15.2 (12.5)
Wales	1.7 (1.4)	6.1 (4.5)	6.8 (4.5)
UK	1.7(2)	12(8.8)	12.5(9.8)

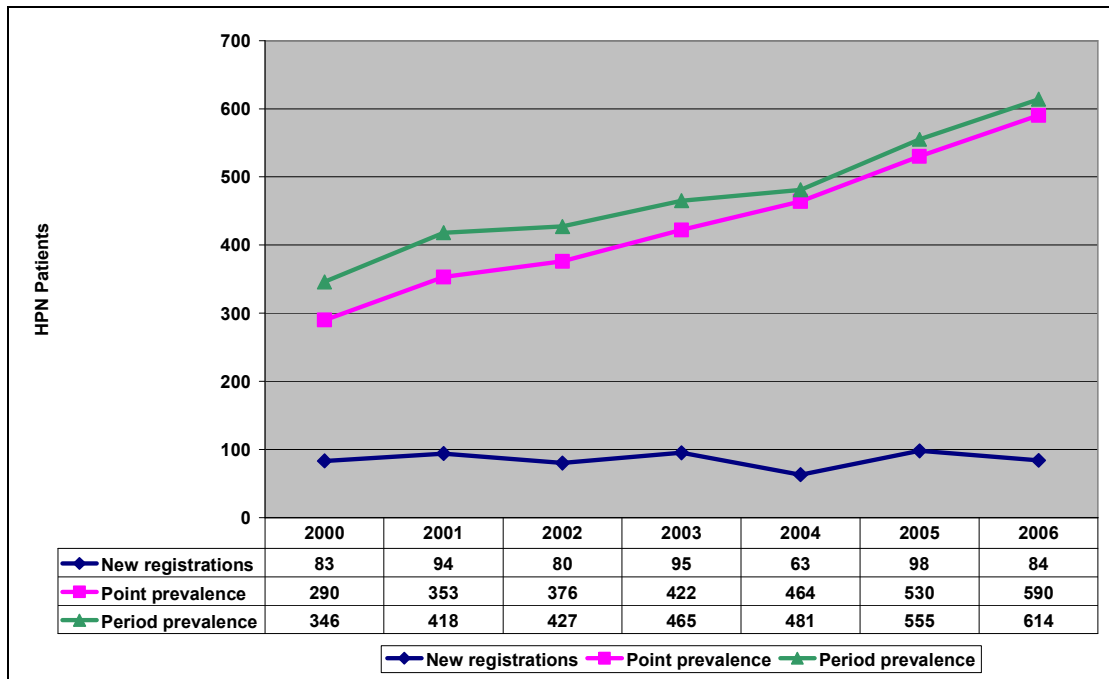
*Sources: Mid-year population estimates, 2004: Office for National Statistics, General Register Office for Scotland and Northern Ireland Statistics and Research Agency.

** 2001 census data. 2003 data from BANS report, 2005.

England

New registrations remain steady at about 100 per year. Point and period prevalence continue to rise in linear fashion. In 2006, a total of 614 patients were registered as receiving HPN with a period prevalence of 12.3/million (Figure 6.5).

Figure 6.5: Trends in HPN in England, 2000 - 2006



Scotland

After an initial rise in new registrants in 2001, coinciding with the inception of the Scottish Managed Clinical HPN Network, new registrations have moderated from 17 to 11 in 2006. Point and period prevalence continue to rise linearly. In 2006, 85 patients were registered to have received HPN with a period prevalence of 16.7/million (Figure 6.6).

Wales

New registrations have varied sporadically but point and period prevalence have shown large increases from a low position in 2000. Period prevalence in Wales reached 20 or 6.8/million (Figure 6.7). This is the lowest prevalence in the UK suggesting inadequate access to HPN in Wales.

Northern Ireland

New registrations rose to 6 between 2000 and 2002 but have fallen away to a single patient in both 2005 and 2006. Despite these low figures, period prevalence has risen from 6 to 26 or 15.2/million (Figure 6.8)

Figure 6.6: Trends in HPN in Scotland, 2000 - 2006

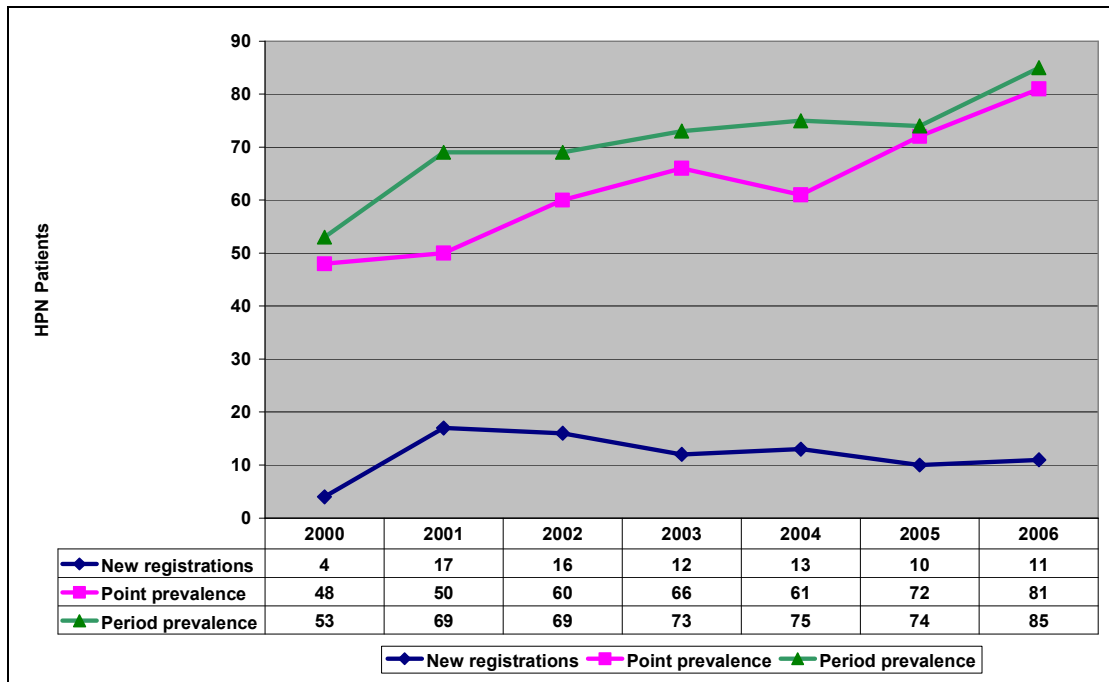


Figure 6.7: Trends in HPN in Wales, 2000 – 2006

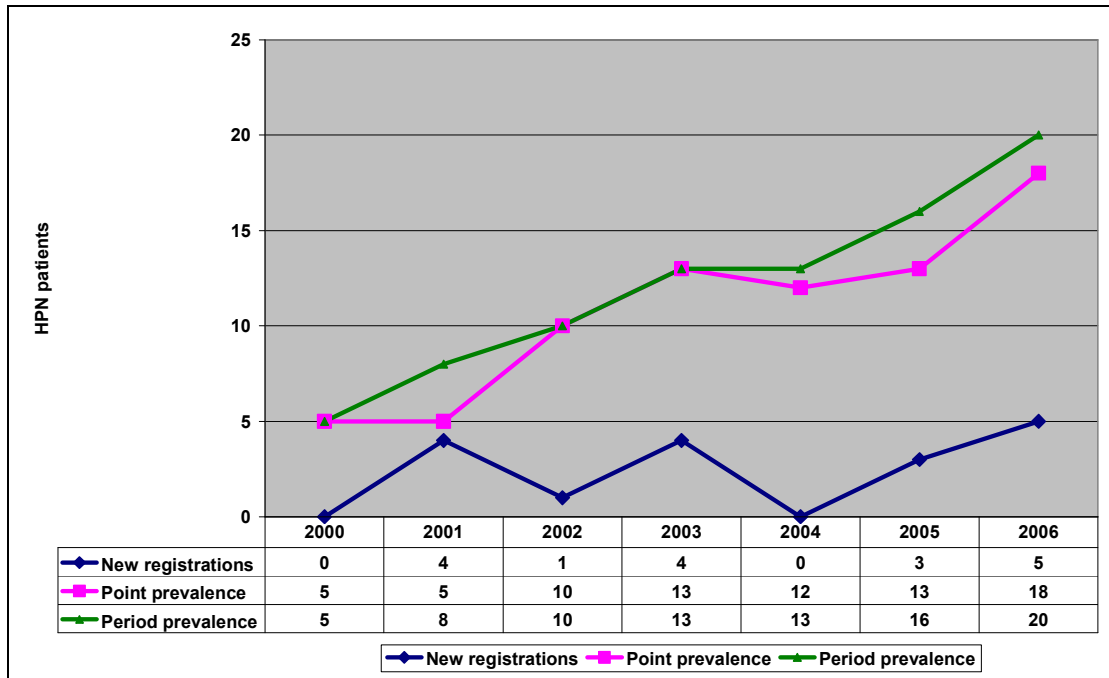
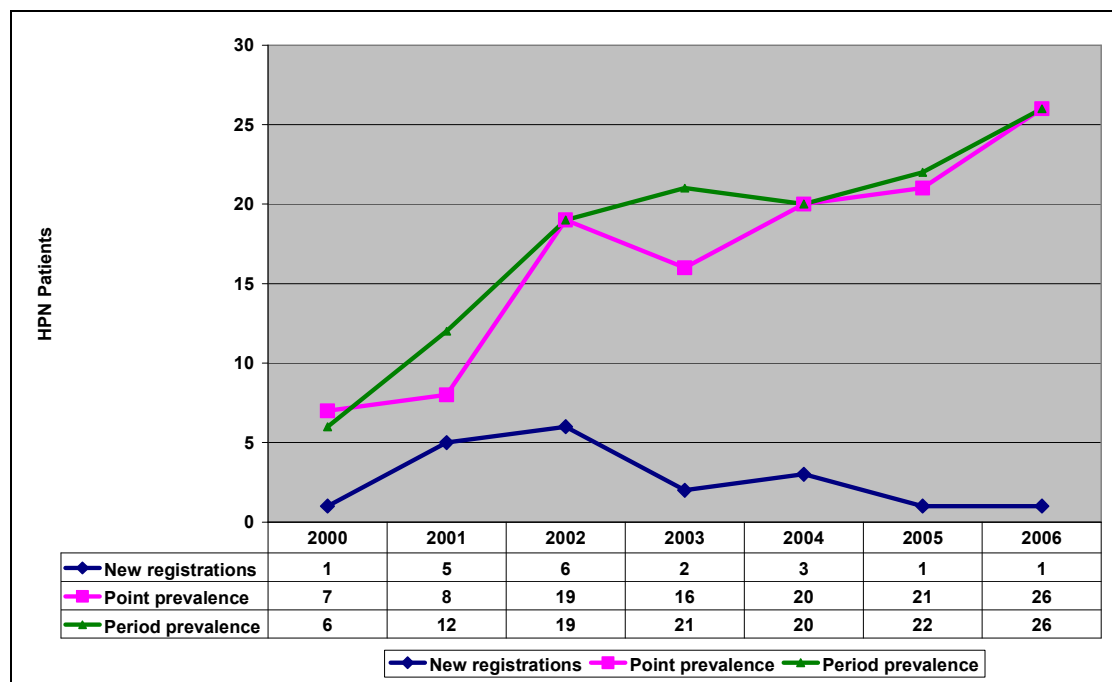


Figure 6.8: Trends in HPN in N Ireland, 2000 - 2006

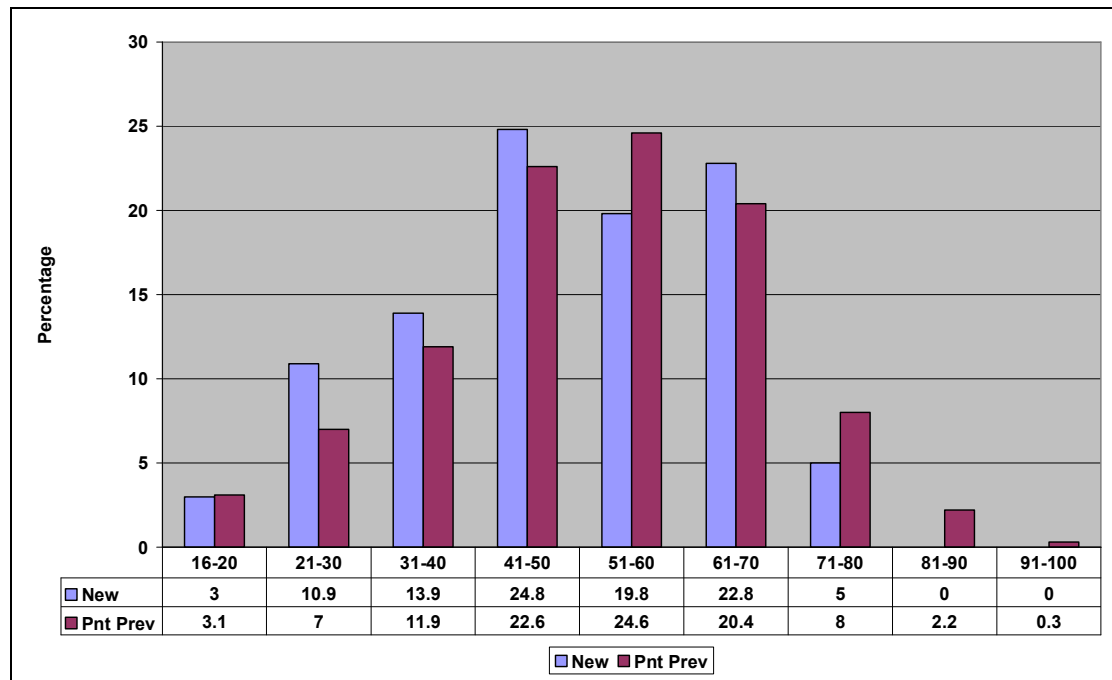


Characteristics of Adult HPN patients in UK, 2006

Age distribution

The distribution by age group in 2006 is shown in Figure 6.9. The proportion of new cases between 16 and 40 years is steady (2000: 27.2%; 2006: 27.8%). Patients in this age group may be the most appropriate to consider for small bowel transplantation.

Figure 6.9: Age distribution of Adult HPN in UK for new registrations and point prevalence, 2006



Diagnoses and Reasons for feeding

Reasons for HPN

As shown in Table 6.2, short bowel syndrome is the dominant indication for HPN. We have no information on the length of remaining small bowel or whether colon is in continuity. This information would be of use in determining the number of patients who might benefit from surgical procedures to increase the capacity of the small bowel.

Obstruction of the gut is predominantly due to cancers with a short prognosis, which explains why the new registrations are greater than period prevalence. The appearance of disorders of swallowing as an indication for HPN is inexplicable from the data available to BANS. Enteral feeding would be the preferred route for these patients.

Table 6.2: Reasons for HPN, 2000 and 2006

	% New		% Point prevalence	
	2000	2006	2000	2006
Fistula	17	16.8	6	9.2
Obstruction of gut	9.1	8.9	6.3	6.4
Malabsorption	12.5	18.8	14.6	17.6
Short bowel	40.9	40.6	61.4	51.5
To improve nutrition	11.4	7.9	4.9	6.1
Swallowing disorder	5.7	2.0	2.3	4.5
Other	3.4	5	4.6	4.7

Diagnoses and HPN

Crohns remains the predominant diagnosis for new and established HPN (Table 6.3). The increase of ischaemia which overtook Crohns as the diagnosis of new cases in 2005 has not been maintained in 2006. The number of patients on established HPN continues to rise. There were 196 such cases in 2006 (table 6.4). Of some concern is the heterogeneous group of “other” diagnoses which comprises mainly of surgical complications. There appears to have been an increase in this group. Cancer as the main diagnosis remains steady at 17% of new cases compared to the contribution of cancer to HETF figures (see Section 4)

Table 6.3: Diagnostic categories of Adult HPN, 2000 and 2006

	% New registrations		% Point prevalence	
	2000	2006	2000	2006
Crohns	25	26.7	34.3	27.4
Ulcerative colitis	3.4	3.0	2.3	2.5
Ischaemia*	14.8	16.8	17.7	19.4
Radiation enteritis	5.7	5.9	5.1	4.1
Pseudo-obstruction	4.5	5.9	9.1	9.9
Systemic Sclerosis	3.4	2.0	2.9	3.2
Other...including	6.8	13.9	11.1	15.2
Surgical complications				
Benign strictures	5.7	0	4.0	1.3
Cancer**	16.8	16.9	5.8	7.9

*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

Table 6.4: Point prevalence of Crohns disease 2000 – 2006

Crohns	2000	2001	2002	2003	2004	2005	2006
%	34.3	31.5	31.6	30.2	28.7	27.5	27.4
Numbers	120	131	147	156	160	175	196

Location, Ability to Manage and Activity level

Most newly discharged patients (97%) reside in their own homes with only 3% in nursing homes.

Their ability to manage improves following discharge home. Only 57.4% were fully independent on discharge with some requiring some help (12.7%) and 29.7% total help. These figures improve over time to 70.3% independent, 12.7% needing some help and 16.2% total help.

There is trend towards improved activity following discharge. Full activity is recorded for 53.5% and limited activity in 39.6% of new patients with only 5.9% bedbound. Corresponding figures for point prevalence are 60%, 35.5% and 3.2%.

Access route and Administration of HPN, 2006

An external catheter was used in 97% of new registrations and 85% of established patients (point prevalence). The remainder had a subcutaneous port.

A commercial homecare company was involved in HPN provision in 95% of new patients but as in previous years, only 85% of established patients (point prevalence)

Outcome 1 year after starting HPN

One year after starting HPN, 64% were still on HPN and 19% had returned to oral nutrition. Mortality was 13%.

Post code analysis of Period prevalence of Adult HPN in England

Andrew Bibby (NSCAG/DoH) and Dr Barry Jones, BANS

As shown in Table 6.5, there is considerable variation in period prevalence from one old Strategic Health Authority (SHA) to another. This variation persists even with the newer much larger SHAs. The variation in point prevalence per million was 3.68 – 22.5 for old SHAs and 6.19 – 16.19 for the new SHAs.

This data accords with previous BANS data (see Annual reports 1999 & 2004) in which wide variations in access to HPN were noted by the now defunct District Pharmaceutical Advisers and later from BANS postcode data for the old SHAs. Although some patients did not have identifiable or attributable

postcodes, this alone would not explain the disparities in prevalence between SHAs. Since the underlying causes of intestinal failure leading to HPN do not vary by such wide margins from region to region, it seems likely that the variations in the prevalence of HPN relate to other factors. We believe that this data reflects variable availability of HPN services throughout England, ie inequity of access or so called “post code treatment”.

BANS is grateful for the assistance of Mr Andrew Bibby of NSCAG in the analysis of BANS derived Post code data. Mr Bibby is also a member of HIFNET (UK Home Parenteral nutrition and Intestinal Failure Network)

Table 6.5: Period prevalence by old and new Strategic Health Authorities (SHA) in England, 2006
England

<i>Old SHA name</i>	<i>Prevalence (per Million)-old SHA</i>	<i>Prevalence (per Million)-new SHA</i>
NORTHUMBERLAND, TYNE & WEAR SHA	11.49	
COUNTY DURHAM AND TEES VALLEY SHA	4.35	9.84
CUMBRIA AND LANCASHIRE SHA	11.48	
GREATER MANCHESTER SHA	22.53	
CHESHIRE & MERSEYSIDE SHA	9.72	16.19
N AND E YORKSHIRE AND N LINCOLNSHIRE	3.68	
WEST YORKSHIRE SHA	8.50	8.95
SOUTH YORKSHIRE STRATEGIC HA	15.59	
TRENT STRATEGIC HA	4.14	
L'CESTER/ N'HAMPTONSHIRE AND RUTLAND SHA	10.57	6.48
SHROPSHIRE AND STAFFORDSHIRE SHA	5.43	
BIRMINGHAM AND THE BLACK COUNTRY SHA	4.35	6.19
WEST MIDLANDS SOUTH SHA	3.86	
NORFOLK, SUFFOLK AND CAMBRIDGESHIRE SHA	9.08	
BEDFORDSHIRE AND HERTFORDSHIRE SHA	9.15	11.00
ESSEX SHA	11.16	
NORTH WEST LONDON SHA	5.96	
NORTH CENTRAL LONDON SHA	4.89	
NORTH EAST LONDON SHA	12.33	
SOUTH EAST LONDON SHA	10.60	
SOUTH WEST LONDON SHA	6.09	9.28
KENT AND MEDWAY SHA	18.68	
SURREY AND SUSSEX SHA	9.04	12.77
THAMES VALLEY SHA	8.84	
HAMPSHIRE AND ISLE OF WIGHT SHA	6.20	7.64
AVON, GLOUCESTERSHIRE AND WILTSHIRE SHA	6.85	
SOUTH WEST PENINSULA SHA	5.00	6.21
DORSET AND SOMERSET SHA	6.68	
SUBTOTAL	8.94	9.70
ENGLAND SUBTOTAL including those with non attributable post codes	10.20	10.20

Section 7

Home parenteral nutrition (HPN) in children

Christine Holden

New registrations, patients point and period prevalences of HPN in children

The number of new registrations is the lowest recorded (10) since 2001. Point prevalence (95) and period prevalence (107) are not dissimilar to 2005 (Figure 7.1).

Figure 7.1: New registrations, point and period prevalences of children receiving HPN, 2000 – 2006

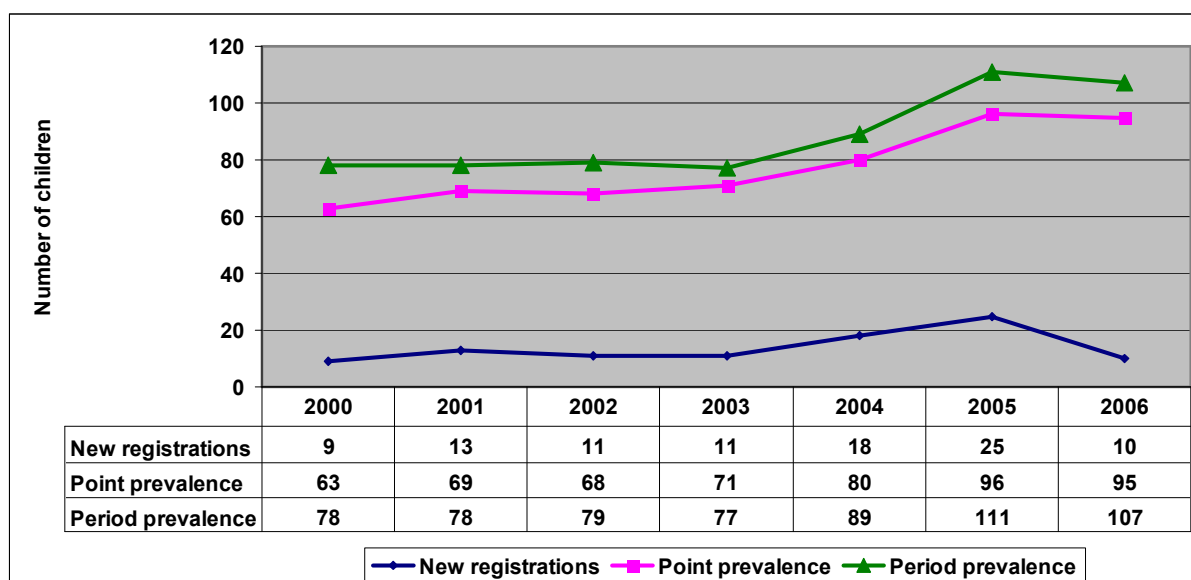
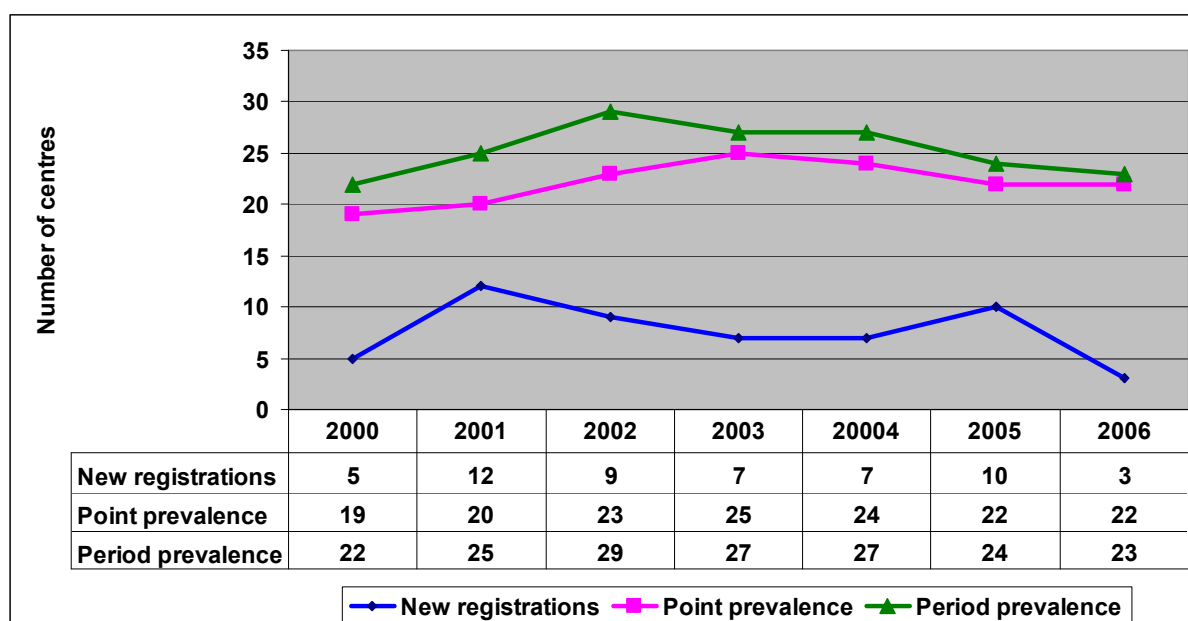


Figure 7.2: Numbers of reporting centres for HPN for children, 2000 – 2006



We also identified that reporting centres for new cases have fallen from 10 to 3 (Figure 7.2). The levelling off of prevalence data and the drop in new registrations reflects the fall in reporting centres. This is a cause for concern to BANS but we hope that the introduction of e-BANS will encourage reporters to return.

Where are children treated?

Point prevalence data for 2006 was reviewed and hospitals reporting >5 patients are included in the Table 7.1.

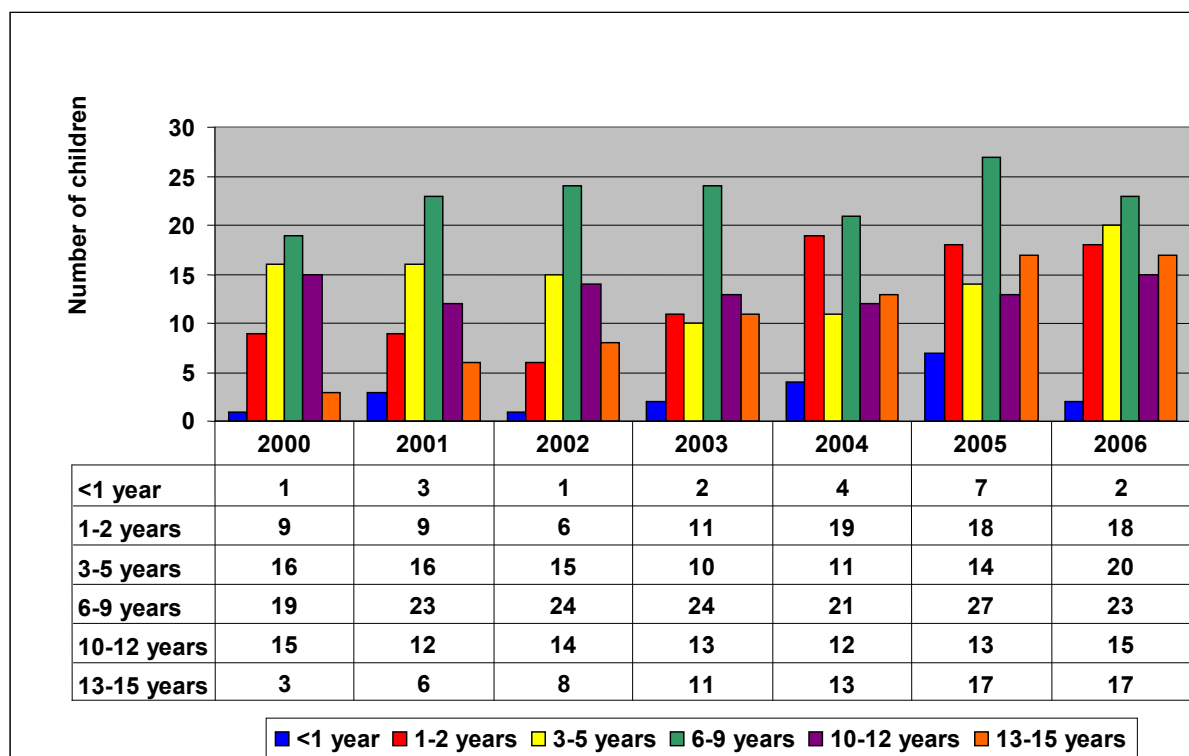
Table 7.1: Reporting centres (HPN)

Name of reporting centre	Number of patients registered
Great Ormond Street, London	28
Birmingham Children’s Hospital	20
Royal Belfast Hospital for Sick Children	6
Booth Hall Children’s Hospital, Manchester	7
Leeds General Infirmary	5
Royal Liverpool Hospital	8

Age distribution

Of 8 New registrations, 4 were under the age of 2 years. Amongst established children, the age group of 6-9 years was most prevalent but the contribution of 13-15 year olds has increased over the period 2000 – 2006. This observation is relevant to planning for facilities for transition from childhood to adult HPN (Figure 7.3).

Figure 7.3: Age bands - Point prevalence of HPN in children, 2000 – 2006



Diagnoses

Diagnoses of new registrations included idiopathic diarrhoea of infancy (2); microvillous inclusion disease (1); other gastrointestinal diseases (3); post necrotising enterocolitis (1); jejunal ileal atresia (1); cancer (1); cystic fibrosis (1)

Point prevalence data for 2006 identified that the main diagnostic category for HPN in children was gastrointestinal diseases 86.5%. Pseudo obstruction (26.3%); idiopathic diarrhoea (15.8%); gastroschisis (9.4%); autoimmune enteropathy (8.4%) featured predominantly, whilst children registered <5% included those with volvulus, short bowel syndrome, necrotising enterocolitis, microvillous inclusion disorder and Crohn's disease.

Activity levels

Point prevalence data for 2006 indicates full normal activity (72) in 75.7% and limited activity (21) 22.1%. Only one child was bed bound (Figure 7.4).

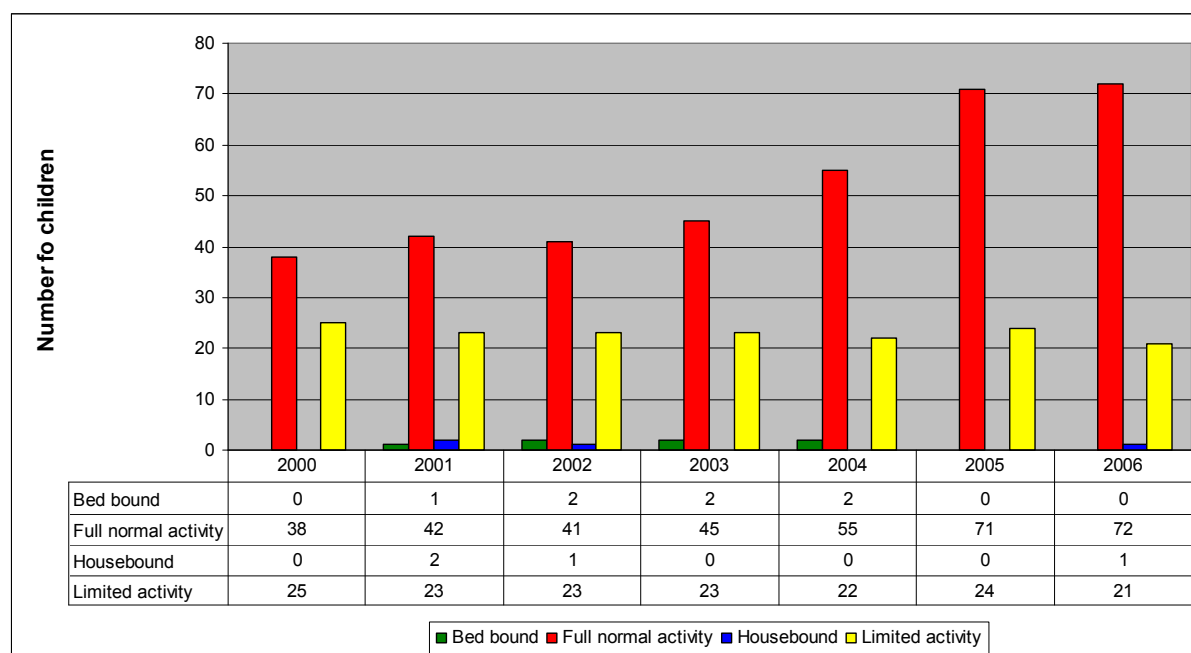
Access route for HPN

100% of new registrations had a cuffed catheter, compared with 91.6% of those established on HPN (point prevalence). The remaining 8.4% had a subcutaneous port.

Contribution of Commercial Homecare companies

A home care company was involved in 90% of new cases, but as in previous years, we have noted that only 62% established patients receive such support. We have no explanation of this observation.

Figure 7.4: Activity levels – point prevalence of HPN children 2000 - 2006



12 month Outcome analysis data*

12 months after discharge on HPN, 51 of 79 (64.6%) children continued to receive HPN, 1 (1.3%) stopped parenteral nutrition; 15 (19%) transferred to oral feeding and 12 (15.18%) children died, 10 due to underlying disease and 2 (2.53%) due to other causes (Figures 7.6).

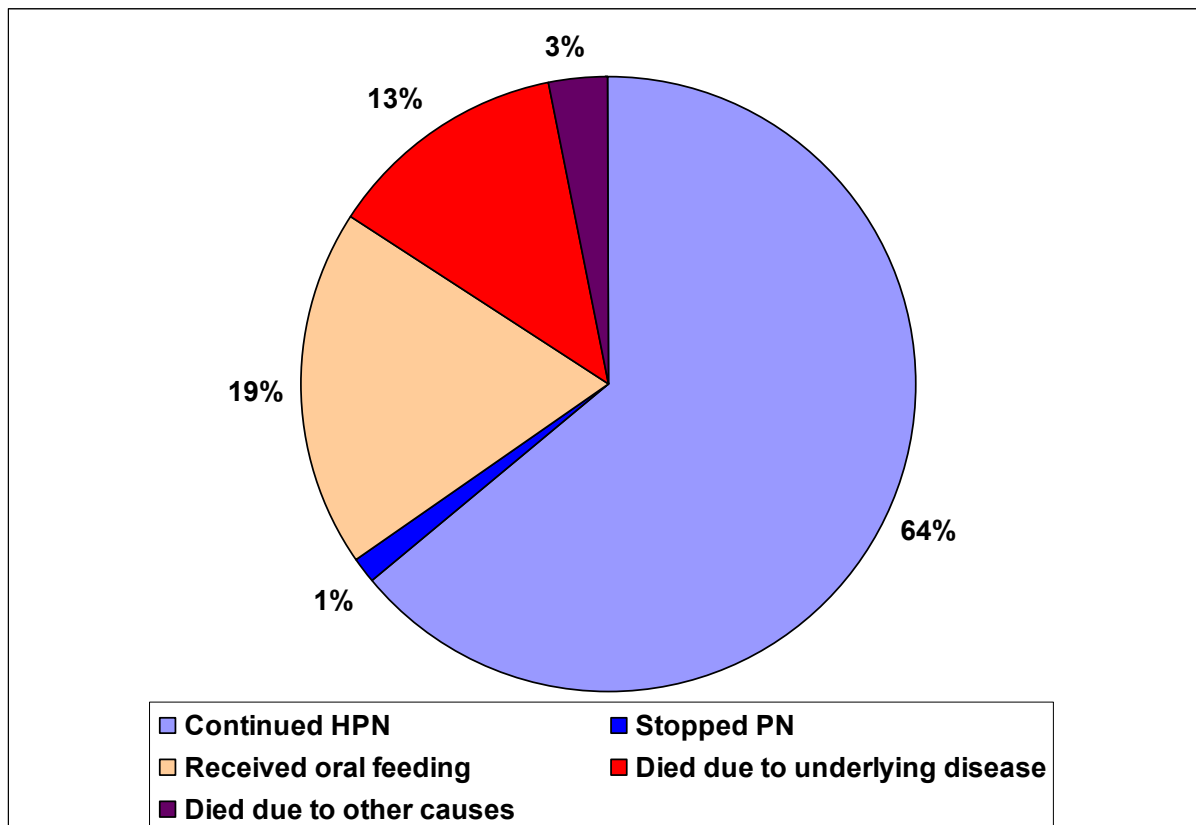
* NB: Outcome analysis is defined as the status of children at a specified time after the registration start date. Children's records were only selected for this analysis if they met the following criteria:

- the outcome code was not 'lost to follow-up' or 'care transferred.'

- the length of feeding start date to end date or to date of analysis if still on HPN was at least 12 months.
- the reporting centre had updated the patient record at least 12 months after the start date of this episode of HPN (updates are requested each six months),

Because of these criteria, not all patients are included in the outcome figures.

Figure 7.5: HPN 12 month outcome data



Categories	%	n
Continued HPN	64.6	51
Stopped PN	1.3	1
Received oral feeding	19	15
Died due to underlying disease	13	10
Died due to other causes	3	2

Section 8

Transition from childhood to adult HAN

Christine Holden

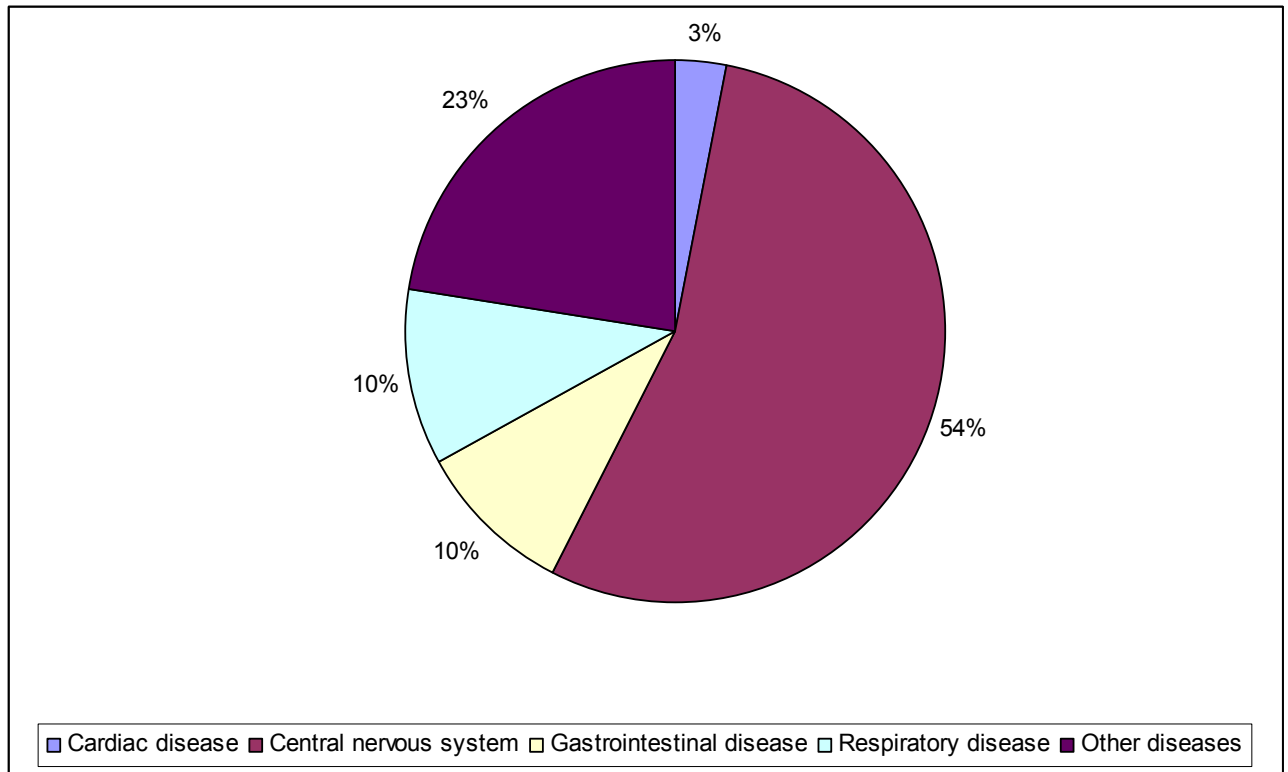
Children with chronic illnesses need complex inter-disciplinary care to help their transition to adult care.

Transition of vulnerable children from children to adult nutritional support services has become a high priority. As noted in Section 5, the proportion of children in the age group 13-15 has increased over the last 6 years. In this year's report, BANS has attempted to estimate the number of children moving from age group 13 – 15 years (i.e. up to 16th birthday) to 16 -19 years of age (i.e. up to 20th birthday) on the adult registers for HETF and HPN.

HETF Transition

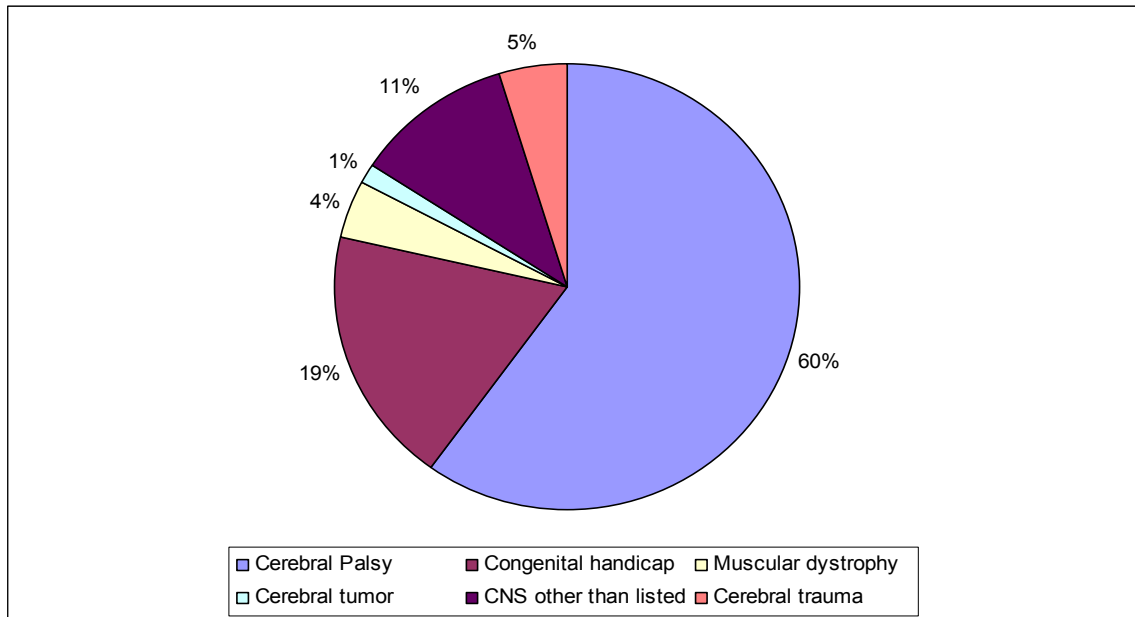
We have searched the 2006 enteral data base to determine how many of 16-20 year age group have transferred to adult care from the 13-15 year group in 2006 or previous years. There were 671 patients identified, 321 females and 350 males. Cerebral palsy (32.4%); congenital handicap (10.13%); cystic fibrosis (9.68%) featured predominantly. Figures 8.1(A, B&C) detail the diagnostic groupings.

Figure 8.1: HETF Diagnostic categories



Diagnostic categories	Numbers of children
Cardiac disease	21
Central nervous system	364
Gastrointestinal disease	65
Respiratory disease	70
Other diseases	151
Total	671

Figure 8.1 (A): Breakdown of HETF diagnostic categories – Central nervous system

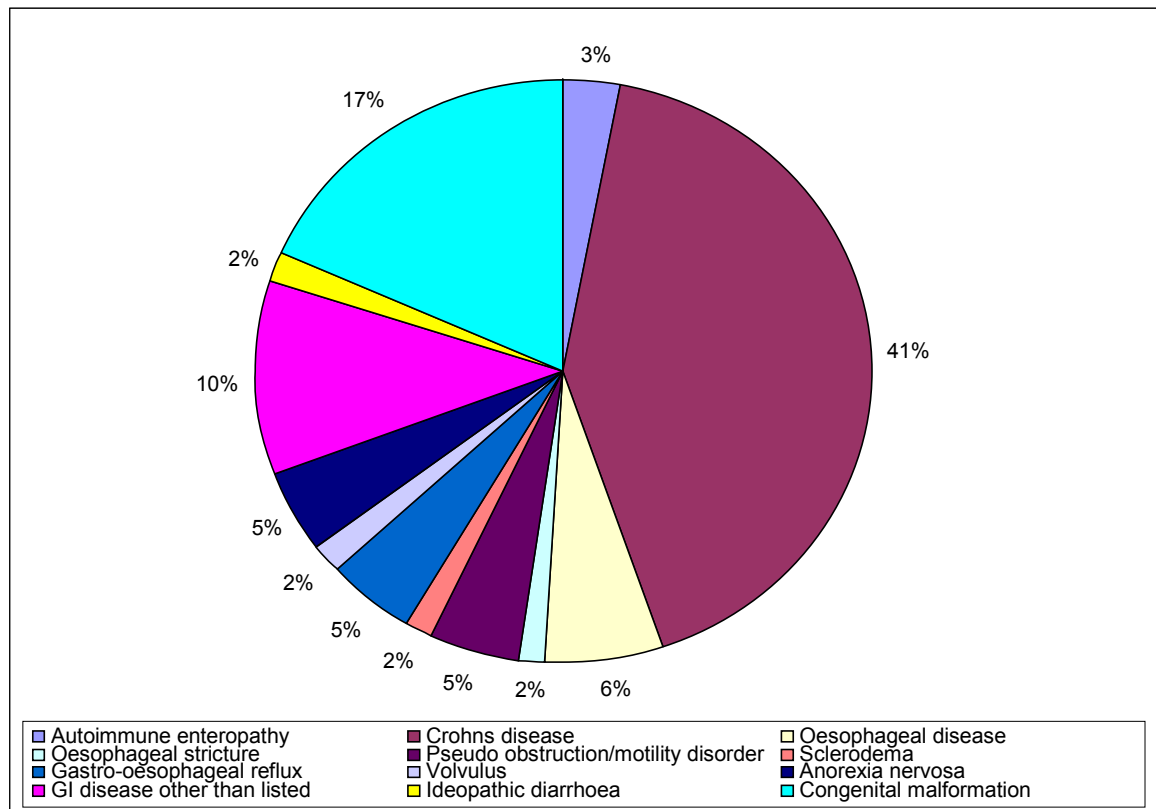


Central nervous system	Numbers of children
Cerebral Palsy	218
Congenital handicap	68
Muscular dystrophy	15
Cerebral tumour	5
CNS other than listed	41
Cerebral trauma	17
Total	364

Cerebral palsy is the dominant neurological condition requiring HETF transition.

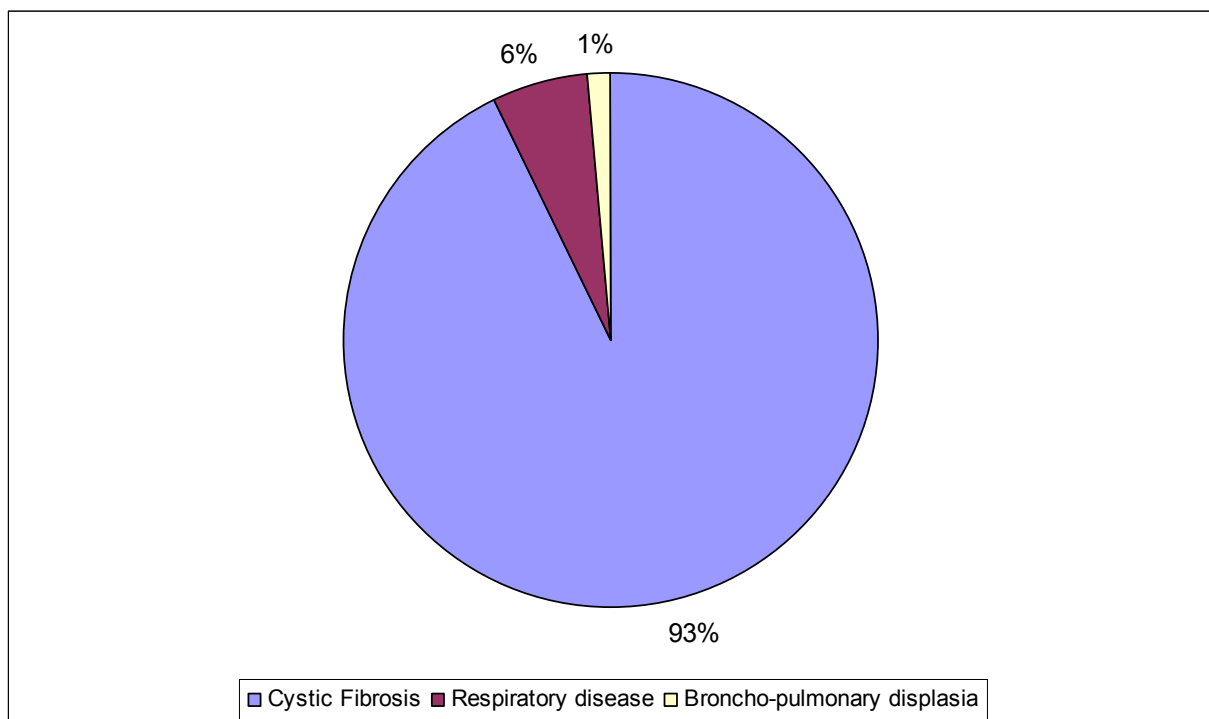
Crohns is the dominant gastrointestinal condition and cystic fibrosis the dominant respiratory condition.

Figure 8.1 (B): Breakdown of HETF diagnostic categories – Gastrointestinal diseases



Gastrointestinal disease	Numbers of children
Autoimmune enteropathy	2
Crohns disease	27
Oesophageal disease	4
Oesophageal stricture	1
Pseudo obstruction/motility disorder	3
Scleroderma	1
Gastro-oesophageal reflux	3
Volvulus	1
Anorexia nervosa	3
GI disease other than listed	7
Idiopathic diarrhoea	1
Congenital malformation	12
Total	65

Figure 8.1: (C) Breakdown of HETF diagnostic categories – Respiratory diseases



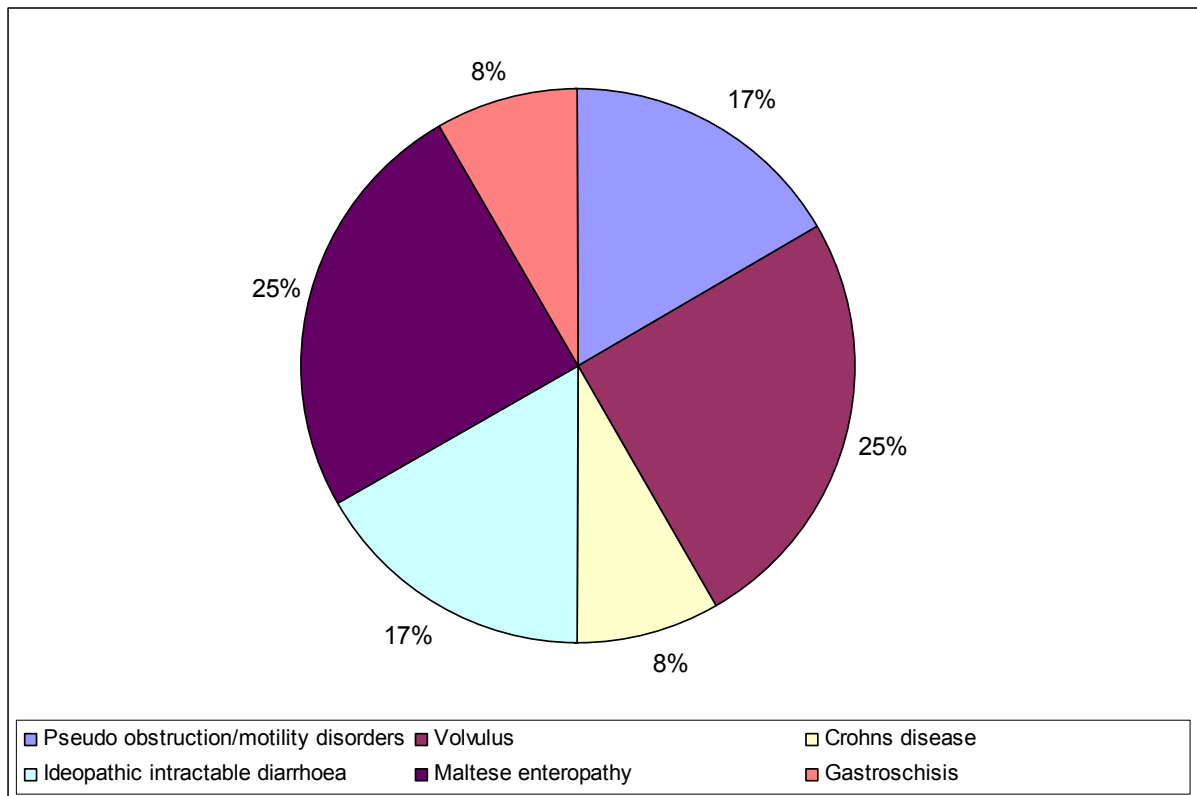
Respiratory disease	Numbers of children
Cystic Fibrosis	65
Respiratory disease	4
Broncho-pulmonary displasia	1
Total	70

HPN Transition

Fourteen patients (3 females and 11 males) were identified (Figure 8.2) in 2006.

All had gastrointestinal conditions requiring HPN. Despite the small numbers, the duration of nutritional support and the complexity of care demands a national coordinated approach to enable such children to make the transition to adult care.

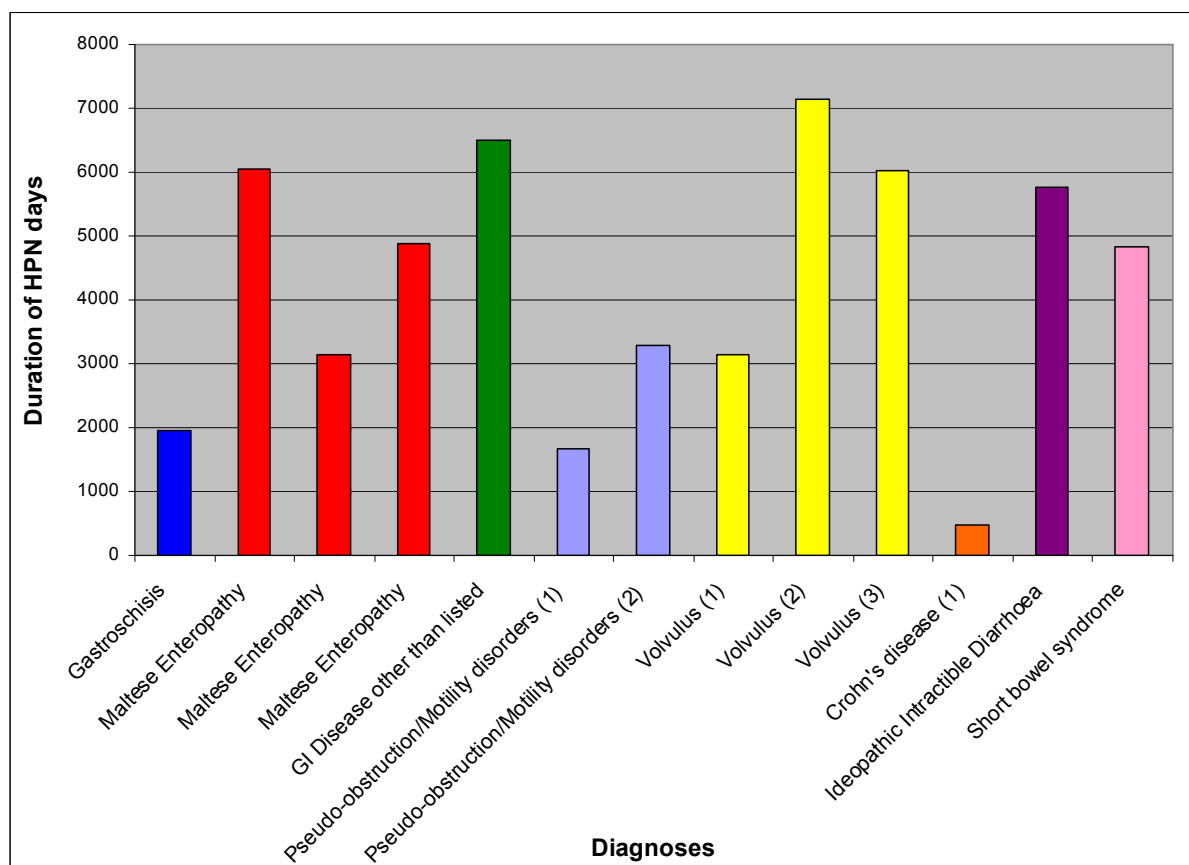
Figure 8.2: HPN Diagnostic categories – Transitional data 2000 - 2006



Diagnosis	Number of patients
Pseudo obstruction/motility disorders	2
Volvulus	3
Crohns disease	1
Idiopathic Intractible diarrhoea	2
GI diseases other than listed	5
Diseases other than listed	1
Total	14

Duration of feeding is detailed in Figure 8.3 with range of 486 to 6038 HPN days, for a total of 54829 days monitored.

**Figure 8.3: Duration and diagnostic categories for HPN patients–
Transitional data 2000 - 2006**



Diagnosis	Duration at end 2006
Gastrostschisis	1948
Maltese Enteropathy	6038
Maltese Enteropathy	3135
Maltese Enteropathy	4892
GI Disease other than listed	6494
Pseudo-obstruction/Motility disorders (1)	1665
Pseudo-obstruction/Motility disorders (2)	3285
Volvulus (1)	3131
Volvulus (2)	7148
Volvulus (3)	6028
Crohn's disease (1)	486
Ideopathic Intractible Diarrhoea	5753
Short bowel syndrome	4826
Total days on PN	54829

Section 9

Independently acquired data compared with BANS data

Janet Baxter and Barry Jones

We have again obtained independent data from commercial homecare companies (CHC) providing support to patients on HAN. This data is aggregated and anonymous but represents the overwhelming majority of patients receiving such support in the UK (Table 9.1). CHCs are not involved in paediatric HAN to the same extent as in adults (table 9.2).

Assuming a correction factor based on CHC data and assuming that the % shortfall in non CHC patients is the same as for CHC supported patients, we have estimated the shortfall in reporting of period prevalence in 2006 (Table 9.1)

In 2006, shortfalls in reporting of HAN fell compared to 2005 which indicates that the reporting base is holding up despite many adverse factors (see Sections 1 & 2). Adult HPN registrations recorded by BANS are only 5.4% less than those predicted from CHC data.

The total number of adults and children estimated to have received HAN in 2006 in the UK was 36427 (HPN 816; HETF 35529; Adults 25308; Children 11119)

Table 9.1: Point prevalence of UK patients receiving nutritional supplies from Home care companies (CHC) – Data from CHCs February 2007 compared to BANS data for 31st December 2006*

	HETF		HPN	
	ADULT	PAED	ADULT	PAED
1. Totals supplied by CHC companies	18585	8014	643	88
2. BANS 2006 total Pt prevalence	19583	4896	716	95
3. % CHC – BANS Pt prevalence, 2006	75.7%	73%	84.9%	62.1%
4. CHC numbers known to BANS, 2006	14824	3574	608	59
5. Estimated point prevalence, 2006	24551	10978	757	141
6. Estimated % shortfall (2005 data)	20.2%(29)	55.4%(65)	5.4%(18)	33%(39)

* The data shown in Table 9.1 does not include any from Northern Ireland where HAN is provided from NHS sources.

Table 9.2: Contribution by Commercial homecare companies to HAN – derived from BANS data, 2006

	New	Point prevalence
	%	%
Adult HPN	95	84.9
Adult HETF	80.6	75.7
Paed HPN	90	62.1
Paed HETF	79.9	73.0

Section 10

Ongoing Developments

10.1 BANS – Obtaining Consent

Ann Micklewright & Barry Jones

Background

Since BANS inception in 1996 there has been ongoing discussion about the need for reporters to obtain consent from patients before submitting details to BANS.

In 1998 the Data Protection Act (DPA98) became law and requires a patient to give consent before his/her details can be passed on to another party. More than 80% patients registered on BANS are on Home Enteral Tube feeding (HETF). Many are too ill or incapable of giving consent at the time of starting feeding. Growing concerns regarding the need for prior consent from patients has led to some organisations withdrawing from submitting data.

Section 60 of the Health & Social Care Act 2001 (H&SCA)¹ permits the temporary setting aside of the Common Law duty of Confidentiality for the use of medical records for specific purposes but does not set aside the requirements of the DPA98. (Guidance Notes: Section 60 of Health & Social Care Act 2001 (H&SCA)).

PIAG² (Patient Information Advisory Group) is a government advisory body responsible for ensuring that the DPA98 and H&SCA are complied with. Organisations such as BANS can apply to PIAG to obtain Section 60 exemption. This protects the provider of information when obtaining extracted information from medical records to submit to another organisation.

BANS Submission to PIAG for Section 60 Exemption in September 2006

PIAG granted approval to continue collecting audit data without consent for 12 months on condition that BANS committee develop an exit strategy from Section 60 support. This requires BANS to:

- consider how Reporters might seek consent from in-patients as an interim measure.
- consider the implications of the Mental Capacity Act and its Code of Practice and how assent may be obtained from family members or representatives of patients who lack capacity.
- develop patient / carer information leaflets to explain the work of the audit, and the right of opt-out, for dissemination via the clinical centres and community staff.

During the past year the BANS committee has pulled together a **portfolio of consent documents** which Reporters will be able to access initially through BAPEN website and later through Electronic BANS.

The portfolio includes:

- Guidance for BANS Reporters when patients lack the mental capacity to consent or refuse permission to enter BANS survey
- Patient information sheet for adults & young people
- Parent or guardian information Sheet
- Information sheet for consultee (relative, carer, advocate) on behalf of patient lacking capacity to consent to inclusion of their details in the BANS survey
- Adult consent form (age 16 and over)
- Consent form for parents/guardian of child
- Assent form for adults unable to consent

The current position with PIAG, 17th October, 2007

At a meeting between PIAG and BANS representatives 17.10.07, much progress was made. BANS is optimistic that Section 60 support will be extended subject to further a further submission to PIAG from BANS to be heard in December 2007. It was acknowledged that much progress has been made to develop an acceptable “exit” strategy over the last year since provisional Section 60 support was given. The success of the resubmission will depend upon our implementation of informed consent for all children and those adults with sufficient mental capacity. For those lacking capacity, assent will be required instead of consent. It seems that there will be a degree of flexibility in the next year regarding the degree of implementation of these measures. We will be collecting data through e-BANS to support our claims for gathering of consent. Please continue to provide your data until further notice. BANS will communicate any further developments to our reporters at the earliest opportunity.

Reference

1. Health & Social Care Act 2001
<http://www.hmso.gov.uk/acts/acts/2001/20010015.htm>
2. PIAG www.advisorybodies.doh.gov.uk/PIAG

10.2: e- BANS 2008 – BANS at the Reporters' fingertips!

Ann Micklewright & Geoff Cooke

Electronic BANS (e-BANS)

Since its inception in 1996 BANS Reporters have provided data in paper form. New patient details are entered onto a yellow registration form which is mailed to BANS where data are entered manually. Some reporters enter new patient data on to the register via an export disk. Some Home Care companies have provided assistance with reporting but this practice will cease shortly. At 6 monthly intervals the reporters receive a hard copy '*current status listing*' to check, update and return. These data are used to maintain the BANS database and for the production of the BANS annual report.

Reporters find the current process time consuming as well as inaccurate due to a coding system which is open to inconsistent interpretation with insufficient diagnostic categories and lost or missing data. Such issues affect the integrity of BANS data and its ability to retain and recruit new reporters.

Following a survey of BANS reporters in 2005, there was a strong consensus that an electronic system would be more effective. Figure 10.2.1 compares the current system (in yellow) and the proposed electronic reporting system (in blue).

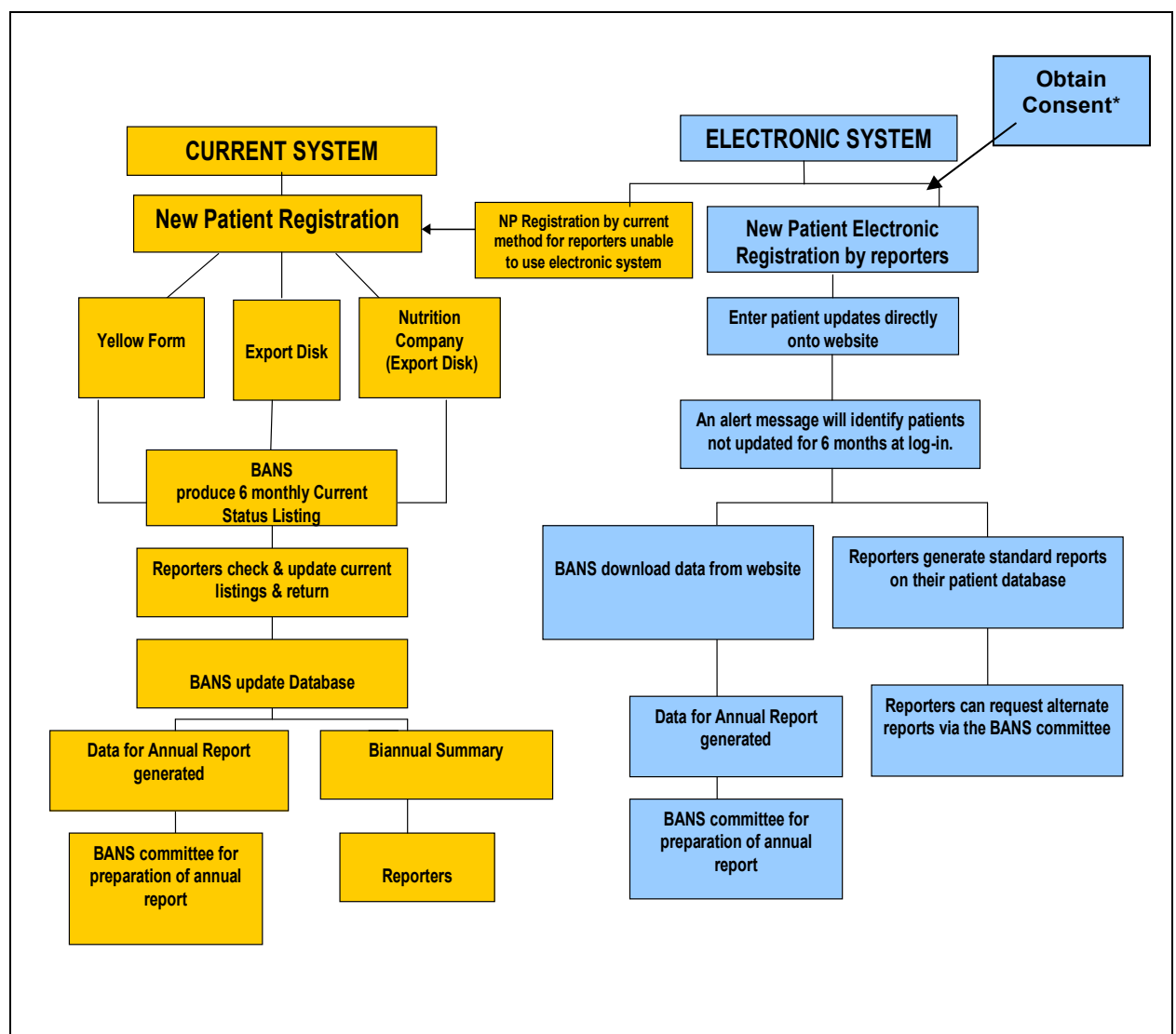
BANS at Reporters' fingertips – the benefits:

- Reporters will input their own data directly into their own database linked to www.e-bans.com.
- New patients will be entered directly onto the system on discharge and updated when changes occur. This will improve the timeliness and accuracy of the data and eliminate the need for second parties (including the homecare companies to input data) and information will not get lost in the post.
- The 'current status' list will be discontinued and reporters will be alerted to patients who have not been updated for 6 months each time they log-on to the system.
- The 'Bi-annual' report will disappear and instead a reporting tool will be installed on the programme, allowing reporters to run a number of standard 'real time' reports to fulfil their clinical and management needs.
- Inconsistencies in interpretation of coding options will be eliminated as drop-down boxes will give more precise choices. More appropriate diagnoses will be included to remove the need to use 'other' category in most circumstances.
- Less useful fields will be removed e.g. 'functional status' and 'location' for children to streamline the system.

This system is designed around feedback from Reporters and the BANS Committee's experience of the current system. Giving reporters the opportunity to manage their own data and to produce reports which provide local clinical and management data as and when required should aid recruitment and retention of reporters, produce more meaningful, timely and accurate data for the Annual Report, reduce postage and stationery costs for BAPEN.

Electronic BANS will be rolled out to reporters from January 2008. We will also have to introduce a new paper version for those unable or unwilling to switch to the electronic system. Otherwise we would be collecting 2 different sets of data.

Figure 10.2.1: Comparison of the current and proposed electronic BANS systems



**consent will be required for all new registrations whether using electronic or paper reporting*

The BANS Committee, 2007

Dr Barry JM Jones, BANS Chair, Consultant Gastroenterologist, BAPEN Medical.

Christine Holden, BANS Hon Sec, Paediatric Nutrition Nurse Specialist, National Nutrition Nurse Group (NNNG).

Prof. Marinos Elia, Consultant Physician & Professor of Clinical Nutrition and Metabolism, Nutrition Society. Founder of BANS, Chair BAPEN.

Ann Micklewright, Dietitian, Parenteral and Enteral Nutrition Group (PENG) of the British Dietetic Association.

Dr Rebecca Stratton, Nutrition Society and also enteral homecare company representative (Nutricia Ltd.)

Dr Nigel Meadows, Consultant Paediatric Gastroenterologist, British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN).

Dr Mark Dalzell, Consultant Paediatric Gastroenterologist, BSPGHAN.

Janet Baxter, Dietitian and Manager, Scottish Managed Clinical HPN Network, Scottish Representative BAPEN and ESPEN – HANS group.

John Kennedy, Nutrition Nurse Specialist, National Nutrition Nurse Group (NNNG)

Carolyn Wheatley, HPN Patient, Chair of Patients on Intravenous and Nasogastric Nutrition Therapy (PINNT).

Carole Glencorse, Dietitian, enteral homecare company representative (Abbott Nutrition).

Lucy Thompson, Pharmacist, British Pharmaceutical Nutrition Group (BPNG),

Geoff Cooke, BANS data analyst, Streets - Heaver Ltd.

Lynn McCready (Calea) and James Astrop (Clinovia), parenteral nutrition homecare company representatives.

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