



Annual BANS Report, 2008

Artificial Nutrition Support in the UK 2000 - 2007

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: Annual BANS Report, 2007; Artificial Nutrition Support in the UK 2000 – 2006. www.bapen.org.uk
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BANS: Trends in artificial nutrition support in the UK, 2000 – 2003.
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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.
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BANS: Trends in Artificial Nutrition Support in the UK During 1996 – 2000.
ISBN 1 899 467 505 (Published 2001)

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.

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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

Abbreviations and Definitions of Terms

Abbreviations

BANS	British Artificial Nutrition Survey
BAPEN	British Association for Parenteral and Enteral Nutrition
BIFS	British Intestinal Failure Survey
CHC	Commercial Homecare Company
ETF	Enteral Tube Feeding
GI	Gastrointestinal
HANS	Home Artificial Nutrition Support
HETF	Home Enteral Tube Feeding
HIFNET	Home parenteral nutrition and intestinal failure network (England)
HPN	Home Parenteral Nutrition
IF	Intestinal failure
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 2.

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 report is the third to be published on the website.

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, and a meeting in October 2007 with PIAG to discuss progress, we have again been given Section 60 support. However, due to administrative errors on the part of PIAG, this did not appear on the PIAG website until this summer. We are now optimistic that we will be given further Section 60 support subject to resubmission to PIAG in December.

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 and is now being rolled out to those reporters wishing to make the switch to the electronic system.

We now have a new logo which literally places BANS at the heart of BAPEN.....



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. The specially developed consent and information forms are now available on BAPEN and e-BANS websites.

We have again 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 almost 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 its reporters across the UK.

A landmark achievement for BANS was reached this year. The publication of the HIFNET is the culmination of a journey which started with data on Adult HPN patients and the variations in access to treatment identified by BANS. This highlighted the need for a coordinated approach to commissioning of HPN services and those required for intestinal failure (over and above those commissioned for severe IF by NSCAG)

.....Which brings me to our reporters. The chair of BANS would again 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.

And finally, as this is my last report as Chair of BANS, I would like to thank all the members of the committee and in particular our Hon Secretaries who have supported me so well.

Dr Barry Jones
Chair of the BANS committee, November, 2008

Section 3.

Executive summary

Adult HETF

1. Despite new registrations falling from a high of 7187 in 2001 to 5182 in 2007, point prevalence has risen to its highest recorded at 21858. Similarly, period prevalence has risen to its greatest level at 24203.
2. New registrations per million UK population were 87, point prevalence 365 and period prevalence 404.
3. An average centre cares for ~66 patients per year.
4. Adult HETF patients are predominantly older in age with 66.5% >60 years old.
5. Approximately 60% live in their own homes but ~70% require total or significant help with their HETF. In the >75 year category, ~90% are bed bound, housebound or have limited activity.
6. Neurological disorders account for 50% of new cases. Cerebrovascular accidents are the commonest indication for HETF. Dementia has declined as an indication for HETF.
7. Both absolute numbers and the proportion of HETF new cases with cancer are steadily rising to 25% of all HETF.
8. Nasogastric tube feeding accounts for only 13% of new cases with Gastrostomy being by far the commonest route of administration (83%).
9. Commercial homecare companies support 80% of new cases and 83% of established patients.

Paediatric HETF

1. New registrations recovered from the low of 772 in 2006 to 821 (6.3% rise). Point and period prevalence also rose by 7.2% and 2.9%.
2. Reporting centres rose from 116 in 2006 to 137 indicating that our reporter base has held up well despite problems mentioned in the Preface.–
3. The number of new registrations per centre in 2007 ranged from 1 – 53. Nine or less new children were registered by 82% (112 centres)–, of which 44% (49) registered only one child each. This raises questions as to the standard of care when experience of HETF is so small in many centres. However, it also suggests that more centres are offering enteral nutritional support to their children.
4. The age group 13-15 years represents 9.3% new and 14.9% point prevalence. It is likely that many of the latter will transition to adult services in the future, an important point for those planning services.
5. 97% of children were discharged home with full activity recorded in 49%, limited activity in 45% but only 5% were housebound.

6. On discharge 33% children were fed via a PEG. This figure rises to 52% in established cases. Nasogastric tube feeding therefore predominates.
7. Commercial homecare companies were involved in 86% on discharge and 75% of established cases.

Adult HPN

1. New registrations rose dramatically in 2007 by 36.6% to 138. Point prevalence rose by 8.9% to 867 and period prevalence by 16.7% to 867. These rises reflect major increases in reporting from England and Northern Ireland.
2. Reporting centres numbers fell in 2006 but this looks to have been an anomalous return.
3. There are still a large number of centres reporting cases each year. As shown in BANS report 2005, the majority of these centres have little experience of HPN.
4. UK point prevalence per million rose from 12 to 13.1 and period prevalence from 12.5 to 14.5
5. English new registrations rose 38% to 116. Point prevalence rose by 11% to 657 and period prevalence rose 18.2% to 726. Point prevalence per million has risen from 11.8 in 2006 to 13.1 in 2007 and period prevalence from 12.3 to 14.5 per million.
6. Scottish point prevalence per million has stabilised at 15.1 and period prevalence at 16.1 (2006: 16 and 16.7 respectively)
7. Welsh point prevalence (7.1) and period prevalence (7.5) per million remain the lowest of the home countries. Under reporting appears to be a problem in the Welsh network despite the existence of a standard requiring reporting of cases to BANS. It is hoped that this will be resolved in the coming year.
8. Northern Irish point prevalence (22.2) and period prevalence (22.8) per million are the highest in the UK (2006: 15.2 and 15.2 respectively)
9. The modal age for adult HPN is 51 – 60 years of age.
10. 43.4% of new cases are aged 16 – 50.
11. Short bowel syndrome remains the main reason for HPN (41.3% new cases; 53.6% established cases)
12. Crohns is no longer the dominant diagnosis of new registrations (13%) but remains the commonest indication amongst established cases (27.3%). Ischaemia of the small bowel is the commonest reason for new cases (19.4%) but accounts for fewer cases of established patients (19.9%) than Crohns. A substantial heterogeneous group including surgical disasters accounts for 15.2% of new cases and 14.1% of point prevalence. Surprisingly, neurological conditions also represent a significant group with 13.8% of new cases but only 4.2% of point prevalence. This would suggest short term HPN in these cases.
13. HPN patients are now discharged to nursing homes more frequently 10.1% than in 2000 (1.1%). These figures are surprising but suggest that some patients are being discharged to nursing homes for short term care as these patients are poorly represented among point prevalence data (4.1%). Although we have no evidence, it is possible

that elderly or cancer patients are being offered short term HPN in nursing homes. If so, this requires confirmation and debate.

14. Although a minority of new cases are described as bed bound (3.6%) or housebound (8%), only 49.3% are described as fully independent, the remainder requiring assistance with their HPN.
15. Subcutaneous ports have enjoyed greater popularity in 2007 (9.4%) compared to 2006 (3%). However, use of this technique has varied considerably over the last 7 years with no clear trend.
16. Commercial homecare companies contribution continues to rise with 95.7% of new cases. This has carried through to established cases with 87% in 2007 compared to 79% in 2000.

Paediatric HPN

1. New registrations rose from 10 in 2006 to 17 in 2007. Point and period prevalence figures are stable. It is difficult to interpret these figures due to under reporting (see Section 8).
2. The number of centres has improved to 9 which is reassuring in view of the poor BANS returns in 2006. This bodes well for the transfer to e-BANS. However, the committee are aware that some large centres do not report to BANS. Hopefully, such centres are involved in reporting to BIFS but perhaps reporting to BANS should be a standard of care as it will be for adult HPN patients within HIFNET (the English network) and as it is already for adults in Scotland and Wales.
3. Post necrotising enterocolitis is the commonest indication for HPN (23.5% new cases) with intractable diarrhoea of infancy at 17.6% and volvulus at 11.8%. Pseudo-obstruction is in second place in established cases (11.8%). BANS has revised diagnostic categories for use with e-BANS so the large miscellaneous group should be exposed to greater clarity.
4. No new cases were discharged with a subcutaneous port but 9.5% of point prevalence (established cases) received HPN via such a port.
5. Commercial homecare companies were involved in support of 100% of new registrations but only 68.4% of established cases.

Independently acquired data

1. The BANS objective to collect 100% of Home Artificial Nutrition patients has been tested once again by obtaining anonymous data from the commercial homecare companies. Using these data we have estimated the total number of cases whether receiving commercial homecare company support or not.
2. For adult HPN, reporters returned 90.7% of the total estimated cases. This bodes well for the introduction of the proposed English HPN and Intestinal Failure network (HIFNET) in 2010. BANS will be an integral part of HIFNET in that all HPN cases must be reported as a standard of care as is the case in Scotland and Wales.
3. For paediatric HPN, BANS surveys 59% of UK cases.
4. Adult HETF returns were 80.3% of estimated cases
5. Paediatric HETF attracts only 45% of estimated cases.

6. Paediatric HAN returns to BANS fall well short of the perhaps over ambitious BANS objective of 100% returns. Nevertheless, after 12 years BANS data is still the most complete source of information on HAN available in the UK. We believe that BANS is also the leading nutritional survey of its kind internationally.

Section 4

Home Enteral Tube Feeding (HETF) in adults (2000-2007)

4.1 New registrations, point and period prevalence

The number of adults receiving HETF and registered with BANS at the end of 2007 (point prevalence) was 21858. This represents a growth of 11.6% since 2006. The period prevalence has also grown by 4.8% since last year (Table 4.1). The observed increase may in part be due to a rise in the numbers of centres reporting between 2006 and 2007 (Table 4.1). The number of new registrations per centre decreased to ~20 between 2006 and 2007, although this figure has been stable at ~23 patients per centre over the past few years (Figure 4.1). Point prevalence figures have increased from ~58 to ~61 patients per reporting centre, while period prevalence figures remain constant at ~ 66 patients per centre (Figure 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 2007

	2000	2001	2002	2003	2004	2005	2006	2007
New registrations	6629 (275)	7187 (280)	6428 (264)	6585 (251)	5656 (252)	5978 (257)	5145 (216)	5182 (254)
Point prevalence	11817 (311)	13742 (318)	15148 (319)	16890 (319)	18260 (323)	18686 (333)	19583 (340)	21858 (357)
Period prevalence	15652 (319)	18376 (331)	19474 (331)	21028 (325)	21677 (327)	23095 (340)	23088 (347)	24203 (367)

Figure 4.1: Adult HETF in the UK - Number of new registrations, point prevalence and period prevalence per centre, 2000 to 2007

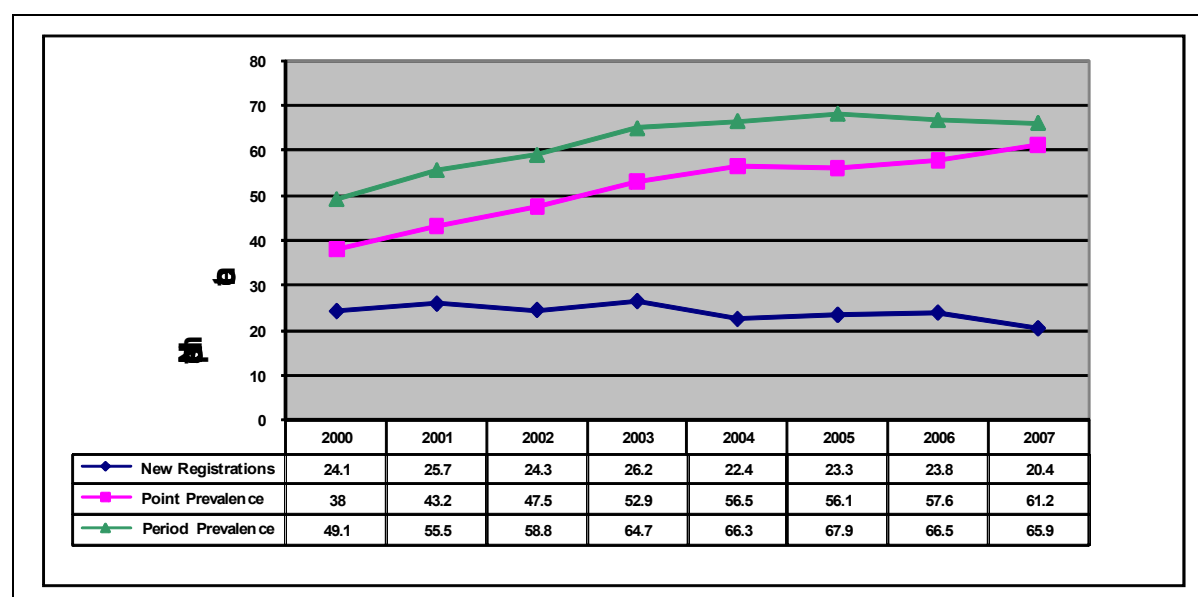


Table 4.2: Adult HETF in home countries / million population (2006 data in brackets)

	<i>New registrations/million</i>	<i>Point prevalence/ million</i>	<i>Period prevalence/ million</i>
England	86(85)	367(326)	400(381)
Scotland	57(78)	337(323)	372(396)
N Ireland	142(136)	366(425)	567(508)
Wales	119(98)	363(302)	440(377)
Isle of Man	48(107)	219(354)	392(419)
United Kingdom	87(86)	365(327)	404(385)

4.2 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 2007). Most were aged over 60y (66.5%), with ~43% 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.

4.3 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, with the most common single condition being cerebrovascular disease (25% of all patients, n 5553) (Table 4.2). New registrations of dementia have fallen to their lowest ever at 109 in 2007 compared to the maximum of 280 recorded in 2001.

Established numbers have stabilised over the last 3 years with 582 point prevalence in 2007 representing 2.7% of all adult HETF patients.

GI diseases were the second most common diagnostic group (~20% of patients, point prevalence), which includes cancers of the gastrointestinal tract. The third largest group was 'other' (17% 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. 10.8% (n 2351) in 2007). Overall 25% of patients (n 5606) (point prevalence) had a diagnosis of cancer, a proportion that continues to rise (Figure 4.3).

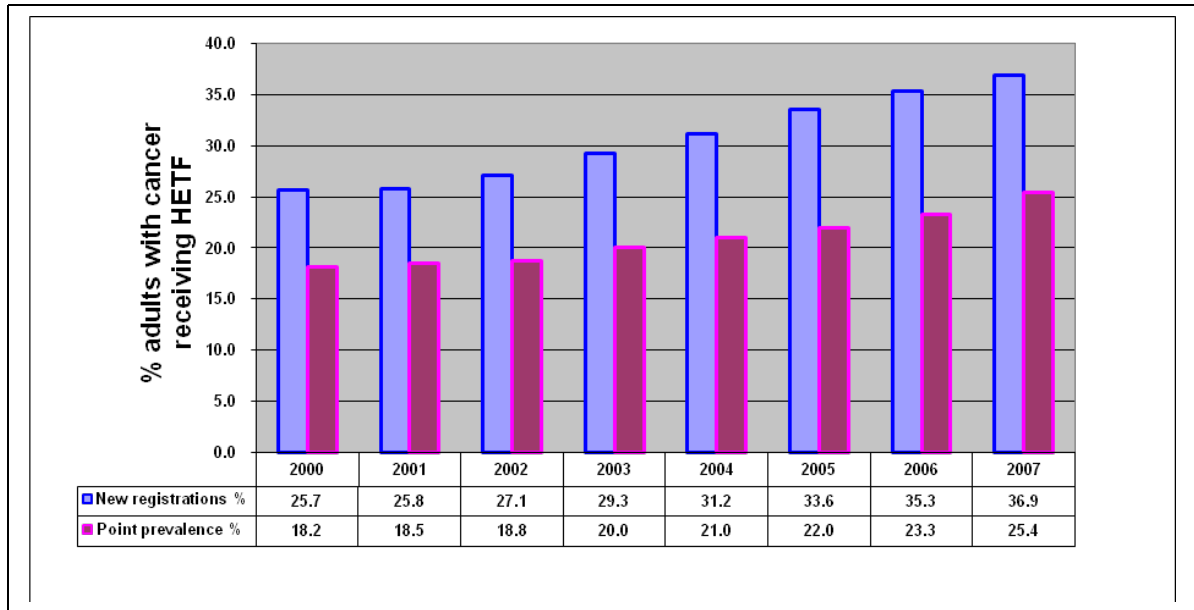
As in previous years, the two main reasons for feeding were a swallowing disorder (66.5% of patients, point prevalence) and improving nutritional status (23.6%, point prevalence). The reasons for feeding were similar in new registrations.

Table 4.3: Adults with Neurological conditions receiving HETF in UK, 2007

	New Registrations		Point prevalence	
	n	%	n	%
Cerebral Palsy	85	1.6	1093	5.0
Cerebral Trauma	140	2.7	831	3.8
Cerebral Tumour	23	0.4	97	0.4
Cerebrovascular Disease	1241	23.9	5553	25.4
Congenital Handicap	27	0.5	371	1.7
Dementia	109	2.1	582	2.7
Huntingdon's Chorea	39	0.8	280	1.3
Motor Neurone Disease	268	5.2	792	3.6
Multiple Sclerosis	214	4.1	1386	6.3
Muscular Dystrophy	19	0.4	130	0.6
Parkinsons Disease	169	3.3	603	2.8
Unspecified CNS condition	254	4.9	1065	4.9
Total	2588	49.9*	12783	58.5*

* % of BANS registrations with neurological disease

Figure 4.2: Increasing proportion of patients receiving HETF with cancer (2000-2007)



4.4 Enteral access route for adult HETF

Gastrostomy feeding continued to be the most common route of access in adult patients (83% (n 18075) of patients at the end of 2007), with only 13% fed via nasogastric tube and 4% by jejunostomy. This has changed very little since 2000.

4.5 Activity levels and ability to manage HETF

Although many patients receiving HETF (~61%) live at home, patients' activity levels and their ability to manage is mostly very limited. As in previous years, nearly 75% of adult patients had limited activity (33%) or were housebound (15%) or bed bound (28%) (based on point prevalence data). In the eldest patients (aged > 75 years), ~90% were bed bound, housebound or had limited activity.

Similarly the ability to manage HETF continued to be limited for the majority of patients. As in previous years, ~70% of patients required total help (n 11571) or some help (n 3832) to manage.

4.6 Use of commercial home delivery companies for adult HETF

More than 80% of adults newly registered with BANS on HETF and 78% of all patients (point prevalence) have a commercial home care delivery company. This has remained similar in recent years.

4.7 Adults and children receiving HETF

The combined total number of adult and paediatric patients receiving HETF and registered with BANS at the end of 2007 (point prevalence) was 27108 (21858 adults and 5250 children). The period prevalence for 2007 was 30034 (24203 adults and 5831 children). There were a total of 6003 new registrations (5182 adults and 821 children).

The point prevalence figure for 2007 suggested that at least 453 adults and children were receiving HETF at any one time per million of population in the UK (estimated UK population 59.8 million).

Since not all patients receiving HETF in the UK are registered with BANS, we have estimated that there were in the region of 39,000 patients receiving HETF at the end of 2007, as illustrated in Section 8.

Section 5

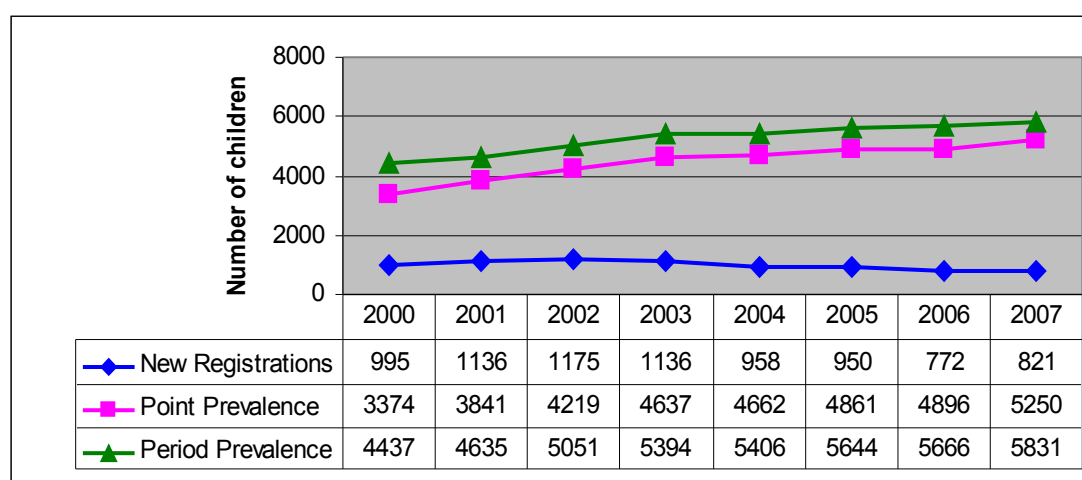
Home enteral tube feeding (HETF) in children

Ann Micklewright and Amanda Hirst

5.1 New registrations, point and period prevalence

The annual decrease in new registrations seen from 2003 to 2006, was reversed in 2007 with an increase of 6.3%, patient numbers rising from a low of 772 in 2006 to 821 in 2007 (Figure 5.1). Both point and period prevalence continued to increase by 7.2% (n, 5250) and 2.9% (n, 5831) respectively. (Figure 5.1)

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



5.2 Reporting Centres

At the same time the number of centres reporting new children increased from an all-time low of 116 in 2006 to 137 in 2007. The number of reporting centres for both point and period prevalence continued to rise reaching 241 and 253 centres respectively. (Figure 5.2 (A))

The number of new registrations per centre in 2007 ranged from 1 – 53. Nine or less new children were registered by 82% (n, 112) of centres, of which 44% (n, 49) registered only one child each. Period prevalence ranged from 1 to 201 children per centre during this one year period with 41% (n, 103) of centres supporting nine or less children, of which 32% (33) had only one child. Only four centres had 100 or more children. (Figure 5.2 (B))

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

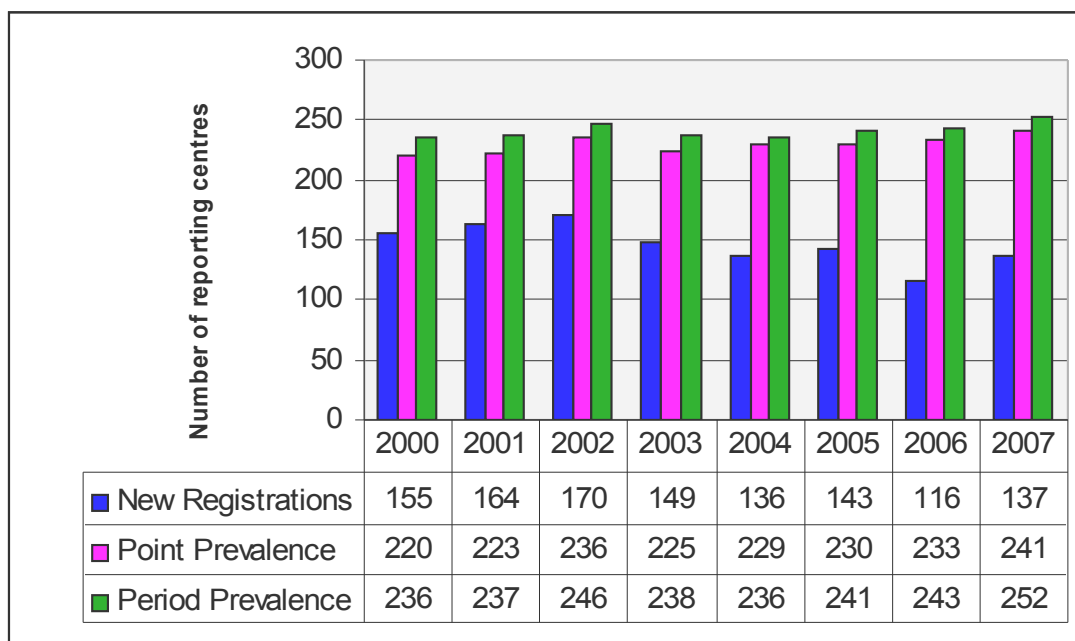
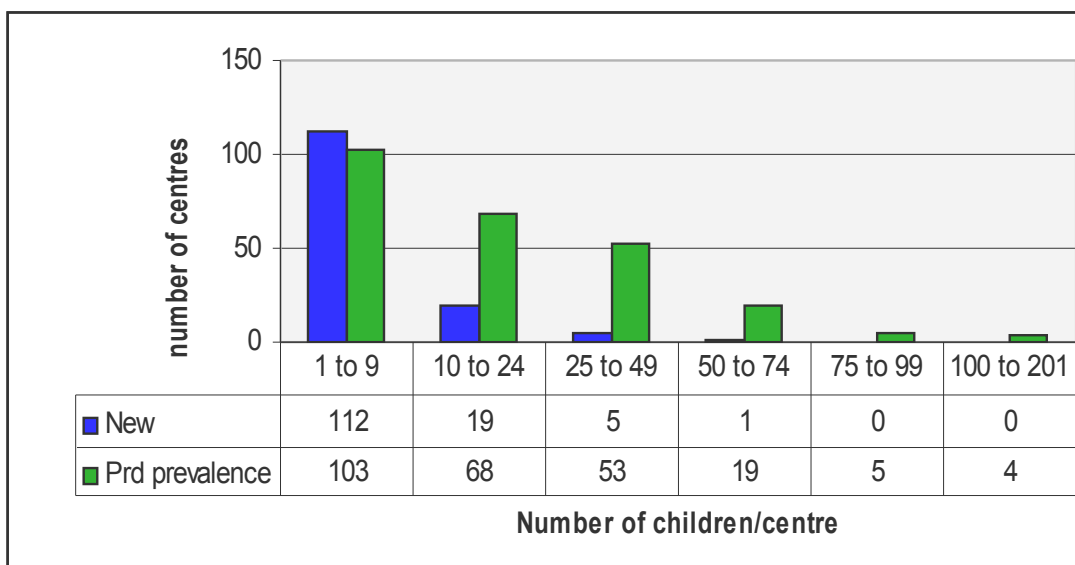


Figure 5.2 (B): Centres grouped by numbers of children - new and period prevalence



5.3 Diagnoses and indications for HETF

The main diagnostic categories recorded for new registrations and for period prevalence are shown in *figures 5.3 (A) and 5.3(B)*. Percentage contribution to both new and point prevalence data respectively is shown below with main primary diagnoses in *italics*.

- **Cardiac (9%, 8%):** *congenital (8%, 5%), other cardiac (1%, 3%).*

- **Neurological (33%, 41%):** cerebral palsy (11%, 17%), congenital handicap (5%, 10%), other CNS (10%, 9%).
- **Cancer (10%, 4%):** leukaemia (3%, 2%) head & neck (2%, 1%), other cancer (5%, 2%).
- **Non-malignant gastrointestinal GIT: (15%, 11%):** Crohn's (3%, 1%), gastro-oesophageal reflux (3%, 2%), other gastrointestinal (4%, 4%)
- **Respiratory disease (6%, 6%):** cystic fibrosis (2%, 3%), other respiratory (4%, 3%).
- **Miscellaneous disorders (27%, 30%):** FTT (failure to thrive) (8%, 7%), congenital malformation (5%, 5%), renal disease (2%, 3%), inborn errors of metabolism (1%, 3%), other miscellaneous (10%, 11%).

In all six categories a percentage of all data are classified as 'other' (see categories above). In total this amounts to one third of all children's diagnostic data, both new and period prevalence. This has caused some concern to both BANS and its reporters and will be rectified when e-BANS is introduced with a more extensive diagnostic 'pick list'. This has been developed through extensive consultation with paediatric doctors, dietitians and nurses. (See section 9).

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

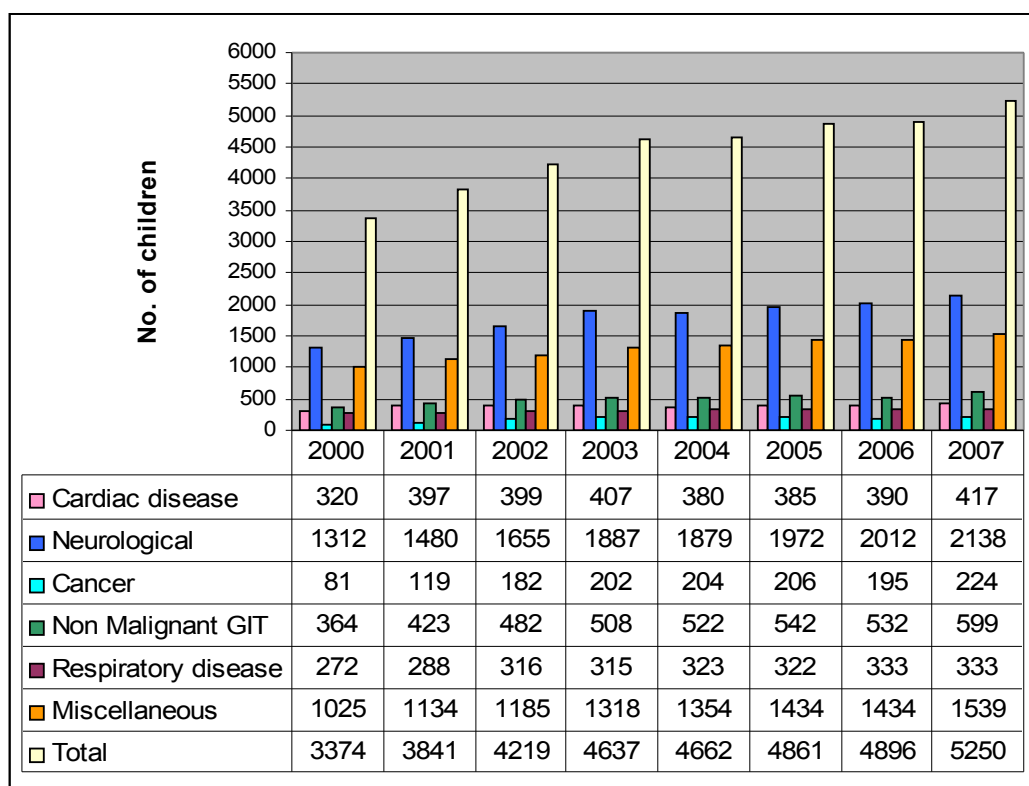
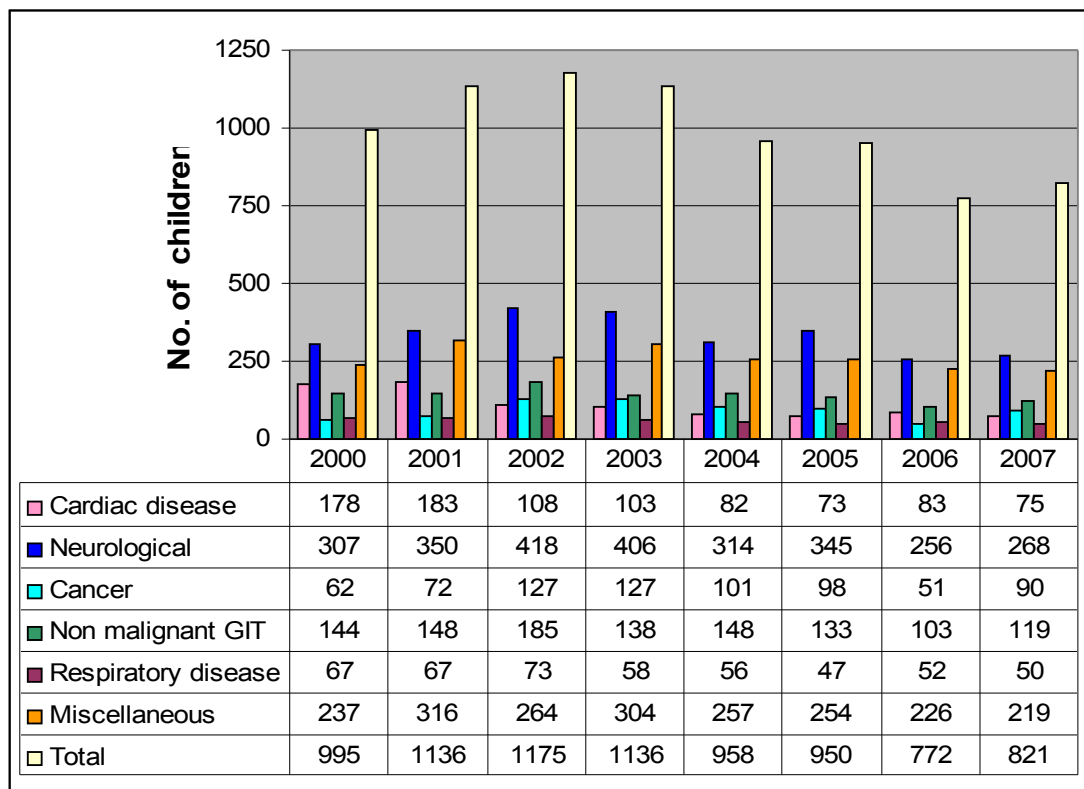


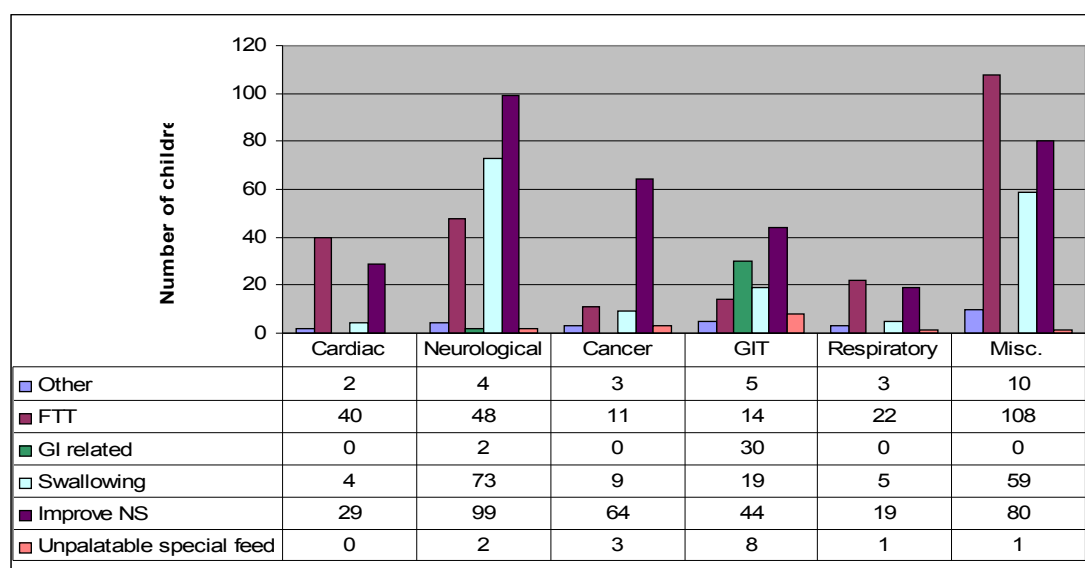
Figure 5.3 (B): main HETF diagnostic categories – point prevalence



5.4 Reasons for Home Enteral Tube Feeding (HETF)

Figure 5.4(A) indicates the reasons for feeding patients starting HETF in 2007. Over two-thirds of cases are accounted for by the 2 categories: 'to improve/maintain nutritional status' (40%) and 'failure to thrive' or the now preferred term 'faltering growth', (29%) and a further 21% for swallowing difficulties. GIT related disorders include: short bowel (1%), obstruction (<1%) and malabsorption (2%) and accounts for a further 4%.

Figure 5.4 (A): reasons for feeding by percentage of new registrations in 2007



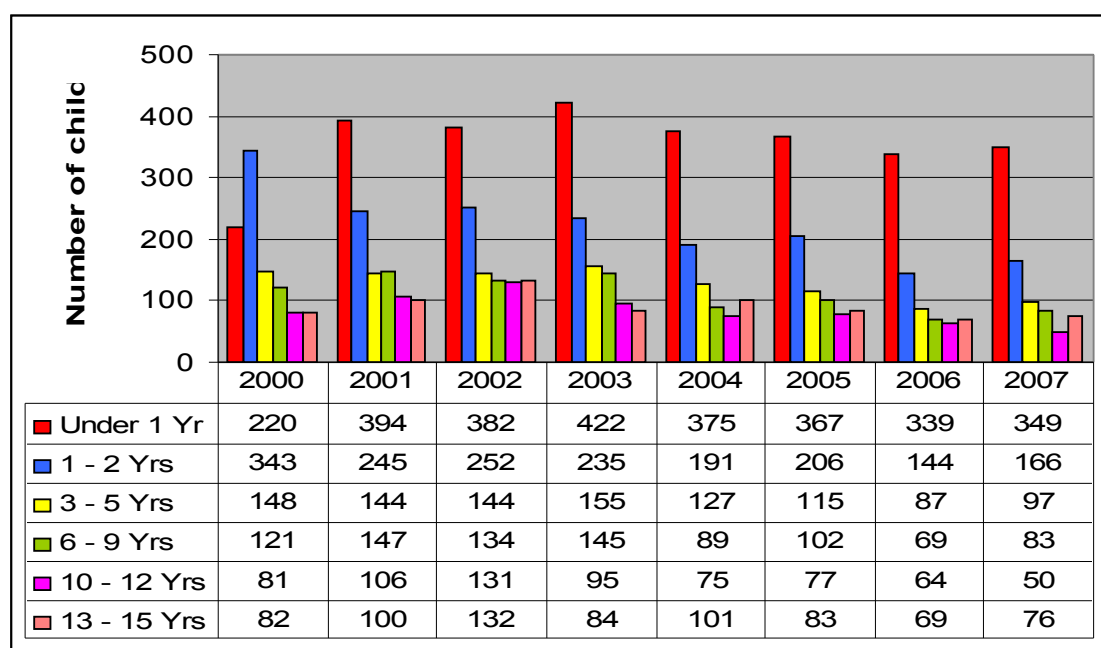
The association between the predominant reasons for feeding and the main diagnostic categories is outlined below:

- ❑ **Failure to thrive (FTT)** is indicated across all diagnostic categories. Congenital heart disease and cerebral palsy dominate cardiac and neurological categories respectively. FTT is also primary diagnosis listed under the miscellaneous category and as such accounts for nearly half of the children in this grouping.
- ❑ **Swallowing difficulties** are cited for neurological conditions, where cerebral palsy dominates. In the miscellaneous category over half the data is accounted for by congenital handicap and congenital malformation.
- ❑ **To improve/maintain nutritional status** is another basis for enterally feeding children with conditions already mentioned such as congenital heart disease, handicap, malformation and cerebral palsy. In addition leukaemia and cystic fibrosis dominate both cancer and respiratory disease respectively.

5.5 Age distribution

Age distribution of new registrants had not changed significantly since 2001 (Figure 5.5) when new registrations indicated a 13% increase in those under 1 year with a similar decrease in those 1-2 years old. Since 2001 there have been small fluctuations (1-3%) across all age groups. In 2007, 42.5% of new registrations were under one year, with 9.3% and 14.9% respectively aged 13-15 years. It is likely that many of the latter will transfer to adult services in the future, an important point for those planning services.

Figure 5.5: Age bands of newly registered children on HETF



5.6. Activity levels and location

Full activity was reported in 49% of new and 39% point prevalence registrations, with limited activity at 45% and 53% respectively. Only 5% of cases (both new and point prevalence) were housebound.

Both new (97%) and point prevalence (95%) data indicate that the majority of children were cared for in their own homes, figures are consistent with previous reports.

5.7 Route of enteral access and nutrient delivery

For new patients enteral access was by a nasogastric tube (66%), gastrostomy (33%) or jejunostomy (1%). By contrast a higher percentage of adults (78%) were discharged with gastrostomy feeding. It is suggested that this difference in practice may be accounted for by the shortage of children's endoscopy services rather than nasogastric access being the superior option.

As feeding become established children change to gastrostomy feeding (52%) in preference to nasogastric feeding (47%).

5.8 Homecare company involvement

Homecare companies were involved with families in 86% of new cases but only in 75% of established patients.

Section 6

Adult Home Parenteral Nutrition (HPN)

Dr Barry JM Jones

6.1 New registrations, point and period prevalence

New registrations have markedly increased in 2007 to 137(36.6%) after a long period of stability at around one hundred per year. Over the last year, point and period prevalence have also risen from 716 to 793 (10.7%) and 746 to 870(16.6%) respectively. This maintains the linear rise noted in previous years (*Figure 6.1(A)*) and is predominantly due to a rise in English data but new registrations in N. Ireland have also increased from 1 to 7.

Figure 6.1(A): Number of new registrations, point prevalence and period prevalence of HPN in UK, 2000 -2007

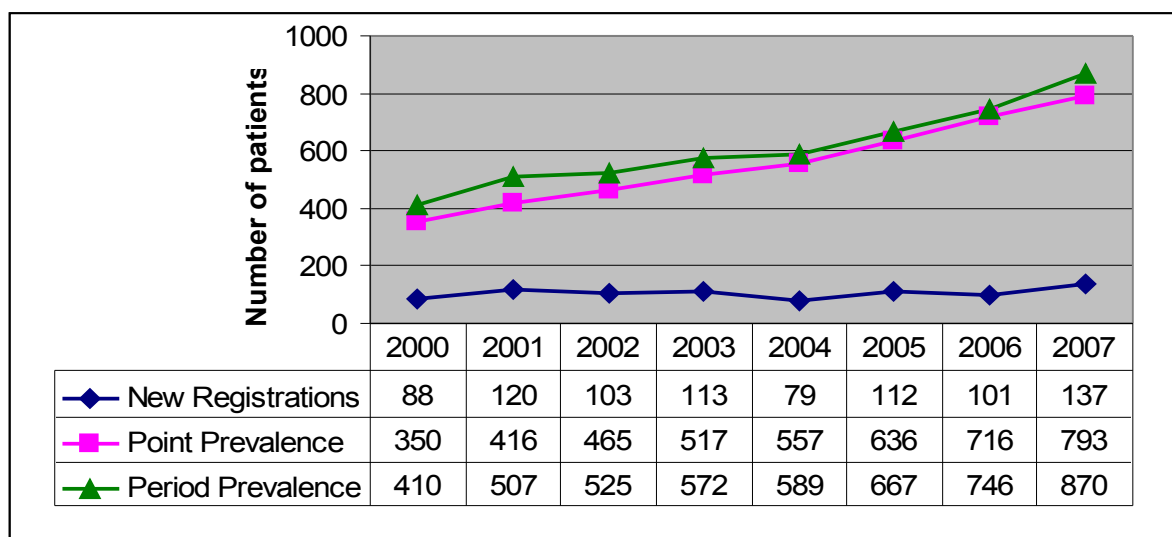


Figure 6.1 (B): Point prevalence in constituent countries of UK, 2000 – 2007

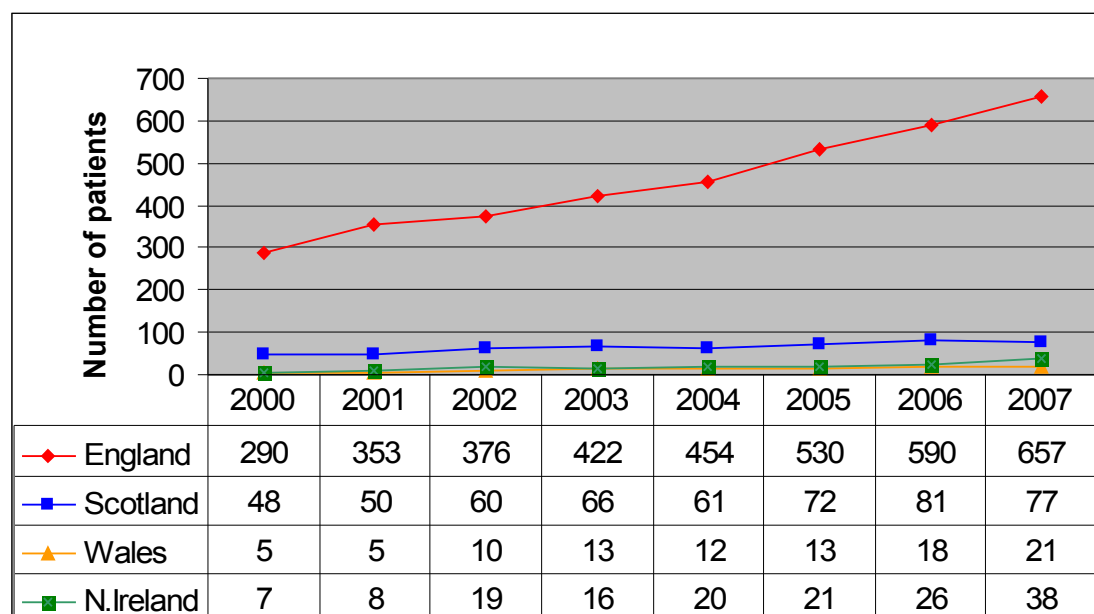


Table 6.1: Prevalence per million population* in UK and home countries in 2007 (2003) in brackets**

	New	Point prevalence	Period prevalence
UK	2.3 (2.0)	13.1 (8.8)	14.5 (9.8)
England	2.3 (2.0)	13.1 (8.6)	14.5 (9.5)
Scotland	2.0 (2.3)	15.1(12.9)	16.1(14.3)
Wales	1.4 (1.4)	7.1 (4.5)	7.5 (4.5)
N. Ireland	4.1 (1.2)	22.2 (9.5)	22.8(12.5)

*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. 2003 data from BANS report, 2005

Expressed in terms of population size, prevalence per million population in England are closing in on those of Scotland. (Figure 6.1 (B) and Table 6.1)). The point (22.2) and period prevalence (22.8) of HPN in N Ireland are now the highest per million/ population of the home countries. The sudden increase in figures from N. Ireland suggests improved reporting as well as real increases in patient numbers. Personal communication (Dr B Hawthorne) indicates underreporting from Wales, despite reporting being a standard for compliance within the Welsh HPN Network.

It is worth noting here that the document just published: “ A Strategic Framework for intestinal failure and HPN services for adults in England” not only suggests more formal arrangements for English HPN (HIFNET), but also

includes a standard indicating that all patients should be reported to BANS (www.nscteam.org.uk/ifstrategy.htm.)

Trends for new registrations and both period and point prevalence are illustrated below. [Figures 6.1 (C-F)]. Comparing 2006 and 2007 data:

- New registrations in England in 2007 rose to 116(38%), point prevalence to 657(11%) and period prevalence to 726(18.2%) compared to 2006 (Figure 6.1 (C)).
- Scottish data indicates a levelling off of new and established cases. (Figure 6.1 (D)).
- Despite acknowledged underreporting (see above) an increase was seen in both point (17%) and period prevalence in Wales (10%) (Figure 6.1 (E)).
- In N. Ireland new registrations rose from one to seven whilst both period and point prevalence rose by around 50% (Figure 6.1(F) due to combination of improved reporting and increased numbers.

Figure 6.1 (C): Trends in HPN in England, 2000 – 2007

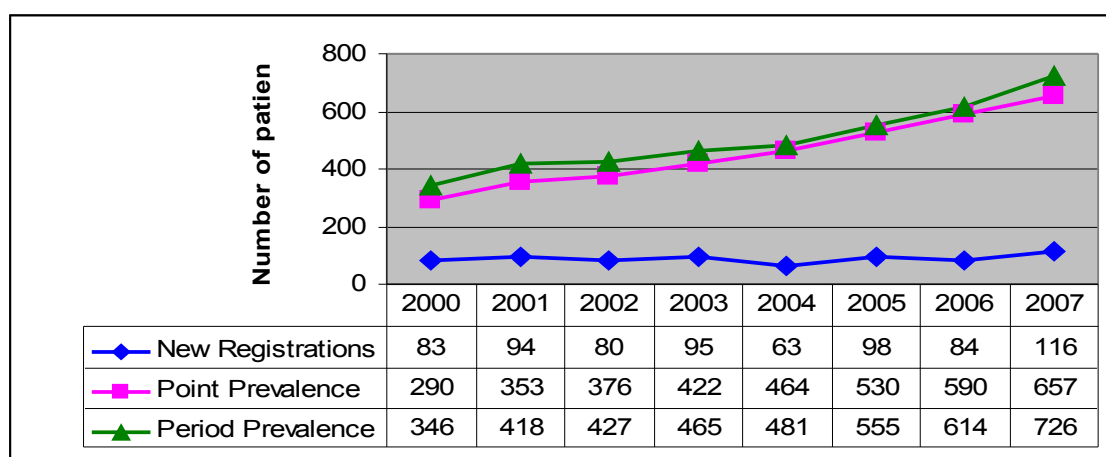


Figure 6.1 (D): Trends in HPN in Scotland, 2000 – 2007

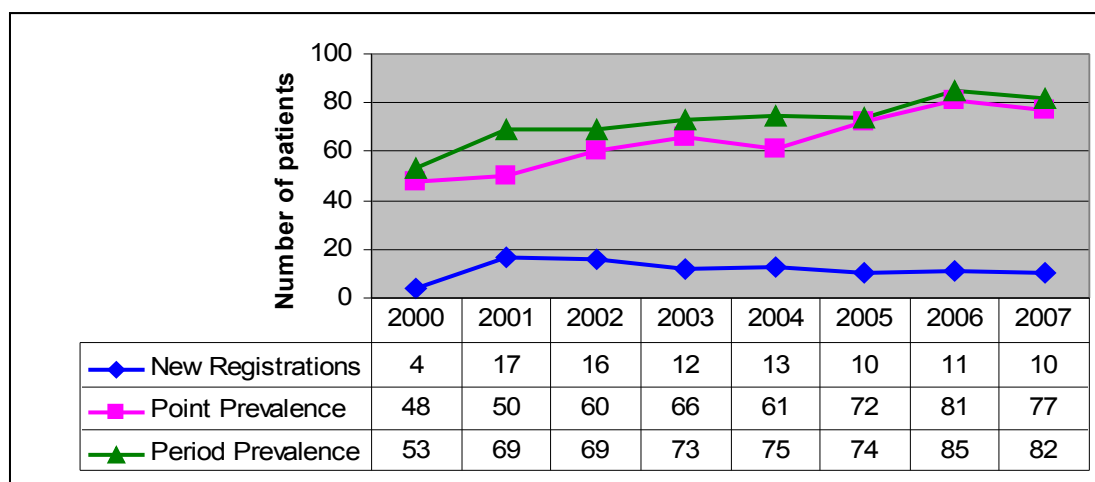


Figure 6.1 (E): Trends in HPN in Wales, 2000 – 2007

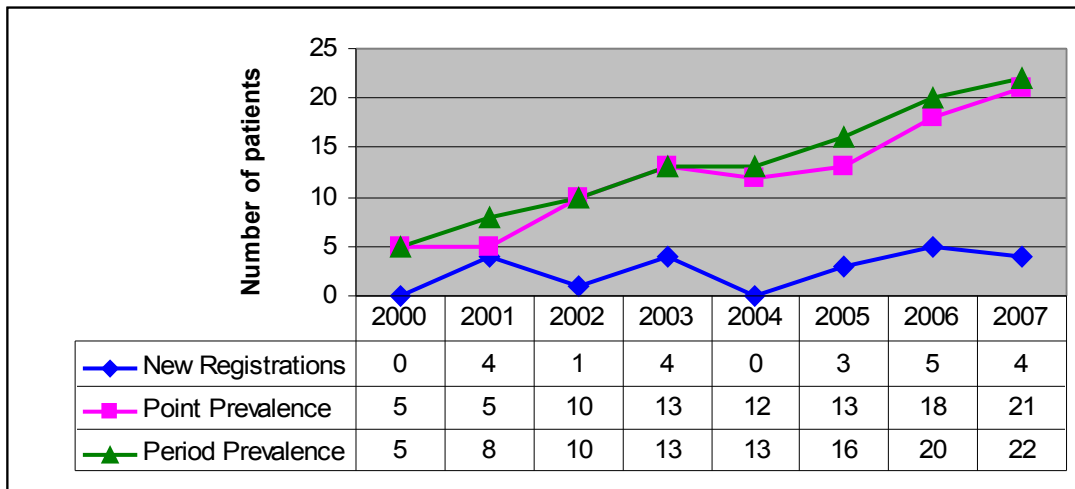
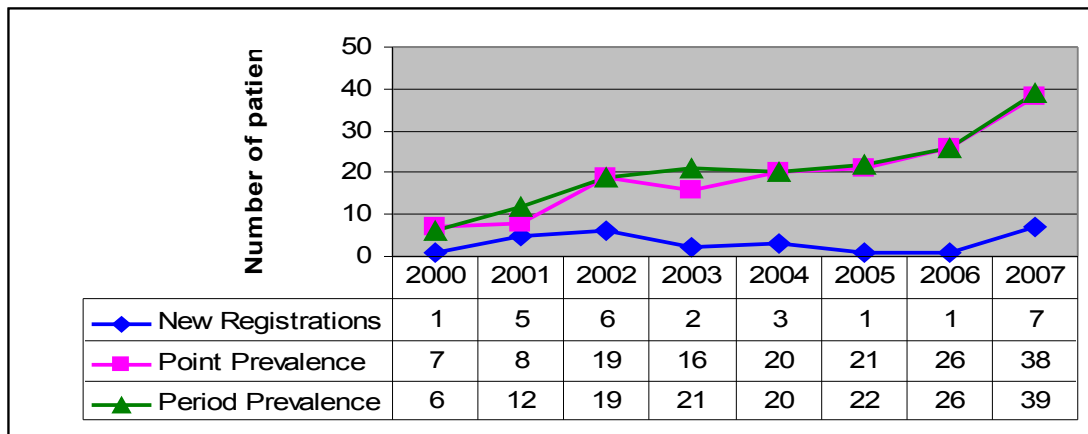


Figure 6.1(F): Trends in HPN in N Ireland, 2000 – 2007



6.2 Reporting Centres

The number of centres registering new cases to BANS in 2006 fell to 15 but has returned to its previous level at 25. This reflects the large number of English reporting centres as in Figure 6.2(A). The surprisingly large number of centres reporting point and period prevalence accords with previous data (BANS report, 2005) suggesting that there are still some centres caring for very few patients. We can not exclude the possibility that some centres do not report to BANS (see 2006 report) although data acquired from independent commercial sources have shown that BANS HPN data accounts for approximately 91% of all known patients (see Section 8).

Figure 6.2 (A): Numbers of adult HPN reporting centres in UK for new registrations, point prevalence and period prevalence, 2000 – 2007

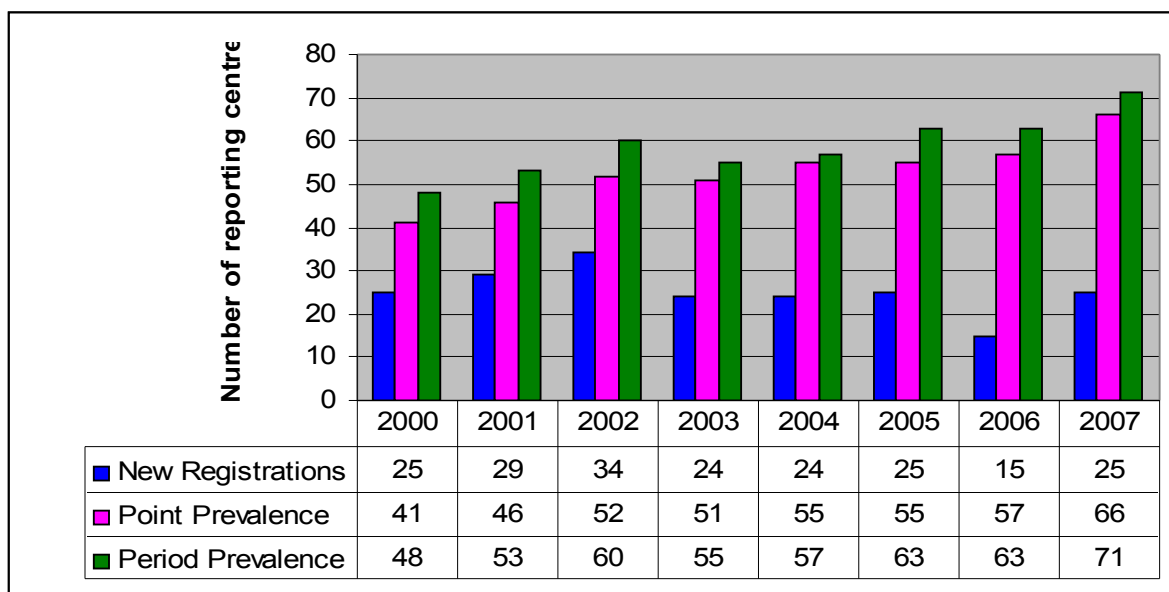
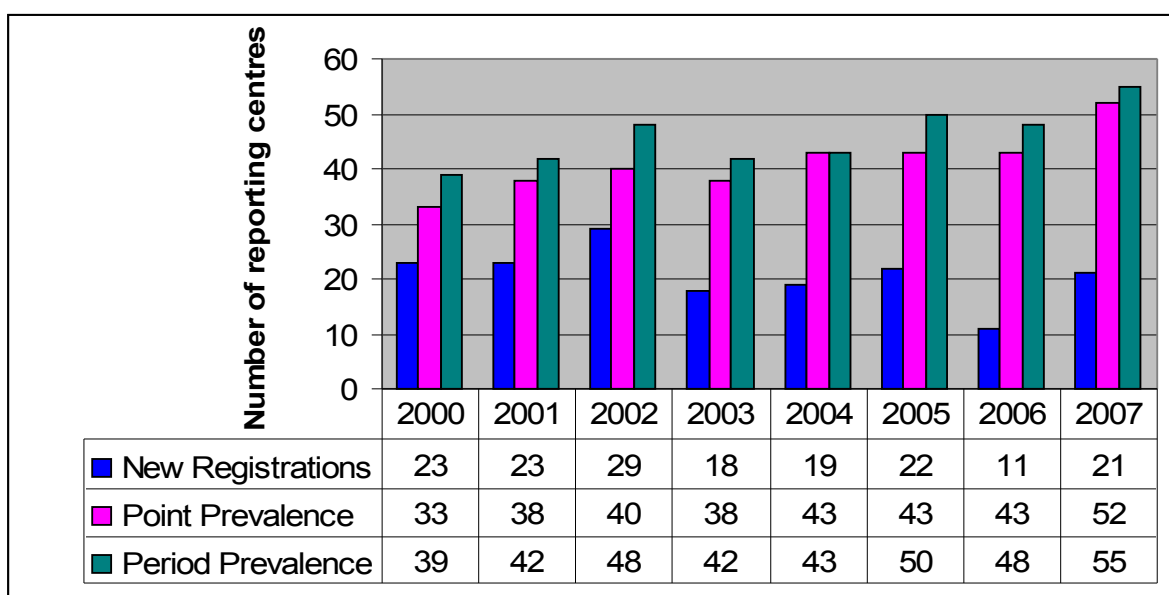


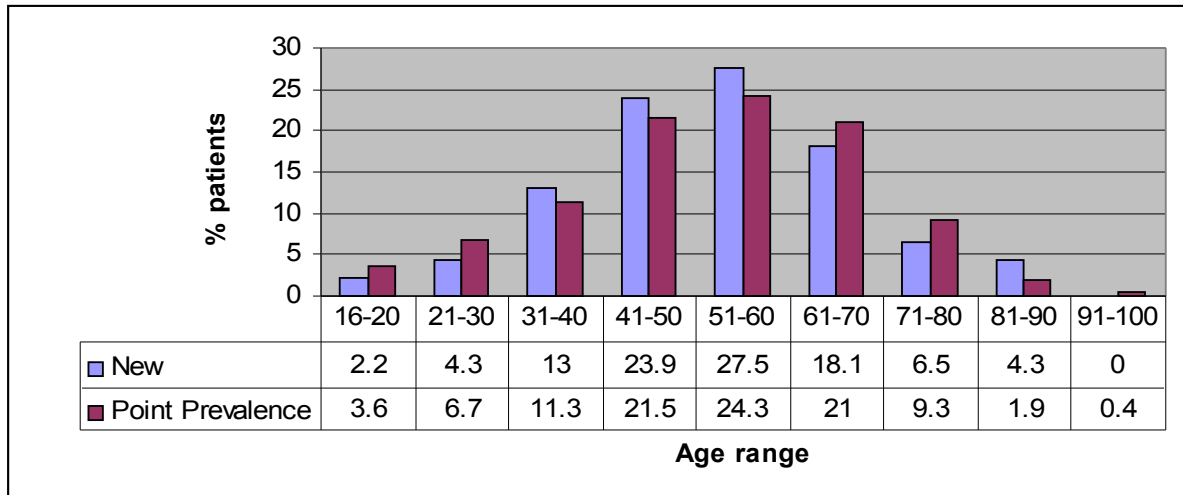
Figure 6.2 (B): Numbers of adult HPN reporting centres in England for new registrations, point prevalence and period prevalence, 2000 – 2007



6.3 Age distribution

There is a unimodal peak of 51 – 60 years of age with a Gaussian distribution at the start of HPN in adults. There is a slight age shift for established cases. Figure 6.3 illustrates this point.

Figure 6.3: Age distribution of Adult HPN in UK for new registrations and point prevalence, 2007



6.4 Reasons for HPN

Short bowel syndrome remains the commonest indication for new HPN patients (41.3%). Fistula is cited as the main reason in 14.5%, malabsorption in 10.1%, “to improve nutrition” in 15.2%, gastrointestinal obstruction in 8% and swallowing difficulties in 5.8%. Short bowel syndrome is also the main reason for HPN in established patients (53.6%). (Figure 6.4)

Table 6.4: Reasons for Adult HPN, 2000 and 2007

	% New		% Point prevalence	
	2000	2007	2000	2007
Fistula	17.0	14.5	6.0	9.3
Obstruction	9.1	8.0	6.3	6.1
Malabsorption	12.5	10.1	14.6	15.5
Short bowel	40.9	41.3	61.4	51.6
To improve nutrition	11.4	15.2	4.9	7.2
Swallowing disorder	5.7	5.8	2.3	3.7
Other	3.4	4.3	4.6	2.9

6.5 Diagnoses and HPN

Crohns remains the leading diagnosis for adults on established HPN (point prevalence 27.3%) but this figure is slowly falling (34.3% in 2000). By comparison, new registrations for Crohns disease have fallen to only 13% in 2007 compared to 25% in 2000. Neurological diseases account for a similar number of new registrations (13.8%) as Crohns in 2007. Cerebral trauma accounts for 4.3% of new registrations but Parkinson's disease, cerebral palsy, motor neurone disease and cerebrovascular diseases are also represented.

Cancer, of all types including leukaemias, account for 11.6% of new registrations, but only 6% of point prevalence. Colonic and small bowel cancers account for 8% of new registrations. (Table 6.5 (A))

Table 6.5 (A): Diagnostic categories of Adult HPN, 2000 and 2007

	% New registrations		% Point prevalence	
	2000	2007	2000	2007
Crohns	25.0	13.0	34.3	27.3
Ulcerative colitis	3.4	2.2	2.3	2.7
Ischaemia*	14.8	19.4	17.7	19.9
Radiation enteritis	5.7	6.5	5.1	4.6
Pseudo-obstruction	4.5	8.0	9.1	10.0
Systemic Sclerosis	3.4	3.6	2.9	3.3
Other...including			11.1	14.1
Surgical complications	6.8	15.2		
Benign strictures	5.7	1.4	4.0	1.5
Neurological conditions	5.7	13.8	1.7	4.2
Cancer**	16.8	11.6	5.8	6.0

*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 6.5 (B): Point prevalence of Crohns disease 2000 – 2007

Crohns disease								
Patients	2000	2001	2002	2003	2004	2005	2006	2007
Numbers	120	131	147	156	160	175	196	213
%	34.3	31.5	31.6	30.2	28.7	27.5	27.4	27.3

6.5 Location, Ability to Manage and Activity level

The percentage of new registrations placed initially in a nursing home has risen from 1.1% in 2005 and 2006 to 10.1% in 2007. Only 0.7% are described

as residing in a residential care home whereas 86.2% are discharged to their own homes. Amongst established patients (point prevalence), the number in nursing homes fell to 4.1% with 90% in their own homes. These figures suggest that some patients, perhaps the elderly, are being placed in nursing homes as an interim measure or for short term or terminal care. We have no specific data to support these suggestions.

Independent patients account for 49.3% of new registrations and 68.9% of established patients. Approximately half of new registrations require “some help” or “total help” but only 30% of established cases require such help.

These figures are mirrored by activity data. Thus, 47.8% of new cases and 61.7% of established cases are described as fully active. Limited activity (40.65 new; 33.8% point prevalence), house bound (8% and 3.2%) and bed bound cases (3.6% and 1%) account for the remainder.

6.6 Access route and Administration of Adult HPN, 2007

Venous access was via an external catheter in 90.6% but subcutaneous ports appear to have been placed more frequently in 2007 (9.4%) than in 2006 (3%).

Commercial homecare companies provided for almost all new patients in 2007 (95.7%). Their contribution to point prevalence has been steadily rising from 79.4% in 2000 to 87.2% in 2007. This suggests that the greater contribution to new patients is being carried through to established patients.

Section 7

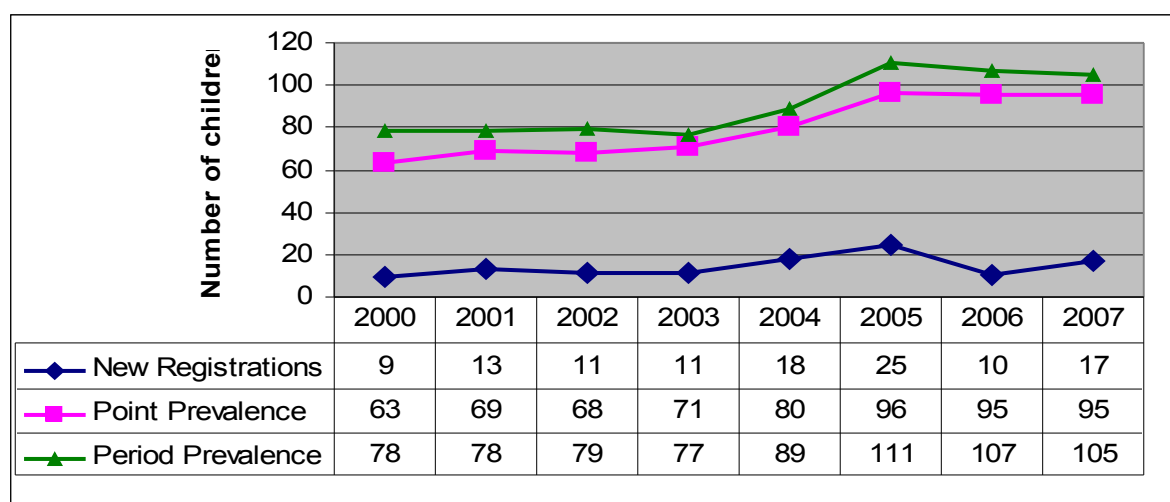
Home parenteral nutrition (HPN) in children

Jamil Khair

7.1 New registrations, point and period prevalence of HPN in children

The number of new registrations (17) in 2007 has risen significantly since 2006 (10). The relative stability of the point and period prevalence values for the past three years, compared with the steady increases seen during the period from 2000 – 2005, might be an indication that we are finally seeing a more accurate reflection of the incidence of paediatric HPN in the UK (Figure 7.1).

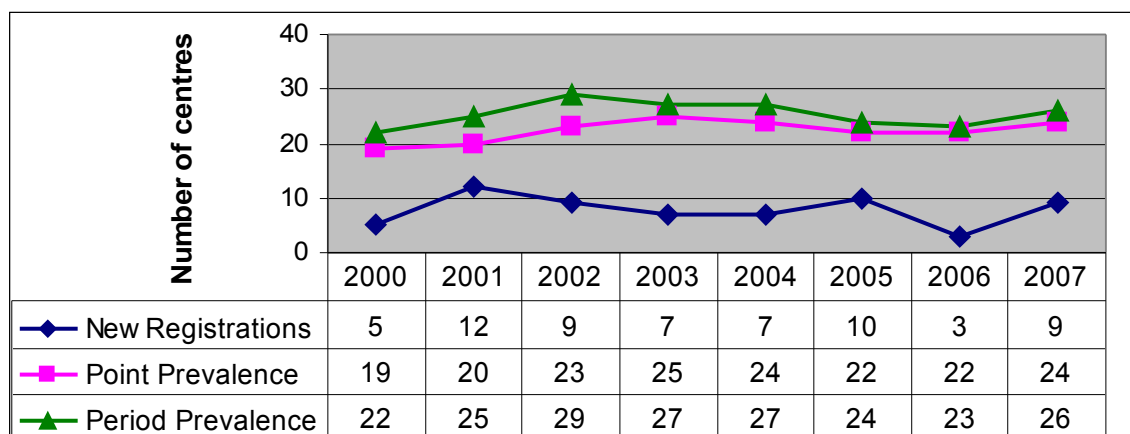
Figure 7.1: New registrations, point and period prevalence of children receiving HPN, 2000 – 2007



7.2 Reporting Centres

HPN patients were registered by 9 new centres in 2007 (figure 7.2), which may allay concerns regarding the reduction in new reporting centres in 2006 (3), and indicate a successful transition to on-line reporting with e-BANS.

Figure 7.2: Numbers of HPN reporting centres for children, 2000 – 2007



7.3 Where are children treated?

Point prevalence data for 2007 were reviewed and hospitals reporting >5 patients are included in *figure 7.3*. We are aware, however, that a number of major UK paediatric centres, who may have significant numbers of HPN patients, are still not reporting to BANS.

Table 7.3: Reporting centres (HPN)

Name of reporting centre	Number of patients registered
Great Ormond Street, London	25
Princess Diana Childrens Hospital	17
Royal London Hospital	9
Royal Belfast Hospital for Sick Children	6
Booth Hall Children’s Hospital, Manchester	6
Leeds General Infirmary	5
Royal Liverpool Hospital	5

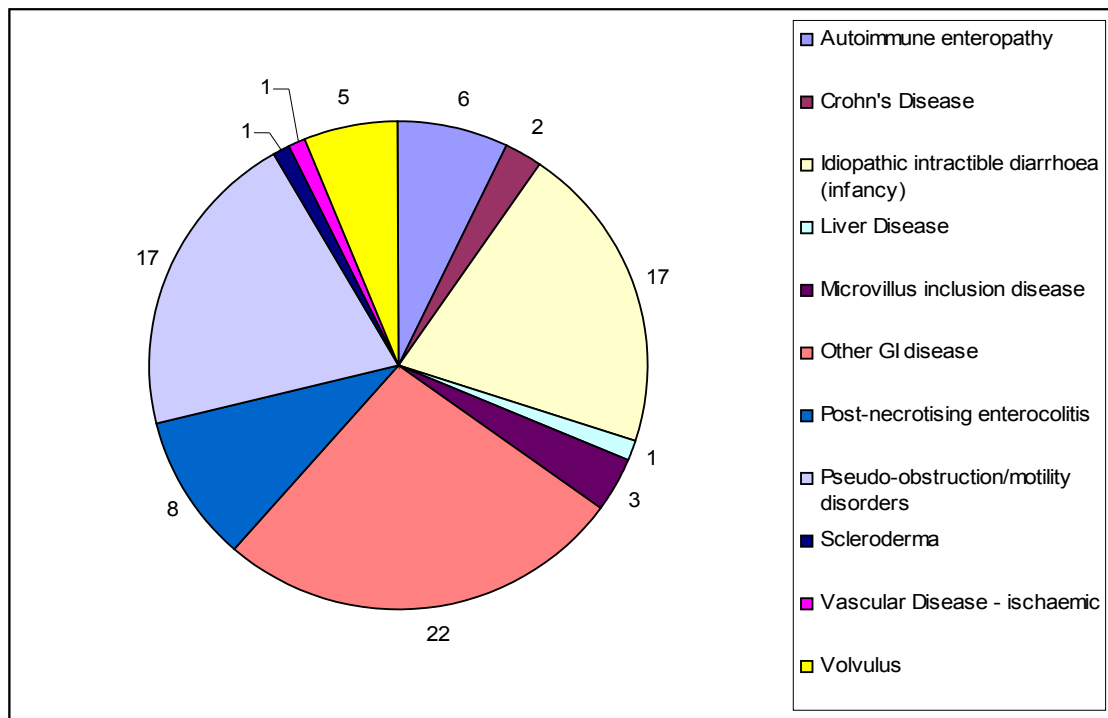
7.4 Age, Diagnoses and reason for Feeding

Of the 17 new registrations in 2007, only 11 were under the age of 2 years, which, at 65%, is the lowest proportion since 2002. Classification of these children by diagnoses, however, does not suggest any significant change in prescribing practices.

Point prevalence data by diagnoses in 2007 shows, 83 (87%) of the children suffering from a gastrointestinal disorder. *Figure 7.4*). Others suffer with disorders of the respiratory tract (2.1%), CNS (4.2%), or one of a number of 'miscellaneous' disorders (6.3%).

A substantial proportion (23%) of the children were registered with undefined or 'other' GI disease (*Figure 7.4*). In fact, all previous years, have recorded between 23% and 38% of patients within this category. This has been of concern to the BANS committee for some years. . This problem has been addressed by revising the children's primary diagnoses to include more specific options such as atresias, gastroschisis, congenital short bowel, meconium peritonitis and trauma etc., options available in the e-BANS 'drop-down' menus. A full list can be seen in Section 9.

Figure 7.4: Point prevalence of HPN in 2007: number of children's with a gastrointestinal diagnosis



Given the high percentage of gastrointestinal disorders it is unsurprising that the predominating reasons for feeding for both new and point prevalence data are short bowel (47.1%, 35.8%), malabsorption (29.4%, 36.8%) and GIT obstruction (11.8%, 6.3%) (*Table 7.4*).

Table 7.4: Reasons for feeding in 2007

	New %	Point Prevalence %
Failure To Thrive	0.0	9.5
Fistula	5.9	2.1
GIT Obstruction	11.8	6.3
Malabsorption	29.4	36.8
Other Than Listed	0.0	3.2
Short Bowel	47.1	35.8
Swallowing Disorder	0.0	2.1
To Improve Nutritional Status	5.9	4.2

7.5 Location & activity levels in 2007

The majority (94%) of new registrants lived in their own home and 88% had full normal activity, the remainder (12%) reporting limited activity

Established patients (point prevalence) lived at home (79%) and full normal activity was maintained by 76%, limited activity (23%) whilst one child was house-bound.

7.6 Delivery of HPN in 2007

All new children received their feed via a catheter with an external port. A percentage (9.5%) obtained vascular access by subcutaneous port as they became more established on HPN (point prevalence).

Home care companies delivered to 100% of newly registered children compared to only 68.4% of those already established.

Section 8

Independently acquired data compared with BANS reporters data.

Janet Baxter

As in previous years, we have obtained data from the commercial homecare companies (CHCs). This data is anonymous and has been aggregated to allow comparison with the numbers of HAN patients reported to BANS. Table 8.1 illustrates the numbers of patients supplied by the CHCs, the BANS data and the estimated percentage shortfall.

In 2007, the shortfalls calculated using CHC data indicates that for HETF, reporting has held up compared to 2006. By contrast, figures for HPN reveal greater shortfalls than in 2006. For adult HPN, BANS is still collecting 90% of national data which is a considerable achievement. For Paediatric HPN, the situation is less satisfactory although BANS is still able to survey approximately 50% of all cases.

Table 8.1: Estimated Point prevalence and reporting shortfall of all UK HPN patients using data from Commercial Homecare companies (CHCs) census on 28th February 2008 compared to BANS data for 31st December 2007*

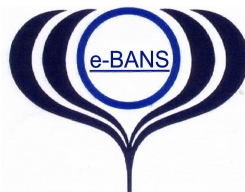
	HETF		HPN	
	ADULT	PAED	ADULT	PAED
1. Totals supplied by CHC companies	21203	9007	762	111
2. BANS 2007 total point prevalence**	21858	5381	793	95
3. % use of CHC from BANS, 2007	77.9%	75.4%	87.2%	68.4%
4. CHC numbers known to BANS, 2007	17027	4057	691	65
5. Estimated point prevalence, 2007	26886	11958	865	161
6. Estimated % shortfall in 2007 (2006 data)	19.7%(20)	55%(55.4)	9.3%(5.4)	41%(33)

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

**** With and without CHC involvement**

Section 9

Update: consent and e-BANS



Ann Micklewright, Geoff Cooke & Barry Jones

9.1 Obtaining consent

In the 2007 report ¹ the requirements for reporters to obtain informed consent from patients prior to submitting their data to the BANS was outlined. At the time ongoing discussions with PIAG (Patient Information Advisory Group at www.advisorybodies.doh.gov.uk/PIAG) were described.

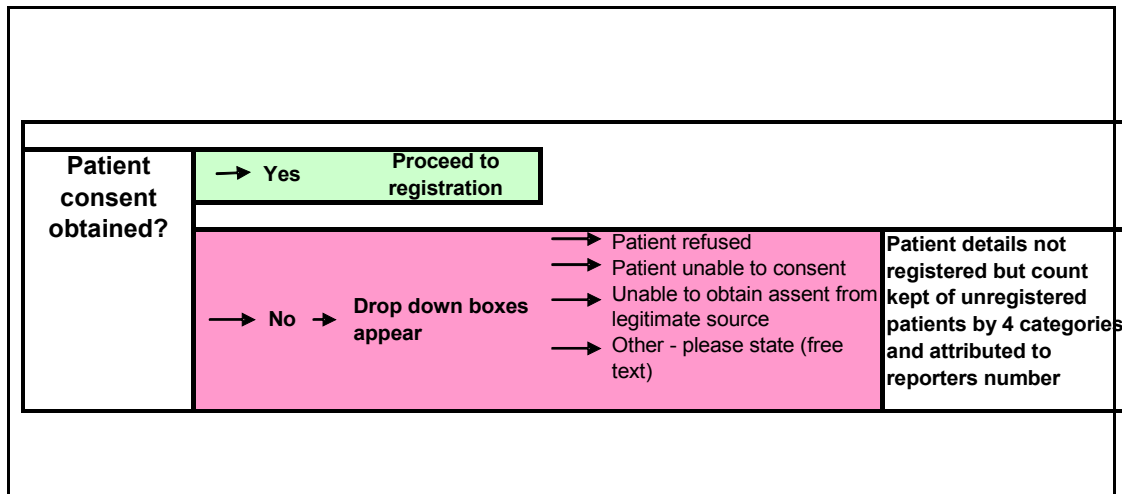
These discussions have enabled BANS to gain conditional exemption through Section 60 of the Health & Social Care Act 2001 (H&SCA) ² to continue collecting data without consent. This conditional exemption stipulated that BANS should work towards obtaining consent from NEW patients and provide evidence that this procedure was being followed.

To this end an audit process has been built into the **e-BANS** patient registration process. Before registering new patients, reporters are required to state whether or not a patient has given consent. If consent has not been obtained the reporter will be unable to register the patient but will be asked to choose from 4 options the reason consent has not been given. This enables BANS to collect important evidence to present to PIAG. (*Figure 9.1*)

Information, consent and assent forms (for those patients unable to consent) have been prepared in 'Word' format to enable reporters to change them if required to meet local needs. These are available from: www.bapen.org.uk, or directly from **e-BANS**.

The BANS committee is aware of concerns amongst reporters over the difficulties of obtaining consent or assent, particularly from HETF patients. Those receiving their HETF via nasogastric tubes appear to be a challenge as many will not have given written consent to placement of their tube or the subsequent feeding regime. The committee feels that obtaining consent should be possible for all HPN patients and hopes that reporters will regard obtaining consent as part of good practice for all patients receiving

Figure 9.1: e-BANS consent audit process for new registrations



9.2: e-BANS goes live at www.e-bans.com!



Over the previous 2 years BANS has been developing and refining an electronic version of the register. This has now been rolled out to 50 reporters and the aim is to get the majority of reporters using e-Bans by the beginning of 2009. Other existing reporters will be contacted shortly.

The advantages to reporters of using e-BANS, was discussed in last years annual report ¹: **e-Bans** is very simple to use and facilitates accurate, timely reporting.

TO GET STARTED:

- Reporters can obtain their logon and password details by contacting: Geoff.Cooke@streets-heaven.com
- Once logged on, existing reporters will find their 'old' patient data already loaded onto the system. Any patient who has not been updated for 6 months will be displayed to enable reporters to make changes if necessary.
- Once **consent or assent** (see 9.1) has been obtained new patients can be registered very rapidly.
- More extensive diagnostic lists have been developed and grouped into categories to reduce the use of the 'other'

category (see section 5 & 7) and to facilitate easier searching. (Tables 9.2 (A-C)).

- Reporters can generate their own local reports from the system.
- A feedback mechanism is present to allow reporters to let BANS know what they think about the system to enable ongoing development.

Figure 9.2 (A): e-BANS Adult HETF primary diagnoses

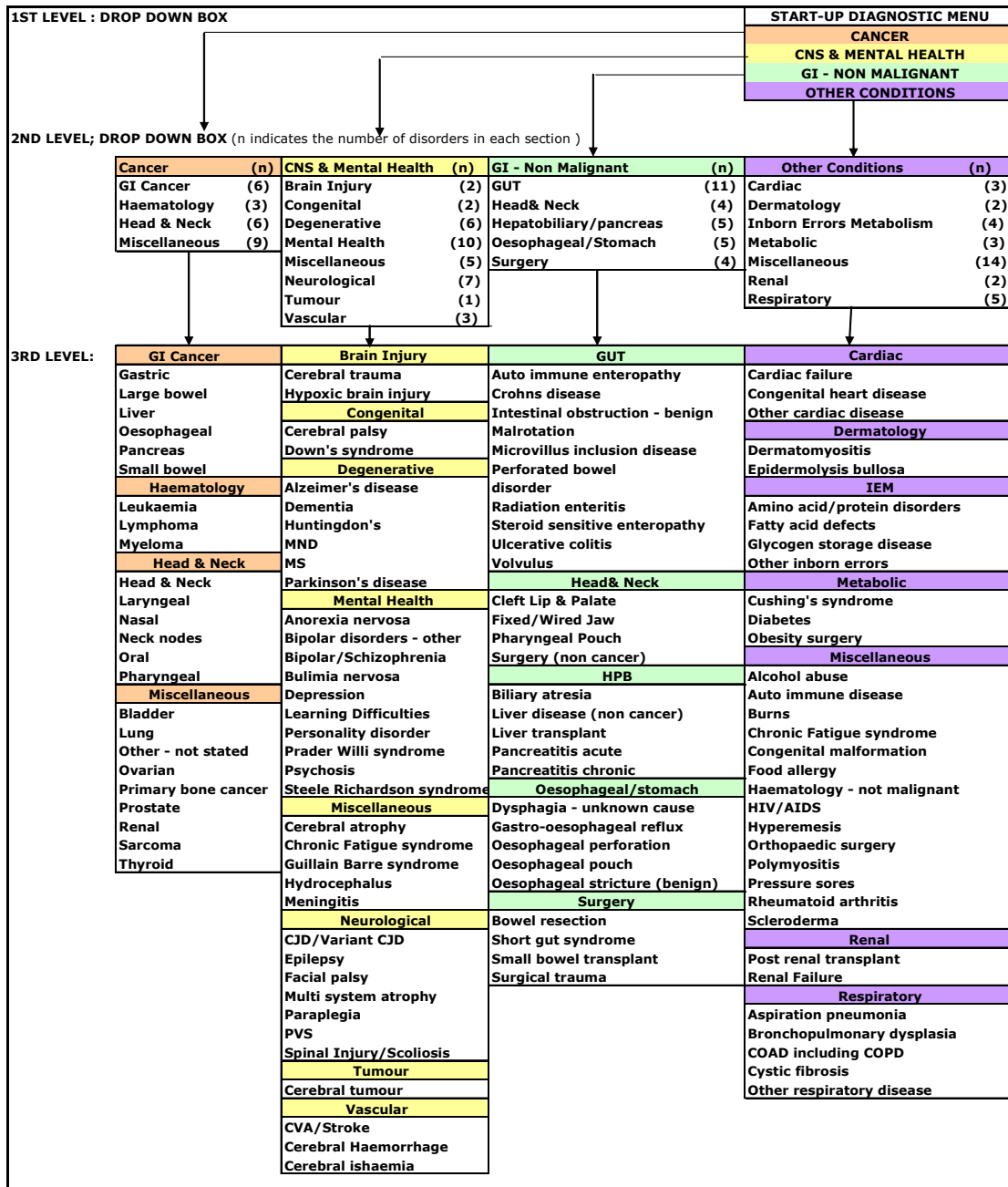


Figure 9.2 (B): e- BANS adult HPN primary diagnoses

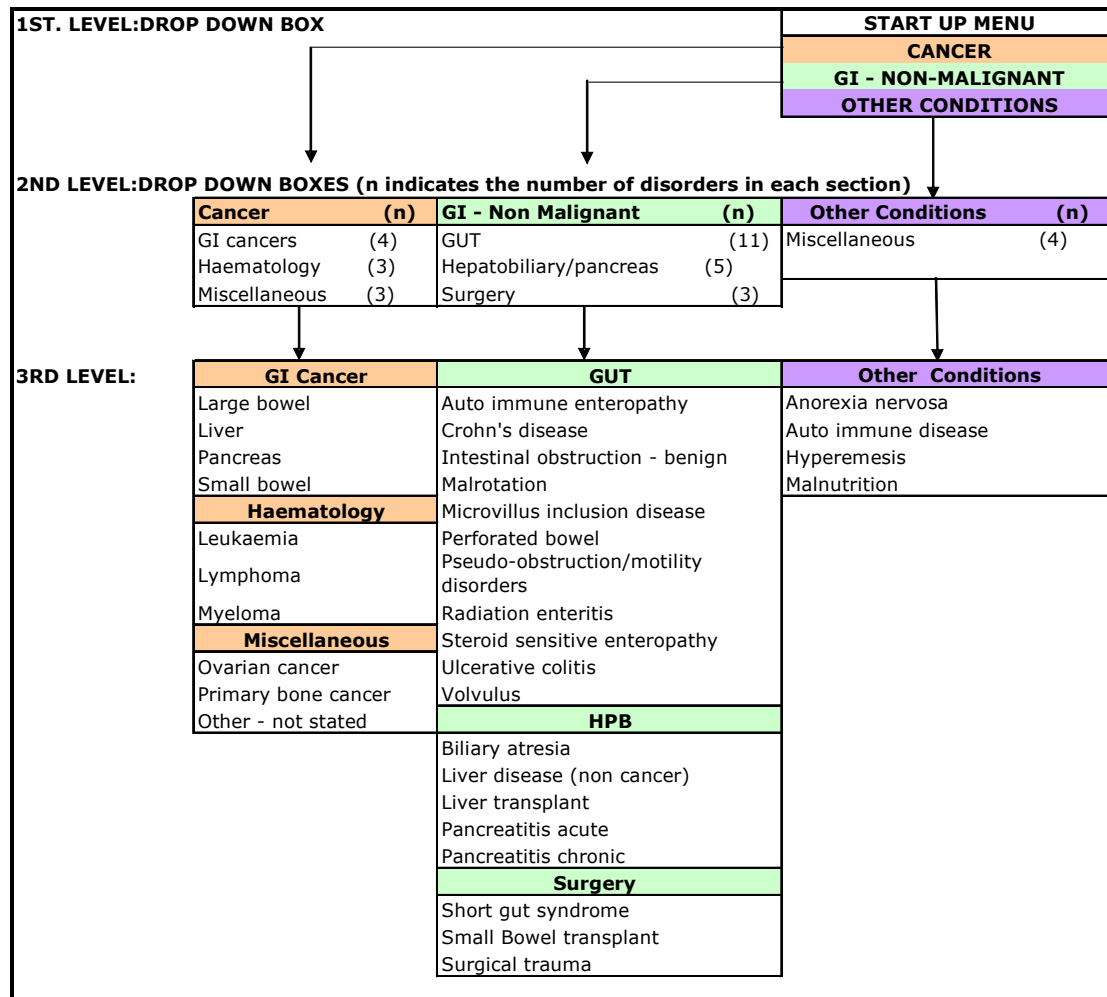
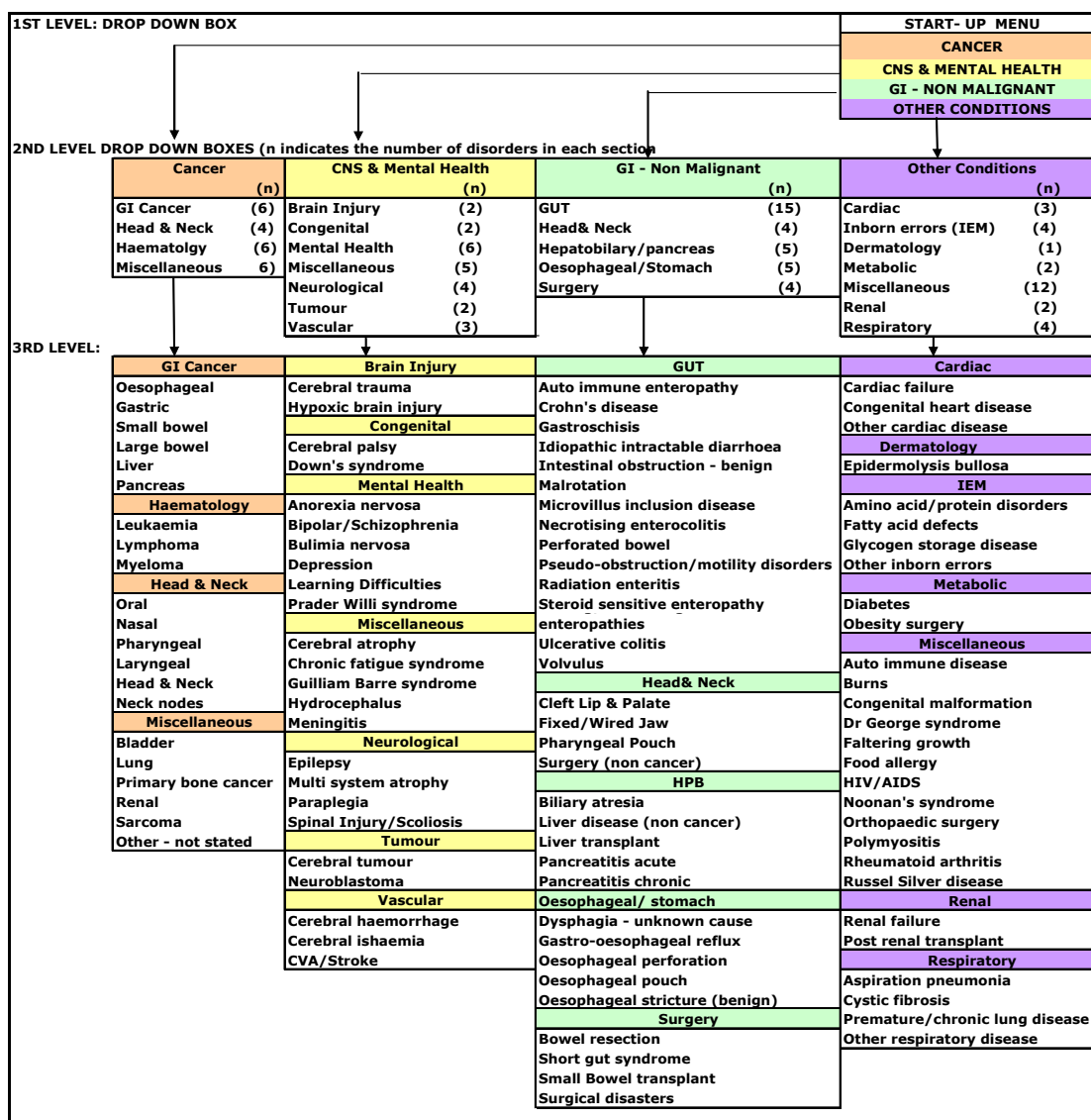


Figure 9.2 (C): e-BANS children's primary diagnoses (HPN & HETF)



References:

Jones B, Holden C, Stratton R et al. Annual BANS Report, 2007, Artificial Nutrition Support in the UK, 2000 – 2006. BAPEN 2007.

www.bapen.org.uk

Health & Social Care Act.

<http://www.hmsso.gov.uk/acts/acts/2001/20010015.htm>

A Strategic Framework for intestinal failure and HPN services for adults in England.

www.nscteam.org.uk/ifstrategy.htm.

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

The BANS Committee, 2007 - 2008

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Lynn McCready (Calea) PN homecare representative

James Astrop (Clinovia), PN homecare representative now demitted.

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

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