



Annual BANS Report, 2009

Artificial Nutrition Support in the UK 2000 - 2008

**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

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BANS: Trends in artificial Nutrition Support in the UK Between 1996 & 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.
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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
NIGB	National Information Governance Board
NSCAG	National Specialised Services Advisory Group
NST	Nutrition Support Team
PIAG	Patient Information Advisory Group
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 fourth 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, gender 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.

Since September 2006, BANS have received temporary support from PIAG for continuation of data collection; this has been reviewed on an annual basis and is subject to BANS developing an alternative strategy ('exit 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. It is now clear that the process of consent has been an enormous challenge for reporters for a variety of reasons and has seriously threatened the future of BANS. This has been recognised by the National Information Governance Board (NIGB), who have taken over from PIAG (January 2009), and we are working closely with them to develop an 'exit strategy' which will involve the collection of pseudonymised data without the need to obtain consent. This work is on-going and we hope will be concluded in February 2010.

The PIAG submissions have run in parallel with our efforts to introduce electronic reporting through "e-BANS". This has now been rolled out to those reporters wishing to make the switch to the electronic system. We have received extremely positive feedback and therefore we are aiming to withdraw the paper reporting system and switch to the exclusive use of e-BANS in 2010. The BANS committee recognises that consent has prevented many reporters from using e-BANS and we will ensure these issues are resolved prior to the final withdrawal of yellow reporting forms.

BANS hopes that these developments will make it easier for reporters to not only enter data, but to access their own data as and when they wish.

BANS is a unique national audit of clinical nutrition practice and has made some vital contributions to the planning and delivery of high quality nutritional care in the UK. BANS reporters are key to this success and the BANS committee thank you all for your hard work, dedication and support. We are confident that the changes we are putting in place over the next few months will secure the future success of BANS and we will keep you updated with our progress.

Finally, I would like to thank Dr Barry Jones who stood down as Chair of BANS last year. He continues to make an extremely valuable contribution to clinical nutrition practice and to the activities of BANS and BAPEN. I am personally grateful to Barry, Ann Micklewright and my colleagues on the BANS committee for their continued support and energy to ensure the future success of BANS.

Dr Trevor Smith
Chair of the BANS committee, December 2009

Section 3

Executive summary

Dr Trevor Smith

Adult HETF

1. New registrations have fallen from a high of 7187 in 2001 to 4326 in 2008 (17% reduction from 2007). Point and period prevalence data have fallen significantly to 5959 and 10690 patients respectively (73% and 56% reductions from 2007).
2. Requirement to obtain consent or assent is likely to be the main explanation for the reduction in reporting rates (communications from BANS reporters).
3. The number of new registrations per million of the UK population was 70.
4. An average centre reports and updates data on 52 patients per year; however this is limited by significant reductions in reporting rates.
5. Adult HETF patients are predominantly older in age with 65% >60 years old.
6. 65% of patients live in their own homes but 68% require total or significant help with their HETF. In the >75 year category, ~90% are bed bound, housebound or have limited activity.
7. Neurological disorders account for 48% of new cases. Cerebrovascular accidents are the commonest indication for HETF. Dementia continues to decline as an indication for HETF.
8. Cancer continues to account for an increasing proportion of new HETF registrations – increasing from 25% in 2000 to 36% in 2008. 90% of new cancer registrations were diagnosed with head and neck or oesophageal cancer.
9. Nasogastric tube feeding accounts for only 15% of new cases with Gastrostomy being by far the commonest route of administration (78%).
10. Commercial homecare companies support 88% of new cases and 80% of established patients.

Paediatric HETF

1. 694 patients were registered with BANS – a 15.5% reduction from 2007. The new patient data was the lowest recorded since 2000. Only 27% and 37% of point and period prevalence data respectively were updated in 2008.
2. Requirement to obtain consent or assent is likely to be the main explanation for the reduction in reporting rates (communications from BANS reporters).
3. Centres reporting new patients fell from 137 in 2007 to 87 in 2008, a decline of 36.5%. The number of centres updating existing patients fell dramatically by 55% (point prevalence) and 48% (period prevalence).
4. The number of new registrations per centre in 2008 ranged from 1 – 49. Nine or less new children were registered by 71% (62 centres), of which 39% (24) registered only one child each.

5. The main reasons for feeding for new children in 2008 were: to improve nutritional status (41%); failure to thrive (27%); swallowing difficulties (23%); gastrointestinal disorders (4%) and a miscellaneous group (5%).
6. The underlying diagnostic categories were: Neurological 26%, Non-malignant GI disease 15%, Cardiac 11%, Cancer 8% Respiratory 5% and Miscellaneous 35%.
7. Feeding routes were similar to previous years for newly registered children: gastrostomy (33%), naso-gastric (65%), jejunostomy (2%)
8. The age distribution has changed significantly; in 2000 22% of the paediatric HETF population was under 1 year – this has increased to 48% in 2008. By contrast the data for established patients (point prevalence) shows only 2% of children were under 1 year in 2000 rising to nearly 5% in 2007. This suggests a large amount of short term feeding for very young infants.
9. 97% of children were discharged home.
10. Commercial homecare companies were involved in 83% of new cases on discharge and 78% of established cases.

Adult HPN

1. New registrations rose in 2008 by 14% to 157. Point and period prevalence fell significantly to 413 (-47%) and 521 (-40%) respectively.
2. The number of centres registering new patients has remained stable at 24, but the number of centres updating existing patients has fallen to 32 (52% reduction).
3. As shown in BANS report 2005, there are still a significant number of centres managing small numbers of HPN patients.
4. UK point prevalence per million fell from 13.1 to 6.7 and period prevalence from 14.5 to 8.5. These large reductions are due to under-reporting rather than a true reduction in HPN prevalence.
5. Requirement to obtain consent or assent is likely to be the main explanation for the reduction in reporting rates (communications from BANS reporters).
6. English new registrations rose 12% to 130. Point prevalence fell by 49% to 336 and period prevalence fell by 41% to 425. Point prevalence per million has reduced from 13.1 in 2007 to 6.5 in 2008 and period prevalence from 14.5 to 8.3 per million.
7. Scottish point prevalence per million has reduced to 10.8 and period prevalence to 13.7 (2007: 15.1 and 16.1 respectively)
8. Welsh point prevalence per million has reduced to 5.7 and period prevalence to 6.3 (2007: 7.1 and 7.5 respectively). Registration of new patients has improved considerably with the development of a Welsh HPN network.
9. Northern Irish point prevalence per million has reduced significantly to 2.3 and period prevalence to 3.4 (2008: 22.2 and 22.8 respectively).
10. The modal age for adult HPN is 51 – 60 years of age.
11. 36.3% of new cases are aged 16 – 50.
12. Short bowel syndrome remains the main reason for HPN (42.7% new cases; 55.7% established cases)
13. Crohns disease and small bowel ischaemia remain the major indications for new registrations (17.2% and 13.4% respectively) and established cases (28.3% and 18.4%). A substantial heterogeneous group including complex

surgical problems accounts for 17.8% of new cases and 13.3% of point prevalence. A growing number of patients are treated with HPN due to severe gastrointestinal pseudo-obstruction (point prevalence increased from 9.1% to 13.6% between 2000 and 2008).

14. The percentage of newly registered patients initially placed in a nursing home has remained very small (1.1% and 0% in 2000 and 2008 respectively) despite a rise to 10.1% in 2007. The vast majority of patients are discharged to their own home.
15. Although a minority of new cases are described as house or bed bound (4.4), only 53.5% are described as fully independent, the remainder requiring assistance with their HPN.
16. Venous access was via an external catheter in 91.7% and subcutaneous ports in 8.3%.
17. Commercial homecare companies provided for all new patients in 2008; their contribution to point prevalence has been steadily rising from 70.6% in 2000 to 90.3% in 2008.

Paediatric HPN

1. New registrations rose from 17 in 2007 to 26 in 2008. Point and period prevalence have fallen from 95 to 29 (-69%) and 105 to 42 (-60%) respectively. It is difficult to interpret these figures due to under reporting.
2. The number of reporting centres has remained stable at 8 which is reassuring in view of the poor BANS returns in 2006. This bodes well for the transfer to e-BANS. However the number of centres reporting prevalence data has fallen to 12 (-54%) - the committee are aware that some large centres do not report to BANS; hopefully, such centres are involved in reporting to BIFS.
3. Point Prevalence data by diagnosis in 2008 showed 18 (62%) children were suffering from a gastrointestinal disorder; congenital enteropathy was the commonest indication for HPN (17%).
4. BANS has revised diagnostic categories for use with e-BANS so miscellaneous diagnoses should be exposed to greater clarity.
5. 88% of new children received their feed via an external catheter and 12% via a subcutaneous port. 21% of established patients (point prevalence) obtained vascular access by subcutaneous port.
6. Commercial homecare companies were involved in support of 92% of new registrations and 93% 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 48% of the total estimated cases, which reflects the significant reduction in reporting rates during 2008.

3. For paediatric HPN, BANS surveys 23% of UK cases.
4. Adult HETF returns were 23% of estimated cases.
5. Paediatric HETF attracts only 12% of estimated cases.
6. This poses a challenge for BANS; the committee has had very productive meetings with the National Information Governance Board (NIGB) to develop a system for reporting pseudonymised data, without the need to obtain consent. The results of this work will be announced in February 2010 and will help secure BANS' future as the leading nutritional survey of its kind internationally.

Section 4

Home Enteral Tube Feeding (HETF) in adults (2000-2008)

Ann Micklewright

4.1 New registrations, Point and Period Prevalence

In 2008, the number of new patients registered was 4326, an overall decrease of 17% on the previous year. This trend was seen across all the UK constituent countries: England (-16%), Scotland (-12%), Ireland (-29%) and Wales (-20%). *Table 4.1* illustrates a noticeable decline in new registrations in 2004, picking up slightly in 2005 followed by a sustained downward trend from 2006. This trend may be explained partially by change in clinical practice following recommendations that referral criteria be tightened up (M Cullinane M, Gray AJG, & Hargraves CMK et al. 2004)

Table 4.1: the number of new registrations, point and period prevalence and reporting centres from 2000-2008 in the UK

	2000	2001	2002	2003	2004	2005	2006	2007	2008
New Registrations	6629	7187	6428	6585	5656	5978	5145	5182	4326
Reporting Centres	275	280	264	251	252	257	216	254	193
Point Prevalence	11817	13742	15148	16890	18260	18686	19583	21858	5959
Reporting Centres	311	318	319	319	323	333	340	357	205
Period Prevalence	15652	18376	19474	21028	21677	23095	23088	24203	10690
Reporting Centres	319	331	331	325	327	340	347	367	205

The 2008 reduction cannot be explained by a decline in the average number of new registrations per centre. Since 2000 these data (*Figure 4.1*) show some fluctuation, peaking at: 26.2 new registrations/centre in 2003 and dropping to a low of 20.4 in 2007, yet rising again to 22.4 in 2008.

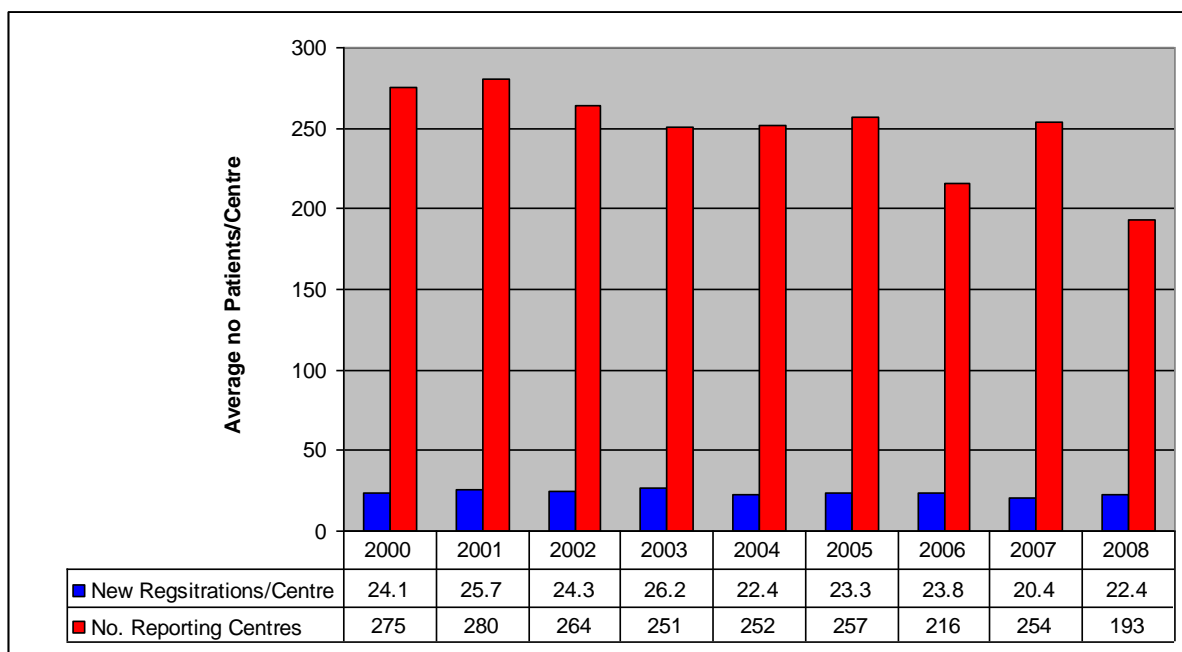
However, the reduction can be explained by a fall in the number of centres reporting these data, which fell by 61 (24%) in 2008 (*Table 4.1*). The breakdown across the constituent countries was: England 44 (22%), Scotland 12 (50%), Northern Ireland 1(7%) and Wales 4(2.8%). (*Figure 4.1*)

The number of centres reporting on established patients (point prevalence) declined by 43%, from 357 in 2007 to 205 in 2008. Only centres who registered new patients updated some of their existing patients i.e. 30% (5,959 patients) of the 20,000 previously recorded were updated. Period prevalence data recorded >24,000 of whom only 44% (10,690 patients) were updated. Consequently no 2008 prevalence data will be discussed further in this chapter.

It can be surmised from these data and feedback from HETF reporters (mainly dietitians) that the issue of **consent** is the basis of this decline. Since the publication of the 1998 Data Protection Act the necessity of obtaining patient consent before submitting data to BANS has been growing. Although BANS has been working with a temporary exemption from gaining full consent (see Section 9) certain changes have affected the reporting of new registrations:

- Nutrition Companies previously undertook a large proportion of new registrations. This has stopped because of confidentiality and consent issues. Dietitians with large case-loads do not have sufficient time to pick up this extra work-load.
- E-BANS was introduced with a requirement for all new patients to be consented before data could be submitted. Time constraints and current working practices limit the opportunities to obtain consent.
- Large groups of patients are unable to give consent and assent is difficult to obtain.
- Reporters admit to large numbers of new patients who have not been registered because of 'consent' issues
- A number of centres have withdrawn from reporting because of consent issues.

Figure 4.1: the average number of new adults per reporting centre



Key Point

*Despite this reduction in new registrations, data is still available on 4326 new patients, a large enough sample for useful analysis. Although consent is not required at the moment for established patients it appears that only those centres reporting new patients continued to update some of their existing ones **Therefore this year's chapter for HETF will be based on new patient data only.***

4.2 New adult HETF registrations per million of the population in 2008

The 2008 UK statistics were 70 new patient registrations per million of the population, a reduction of 19.5% over the previous year. The population figures used to calculate these data are based on mid point 2008 national statistics which take into account an overall 0.7% growth in the UK population since 2007. (Table 4.2)

The range of new patient registrations per million of the population across the constituent countries was 49-98. Scotland had the lowest number of patients in each category whilst Northern Ireland had the highest. These differences may be influenced by the completeness of the reporter base. (Table 4.2)

Key point

It is interesting that the Isle of Man reports higher new registration figures (118 per million of the population).

Table 4.2: New registrations in constituent countries / million population - 2008 (2007 data in brackets)

	Population	New Registrations	Reporting centres
	Millions*	million/population	n
England	51.446	71 (86)	152 (196)
Scotland	5.144	49 (57)	12 (24)
N.Ireland	1.774	98 (142)	13 (14)
Wales	2.993	94 (119)	15 (19)
Isle of Man	0.078	115 (117)	1 (1)
UK	61.383	70 (87)	193 (254)

*Source: Office for National Statistics, General registry Office for Scotland, Northern Ireland Statistics and Research Agency.

4.3 Age, level of activity, dependency and location of patients

Age: almost 65% patients starting HETF in 2008 were over 60y, of these 43% were >70y, (of whom, 19% over 80y and 2.5% over 90y). Only 11% were <41y. Over the eight year period (2000-2008) there was a 9% reduction in the proportion of new patients >70y, although the 61-70y group increased by 6%.

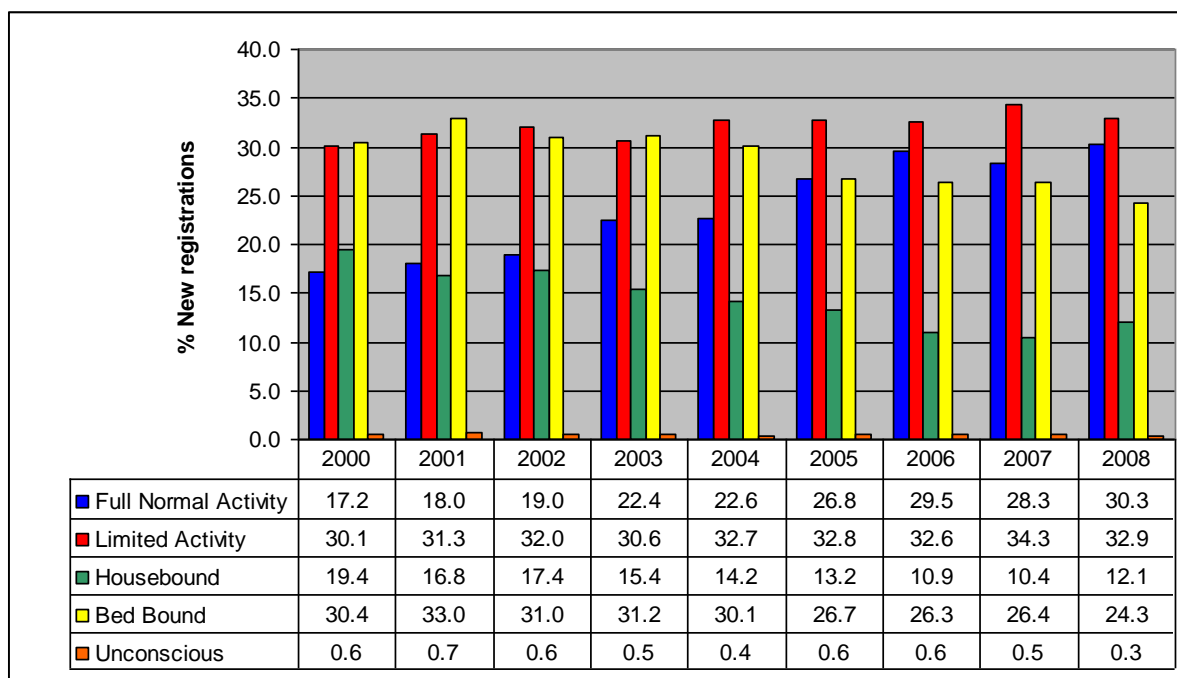
Level of activity: figure 4.2 shows activity levels at registration. In 2008, 63% were reported to have full normal (30%) or limited activity levels (33%) whilst 36% were housebound (12%), bedbound (24%) or unconscious (<1%). It is noticeable that since 2000 there has been a gradual annual increase in the proportion of fully active patients rising from 17% to 30% and a subsequent reduction in those either housebound or bed-bound.

Elderly patients starting HETF had the lowest activity levels. Comparison of those aged 16- 64y with those over 75y shows that 77% vs 42% were described as either having full normal activity (45% vs 10%) or limited activity (32% both groups); 23% vs 57% patients were housebound (9% vs 17%) or bedbound (14% vs 40%).

Dependency: in 2000 only 21% new patients were classed as independent, with 18% requiring some help and 57% requiring total help. By 2008, 32% new patients were independent; 21% required some help, and less than half (47%) total help

Location: in 2008 nearly two thirds of new patients (65%) lived at home; the remainder lived in nursing homes (31%) or residential care (2%). This contrasted with 56%, 40% and 2% respectively in 2000.

Figure 4.2: levels of activity of new patients



Key points:

The new registration data from 2000-2008 shows a number of trends emerging:

- less patients over 70y are been treated (9%)
- more patients begin HETF in their own homes (10%)
- more are classed as independent (11%)
- less patients are house-bound (7%) or bed-bound (6%)
- a reduction in patients requiring nursing home/residential care (9%)

4.4 Reason for feeding, feeding routes and delivery of supplies

Reason for feeding: in 2000 the two main reasons for starting feeding were swallowing disorders (SD) (72%) or to improve nutritional status (NS) (19%). A gradual change in the proportion in each of these categories was reported and by 2008, SD reduced to 66% and NS increased to 28%. This may reflect the reduction in the percentage of neurological conditions.

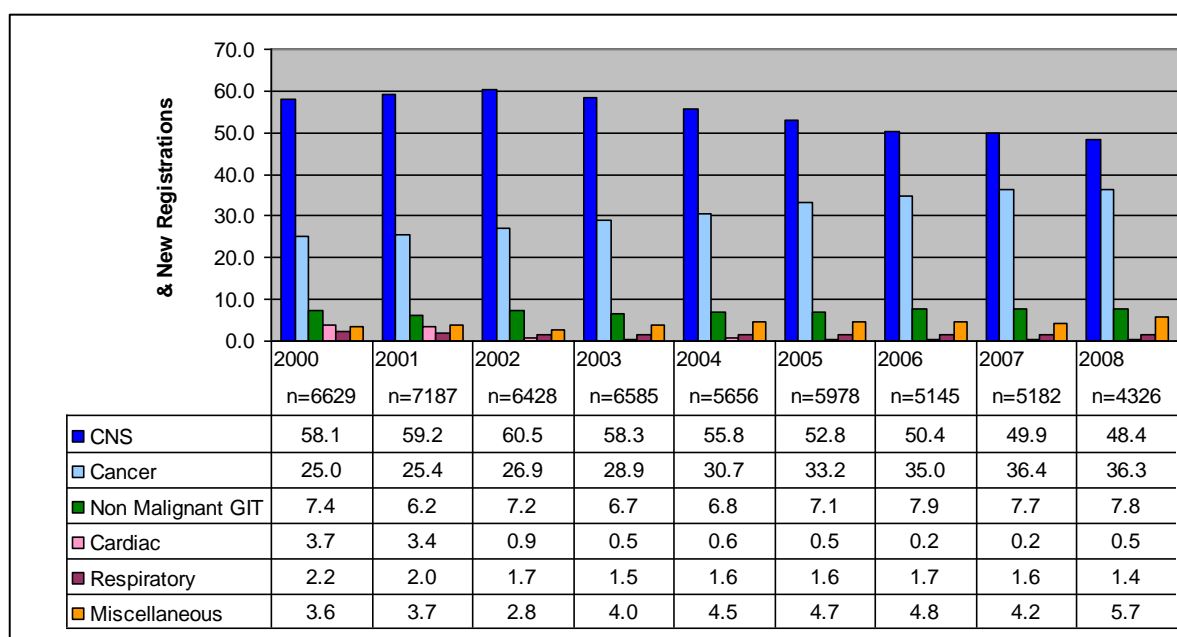
Feeding Routes: in 2008 were gastrostomy 78%, jejunostomy 7% and nasogastric 15%. The main change since 2000 was a >3% increase in jejunostomy feeding. This change is not shown in the point prevalence data where feeding routes are 84%; 4%, and 12% respectively.

Delivery of Supplies: Home Care companies supplied 88% of new patients in 2008; surprisingly the point prevalence data shows a reduction to 80%. Overall since 2000 14% more new patients have accessed a commercial home care service.

4.5 Diagnoses and indications for adult HETF - new registrations

Almost 84% of the 4326 patients starting HETF in 2008 suffered from either neurological problems (48%) or cancer (36%). Non malignant Gastrointestinal tract (GIT) disorders* (8%), cardiac (0.5%), respiratory (1.5%) and miscellaneous conditions (6%) accounted for the remainder. Reviewing these conditions over the period 2000-2008 shows a 10% reduction in neurological problems and an increase in cancer (11%) as the primary indication for HETF (Figure 4.3). This probably accounts to some extent to the changes described in relation to activity and dependency (higher proportion of patients fully active and independent) and location (more patients living at home)

Figure 4.3: Percentage associated clinical disorders (new adult registrations)



*In previous years GIT cancer was included with GIT disorders. These data have been amended and all cancers are classed together.

4.6 Cancer and HETF

Cancer is now the second most common disorder associated with HETF. New registrations have grown from 25% of the total in 2000 to >36% in 2008. (Figure 4.3).

In 2008 Head and Neck cancer (H&N) was the most common cancer. H&N cancer appears to have grown rapidly since 2000 when oropharyngeal cancer (OPC) was greater. However, as the incidence of H&N has increased OPC appears to have decreased; by adding both categories (*sub total table 4.3*) some fluctuation can be seen over the nine year period, peaking at 1357 new cases in 2007. These data suggests that most Reporters are now using the general category of H&N rather than reporting OPC as a separate entity.

Table 4.3: Site specific cancers associated with new registrations

Cancer site	2000	2001	2002	2003	2004	2005	2006	2007	2008
Head & Neck	429	611	524	711	700	853	801	862	824
Oropharyngeal (incl orolaryngeal)	689	602	645	596	496	515	443	495	294
<i>sub total</i>	<i>1118</i>	<i>1213</i>	<i>1169</i>	<i>1307</i>	<i>1196</i>	<i>1368</i>	<i>1244</i>	<i>1357</i>	<i>1118</i>
Oesophageal	333	379	334	363	343	384	333	309	278
Gastric	63	73	67	80	73	83	51	68	66
Colon	19	20	17	19	9	12	13	16	8
Leukaemia	23	20	18	17	13	22	17	21	7
Pancreas	18	8	11	10	15	14	10	11	6
Small Bowel	11	5	9	5	8	5	9	6	4
GI Lymphoma	7	9	10	6	3	2	9	8	4
Miscellaneous	0	0	0	0	0	0	0	0	3
Cancer: elsewhere	67	100	91	96	74	95	116	92	70
Totals	1659	1827	1726	1903	1734	1985	1802	1888	1564

In 2008, 90% of all new cancer registrations were accounted for by H&N (53%), OPC (19%) and oesophageal cancer (18%). The reason for feeding for the majority of these patients was likely to be a swallowing problem whereas those with other cancers might require HETF as a means of maintaining nutritional status.

The incidence of H&N (eye, nasal, oral, salivary glands) and oesophageal cancers in the UK in 2005 was recorded as 131 and 126 per million of the population (>8,000 and 7,800 cases) respectively (Cancer Research UK, 2005). In the same year BANS recorded 1,368 patients with H&N cancer and 343 patients with oesophageal cancer. The need for HETF reflects the cancer site, extent and/or severity of the cancer and its effect on an individual's ability to achieve adequate nutrition by the oral route.

Section 5

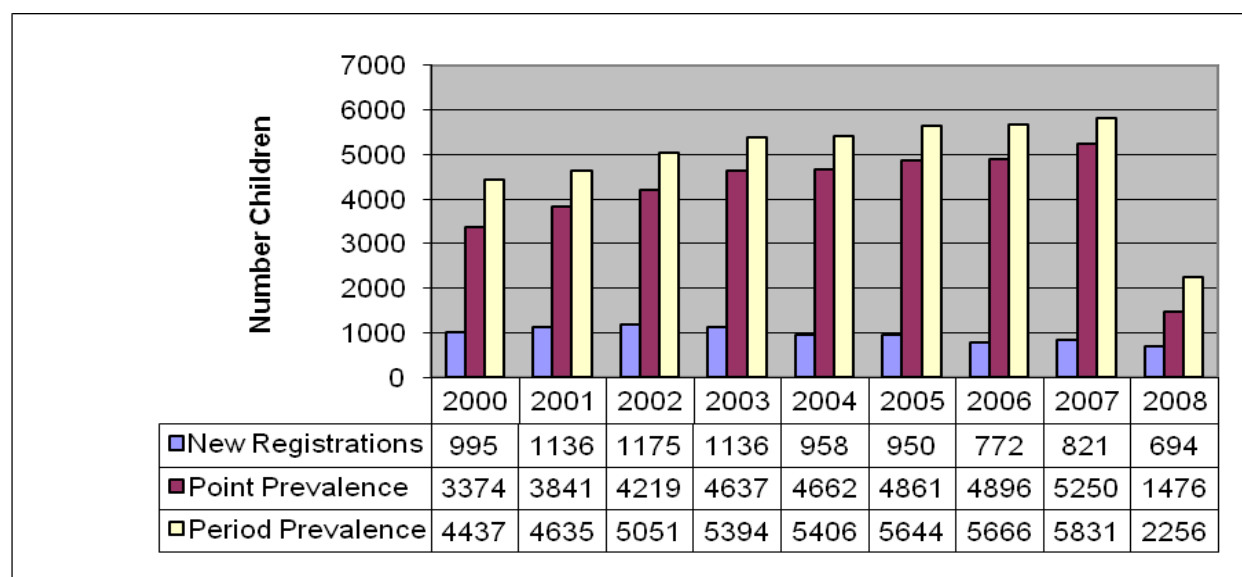
Home Enteral Tube Feeding (HETF) in children

Ann Micklewright and Amanda Hirst

5.1 New registrations, point and period prevalence

In 2008, 694 new patients started HETF. Despite the growth reported in 2007 there was a reduction in new patients of 15.5%. The new patient data was the lowest recorded since 2000. Figures for point and period prevalence are difficult to interpret as only 28% and 37% of point and period prevalence data respectively were updated in 2008.

Figure 5.1: New registrations, point and period prevalence of children receiving HETF in UK, 2000 – 2008



Point & period prevalence figures for 2008 show only the numbers of patients who were updated in year.

This is a similar picture to adult HETF, which was discussed in the previous chapter, where it was concluded that the issue of **consent** is the basis of the present decline in reporting which has caused some negative changes in practice;

- Nutrition Companies previously undertook the new registrations – this has ceased because of confidentiality and consent issues.
- Time factors – dietitians and nurses have very large case loads and are unable to take on this extra work at the expense of clinical time.
- Many reporters have a backlog of unregistered new patients.
- There are a number of centres who have withdrawn from reporting.

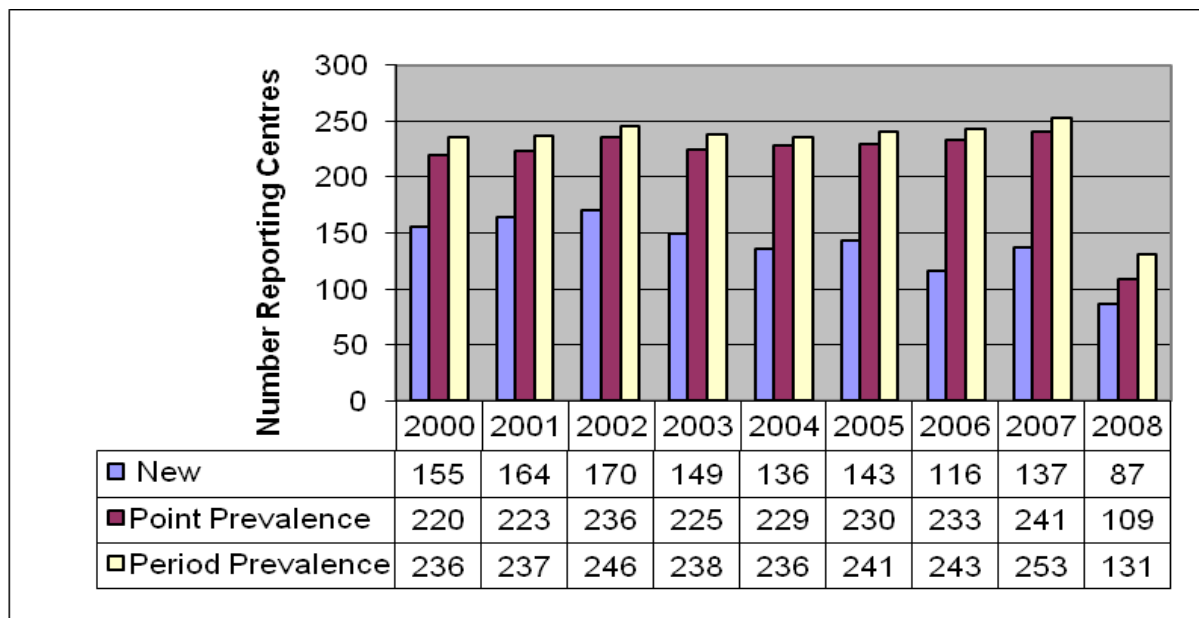
Key Point

The BANS Committee accept that the Children's HETF data has always been less complete than the adult HETF and HPN data because there are a number of large children's centres who have never reported and are difficult to recruit because of the work involved in consenting and registering large numbers of children.

5.2 Reporting Centres

At the same time the number of centres reporting new children decreased from an all-time low of 116 in 2006 to 87 in 2008, a decline of 36.5% since 2007. The number of centres updating existing patients fell dramatically by 55% (point prevalence) and 48% (period prevalence). (Figure 5.2)

Figure 5.2: number of centres reporting children receiving HETF (2000-2008)



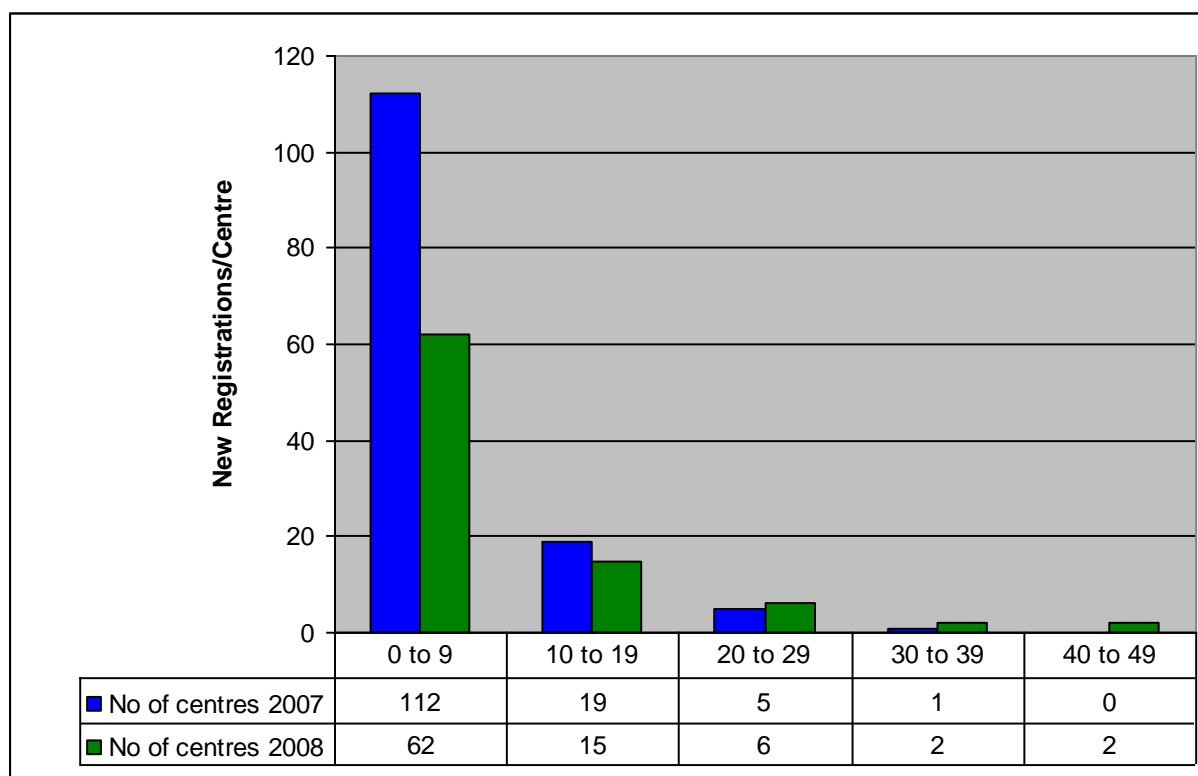
A similar pattern was seen across the UK constituent countries (Table 5.1) apart from Northern Ireland, which increased its new Reporting Centres by 50% between 2007 and 2008; the other 3 countries showed significant declines for new registrations: England (36%), Scotland (67%), Wales (67%).

The number of new registrations per centre in 2008 ranged from 1 – 49. (Figure 5.3) Nine or less new children were registered by 71% (n 62) of centres, of which 39% (n 24) registered only one child each. This was a similar distribution to 2007.

Table 5.1: Number of children registered in each constituent country in 2008 and the number of reporting centres. (2007 data in brackets)

	New n	Reporting Centres n
England	621 (755)	72 (113)
Scotland	7 (16)	3 (9)
Ireland	48 (28)	9 (6)
Wales	18 (22)	3 (9)
UK	694 (821)	87 (137)

Figure 5.3: Centres grouped by number of new children registered (2007-2008)



Key Point

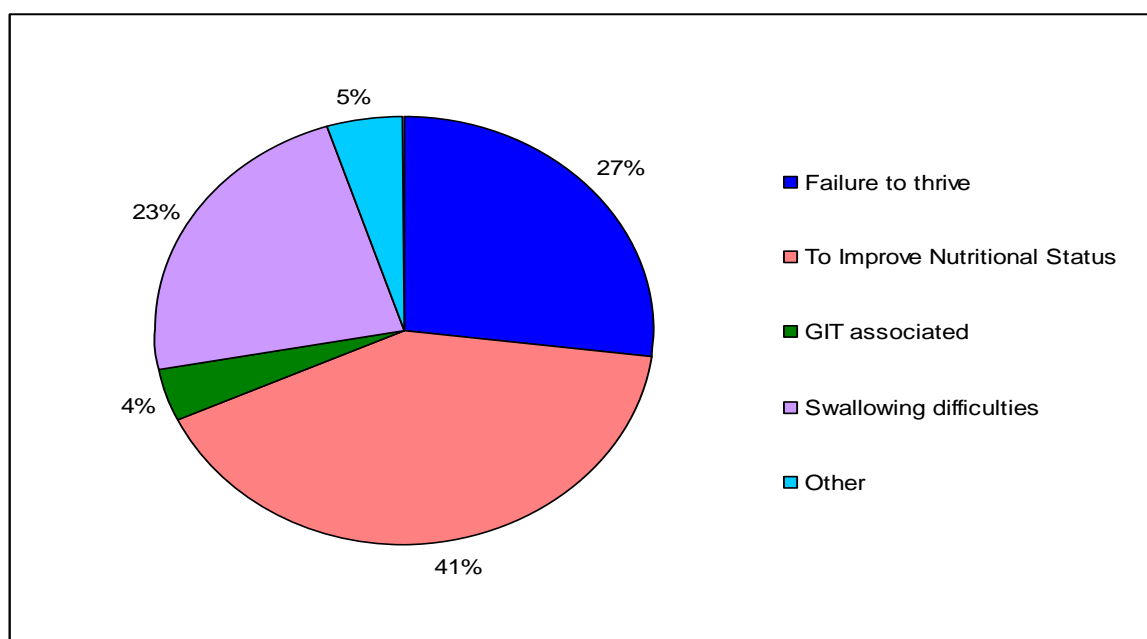
It is impossible to draw any reasonable conclusions from the existing patient data base for 2008 (point and period prevalence) because of the reduction in the number who were updated. Therefore, no further comments will be made on point or period prevalence for that year. The remainder of the Chapter will focus on new registrations and comments made only on pre-2008 prevalence data where appropriate.

5.3 Reason for feeding & feeding routes

The main reasons for feeding for new children in 2008 were: to improve nutritional status (41%); failure to thrive (27%); swallowing difficulties (23%); gastrointestinal disorders (4%) (including fistula (<1%), short bowel (1.5%), malabsorption (1.5%) and obstruction (<1%)) and a miscellaneous group (5%), which included: anorexia (<1%), unpalatability of specialised feeds (<1%) and 'other' (2.5%) (Figure 5.4). The pattern was similar to previous years for both new registrations and point prevalence.

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; this has caused some concern to both BANS and its reporters and will be rectified as e-BANS is used, where a more extensive diagnostic 'pick list' has been introduced. This has been developed through extensive consultation with paediatric doctors, dietitians and nurses. (www.e-bans.com)

Figure 5.4: Reason for feeding by percentage of new registrations in 2008



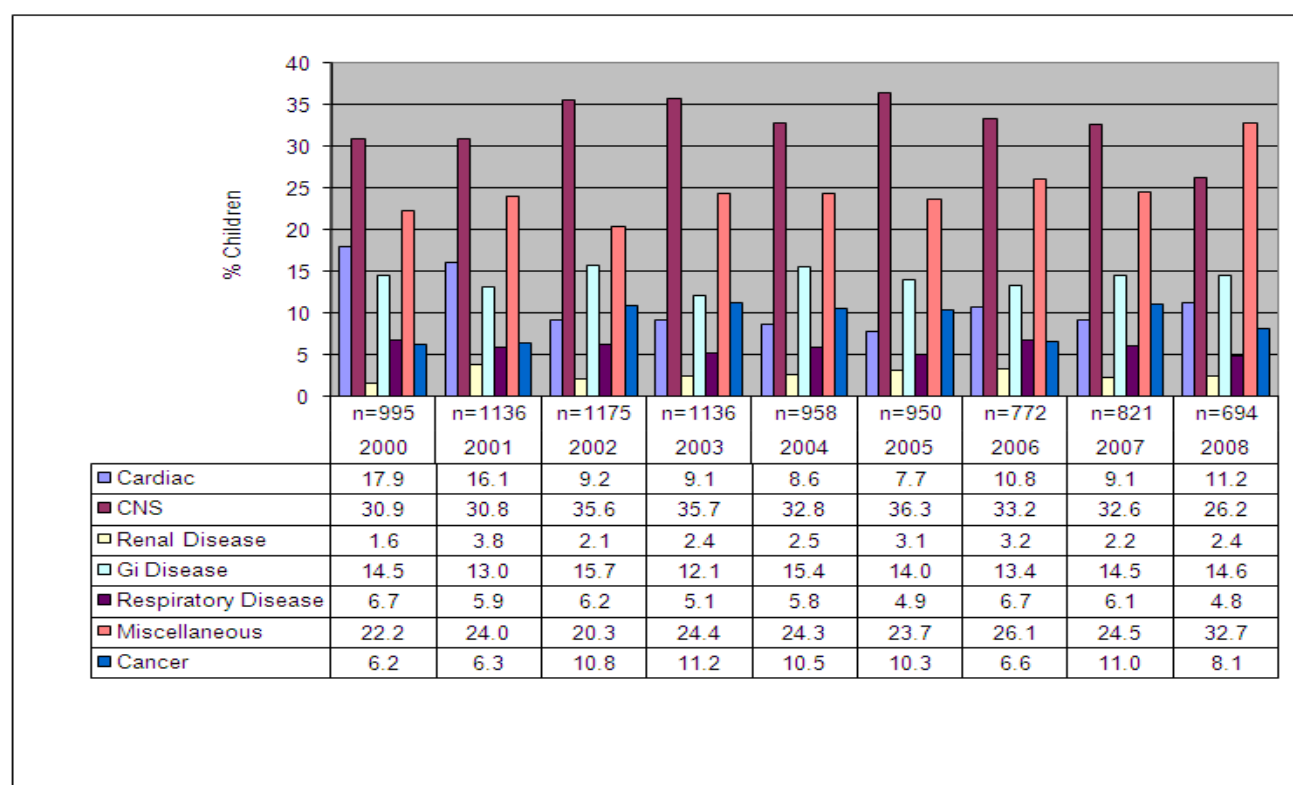
Feeding routes were similar to previous years for all 3 routes for new children: gastrostomy (33%), naso-gastric (NG) (65%), jejunostomy (2%). Point prevalence data (pre 2008): gastrostomy (52%) and naso-gastric feeding (46%). These data support the premise that although two thirds of children start off with NG feeding around 20% change to gastrostomy feeding as they become established.

5.4 Diagnoses and indications for HETF

The main diagnostic categories recorded for new registrations are shown in figure 5.4. Percentage contribution is shown below with the main primary diagnostic categories in italics.

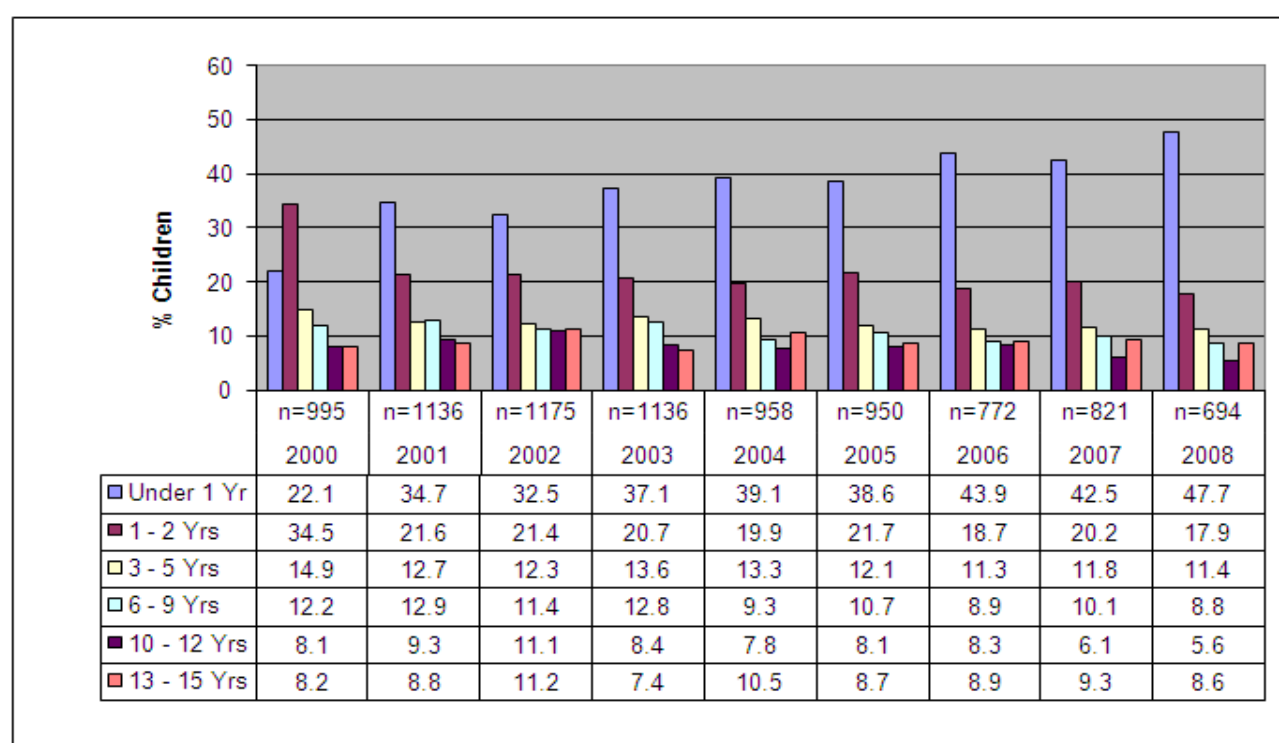
- **Cardiac (11%):** *congenital (9%), other cardiac (2%).*
- **Neurological (26%):** *cerebral palsy (9%), congenital handicap (5%), other CNS (12%).*
- **Cancer (8%):** *leukaemia (3%) head & neck (<1%), other cancer (4%).*
- **Non-malignant gastrointestinal (15%,):** *Crohn's (3%), liver (2%), gastro-oesophageal reflux (2%), other gastrointestinal (8%)*
- **Respiratory disease (5%):** *cystic fibrosis (2%), other respiratory (3%)*
- **Miscellaneous disorders (35%):** *failure to thrive (10%), congenital malformation (2%), renal disease (2%), inborn errors of metabolism (3%), other miscellaneous (18%).*

Figure 5.4: main HETF diagnostic categories for new registrations in 2008



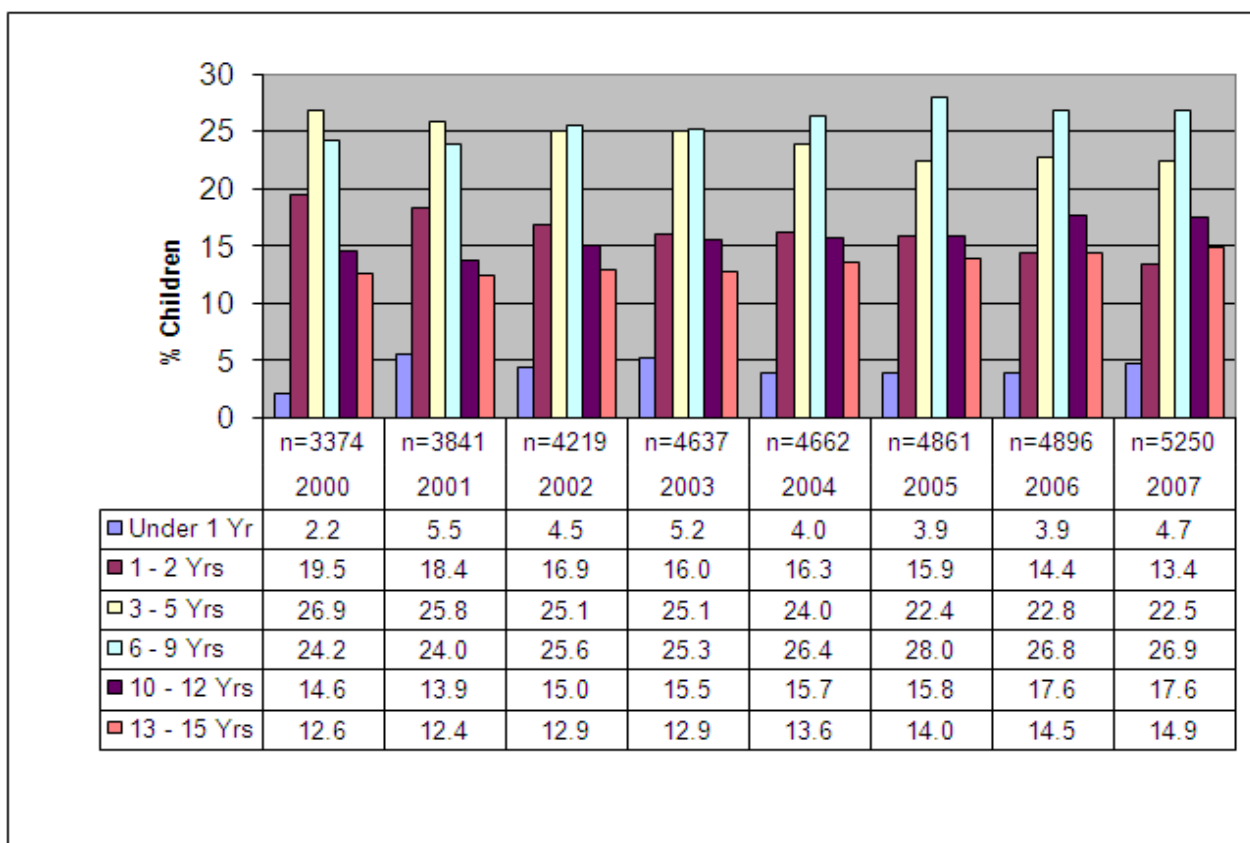
5.5 Age distribution

Figure 5.5(A): age band of new registrations (2000-2008)



The age distribution has changed significantly; Figure 5.5 (A) shows a year on year increase in infants under 1 year receiving HETF, from 22% in 2000 to 48% in 2008. By contrast the data for established patients (point prevalence) Figure 5.5 (B) shows only 2% children were under 1y in 2000 rising to nearly 5% in 2007. This suggests a large amount of short term feeding for very young infants. For those aged 1-2 the proportion of new registrations decreased from 35% to 18% over the same period.

Figure 5.5(B): age band of children – point prevalence (2000-2007)



5.6. Location and delivery of supplies

97% of new children and 95% of established (point prevalence pre- 2008) children lived in their own home; 2% and 1% respectively lived in residential care/nursing homes. (Shortfalls in the data relate to 'not recorded' and 'elsewhere' categories.)

In 2008 Homecare companies were involved with families in 83% of new cases. The use of home care companies has grown since 2000 when only 62% of new patients used this service. However point and period prevalence data since 2000 shows that once established more families (78%) move over to home care.

Section 6

Adult Home Parenteral Nutrition (HPN)

Dr Barry JM Jones, Dr Janet P Baxter, Dr Trevor Smith and Arlene Petrie

6.1 New registrations, point and period prevalence

New registrations have increased for the second consecutive year after a long period of stability at around one hundred per year. In 2008 157 new cases were registered (14% increase). These were almost entirely due to increased registrations in England (116 to 130), a rise of 12%. New cases in Wales rose from 4 to 13. Over the last year, point and period prevalence have fallen from 781 to 413 (-47%) and 867 to 521 (-40%) respectively (*figure 6.1(A & B)*). This reduction reflects the general difficulties encountered by reporters with regard to obtaining consent prior to registering and updating patients. Similar issues were described with patients receiving home enteral tube feeding (see sections 4 and 5). The relatively small cohort of new HPN patients probably explains why centres have been able to continue reporting new patients, although the BANS committee recognises that some centres are not currently reporting to BANS.

Figure 6.1(A): Number of new registrations, point prevalence and period prevalence of HPN in UK, 2000 -2008

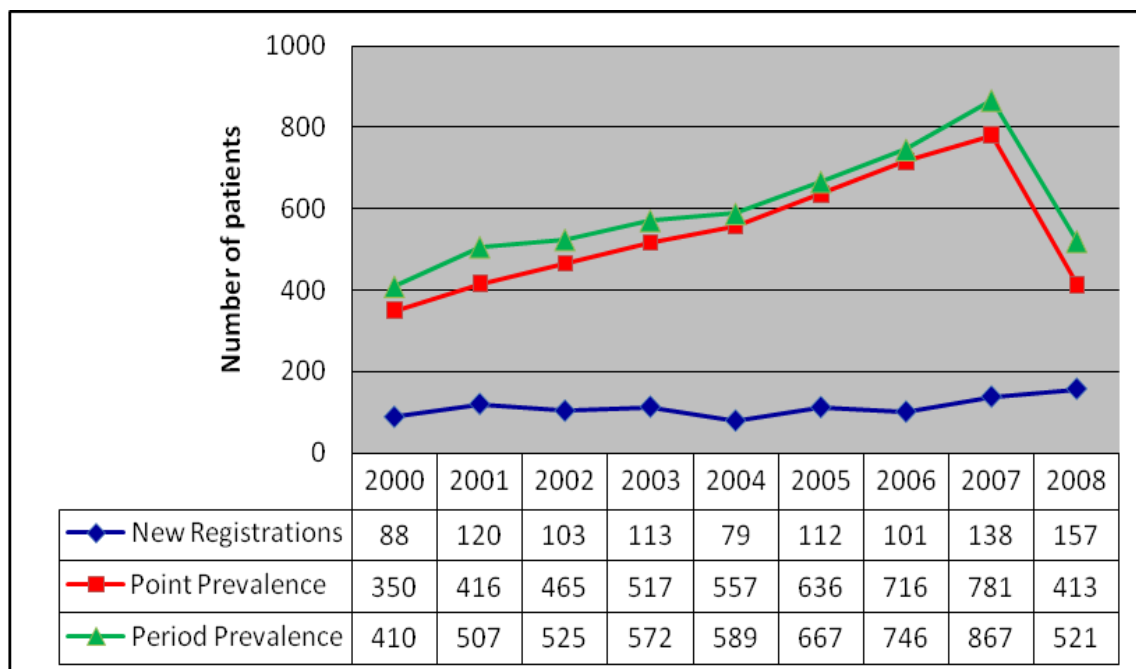


Figure 6.1 (B): Point prevalence in constituent countries of UK, 2000 – 2008

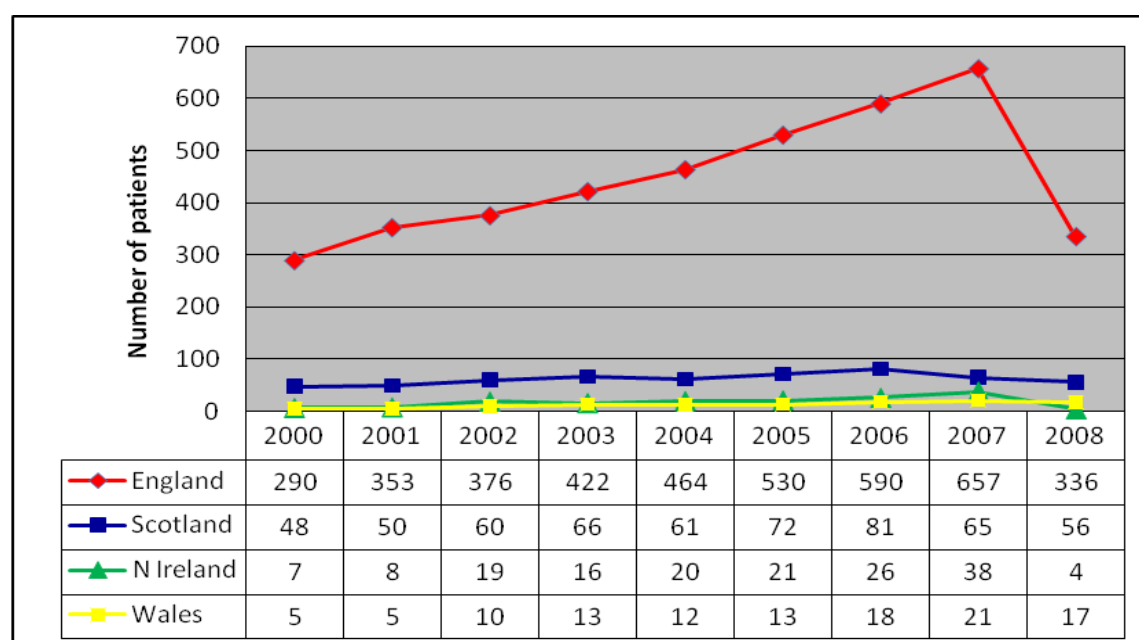


Table 6.1: Prevalence per million population* in UK and home countries in 2008 (2003) in brackets*

	New	Point prevalence	Period prevalence
UK**	2.6 (2.0)	6.7 (8.8)	8.5 9.8)
England	2.5 (2.0)	6.5 (8.6)	8.3 (9.5)
Scotland	1.9 (2.3)	10.8 (12.9)	13.7 (14.3)
Wales	4.3 (1.4)	5.7 (4.5)	6.3 (4.5)
N. Ireland	2.3 (1.2)	2.3 (9.5)	3.4 (12.5)

*Sources: Population estimates, 2008: Office for National Statistics, www.statistics.gov.uk

(Population UK 61,383,000; England 51,446,000; Scotland 5,169,000; Wales 2,993,000; N Ireland 1,775,000). **Total figures include Isle of Man

Expressed in terms of population size, prevalence of new HPN patients per million population in England have now overtaken those of Scotland. (Table 6.1). However, the combined population data need to be interpreted with caution due to the dramatic fall in reporting rates. For example, the increase in point and period prevalence in N. Ireland reported in 2007 has fallen significantly due to under-reporting. Personal communication in 2008 (Dr B Hawthorne) indicated under-reporting from Wales, despite reporting being a standard for compliance within the Welsh HPN Network. This problem appears to have been rectified for new patient registrations (Table 6.1). Prevalence data in Scotland have been reasonable well preserved largely due to the work of the National Managed Clinical Network.

It is worth noting here that the document published in 2008: “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 <http://www.specialisedcommissioning.nhs.uk/>. The BANS committee continues to liaise closely with the National Information and Governance Board (NIGB) to simplify the process of reporting to BANS and secure the future success of BANS.

Trends for new registrations and both period and point prevalence are illustrated below. [Figures 6.1 (C-F)]. Comparing 2007 and 2008 data:

- New registrations in England in 2008 rose to 130 (12%), point prevalence dropped to 336 (-49%) and period prevalence to 425 (-37%) compared to 2007 (Figure 6.1 (C)). Given the difficulties encountered by BANS reporters during 2008, the new registration rate is likely to be under-represent increasing HPN activity.
- Scottish data, which is reported via the Scottish Managed Clinical Network, indicates a levelling off of new cases. (Figure 6.1 (D)).
- Previous acknowledged under-reporting is being rectified through the Welsh HPN Service. New patient reporting (13) must now be regarded as complete. (Figure 6.1 (E)).
- In N. Ireland, the number of new cases has remained stable, but reporting of existing cases has fallen dramatically. (Figure 6.1(F)).

Figure 6.1 (C): Trends in HPN in England, 2000 – 2008

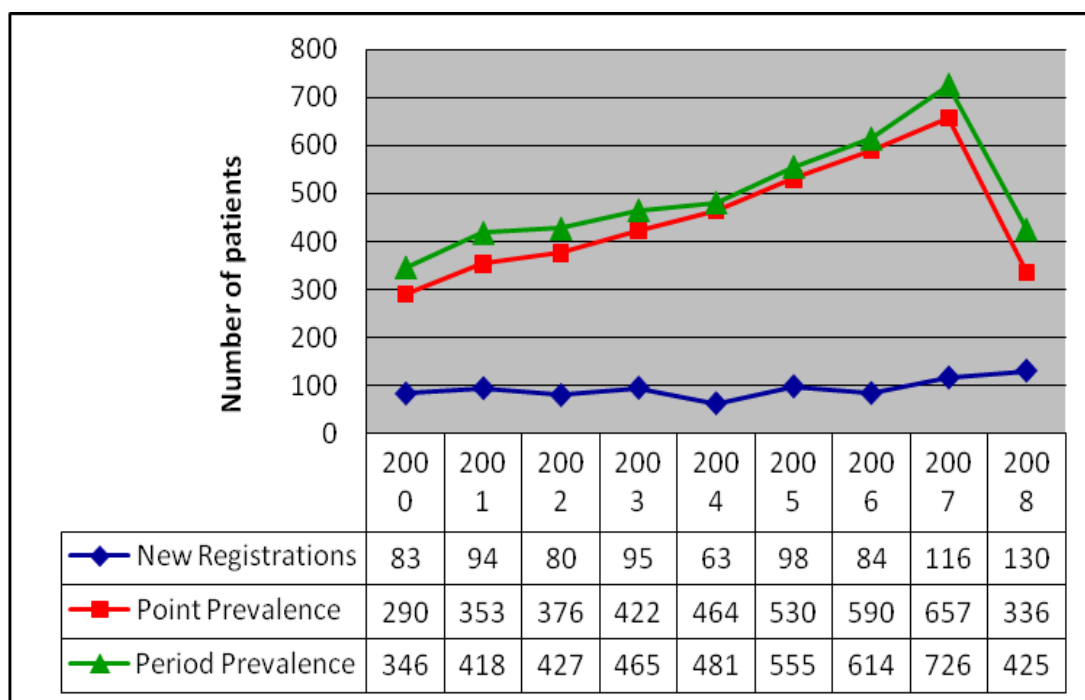


Figure 6.1 (D): Trends in HPN in Scotland, 2000 – 2008

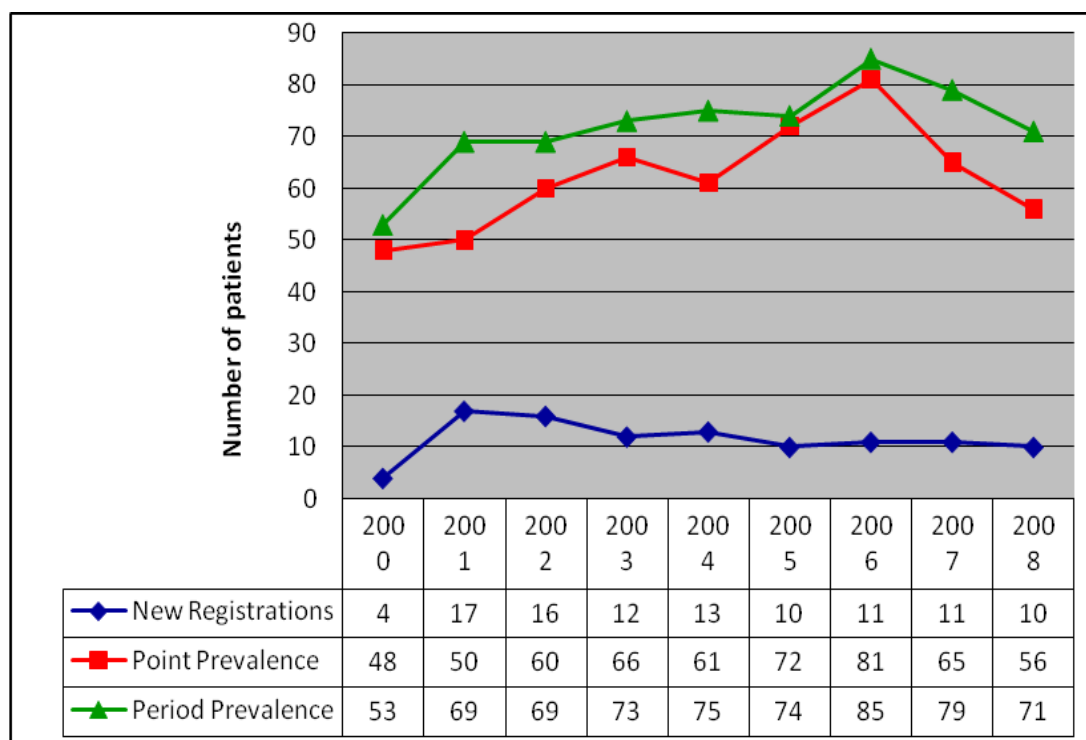


Figure 6.1 (E): Trends in HPN in Wales, 2000 – 2008

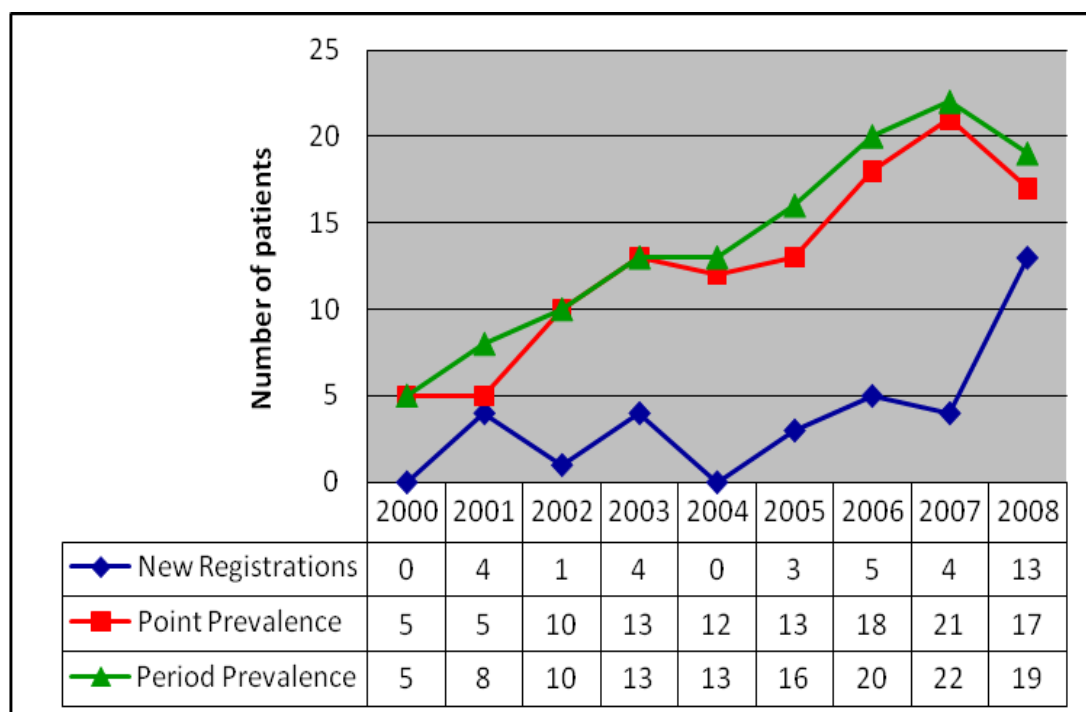
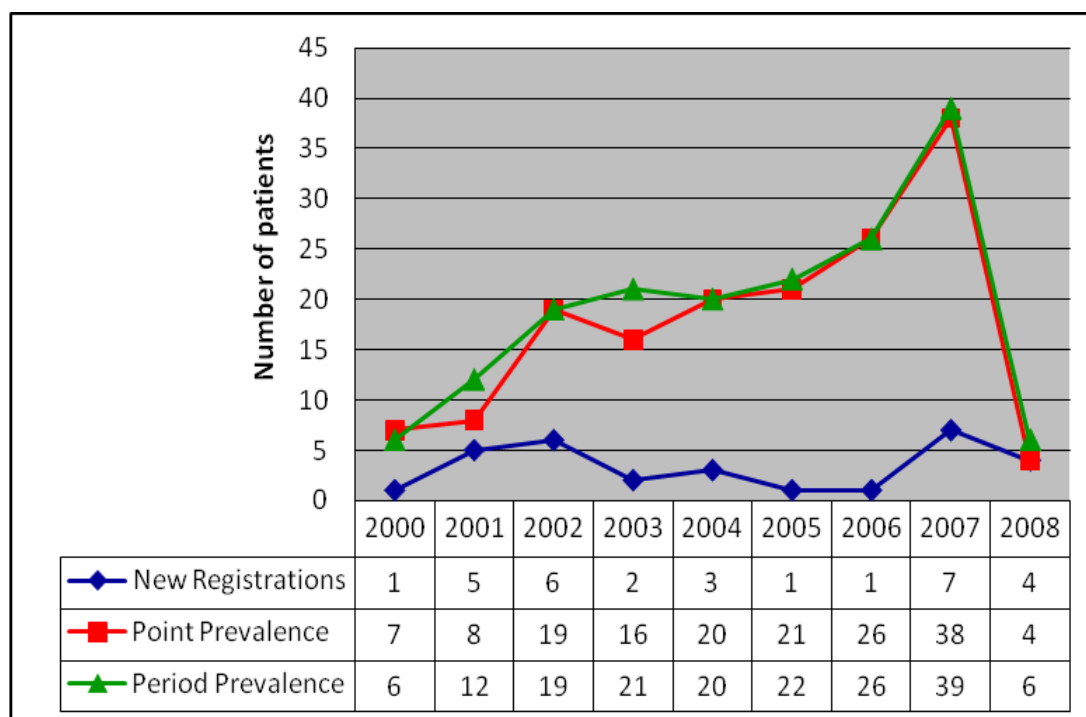


Figure 6.1(F): Trends in HPN in N Ireland, 2000 – 2008



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 24 in 2008. This reflects the large number of English reporting centres as in Figure 6.2 (A & B). Point and period prevalence of 32 and 40 reporting centres represents a reduction compared to previous years, which mirrors the reduction in reporting rates and again reflects difficulties reporters have faced with patient consent. Despite these difficulties, the data accord with previous reports (BANS report, 2005) suggesting that there are still many centres caring for very few patients.

Figure 6.2 (A): Numbers of adult HPN reporting centres in UK for new registrations, point prevalence and period prevalence, 2000 – 2008

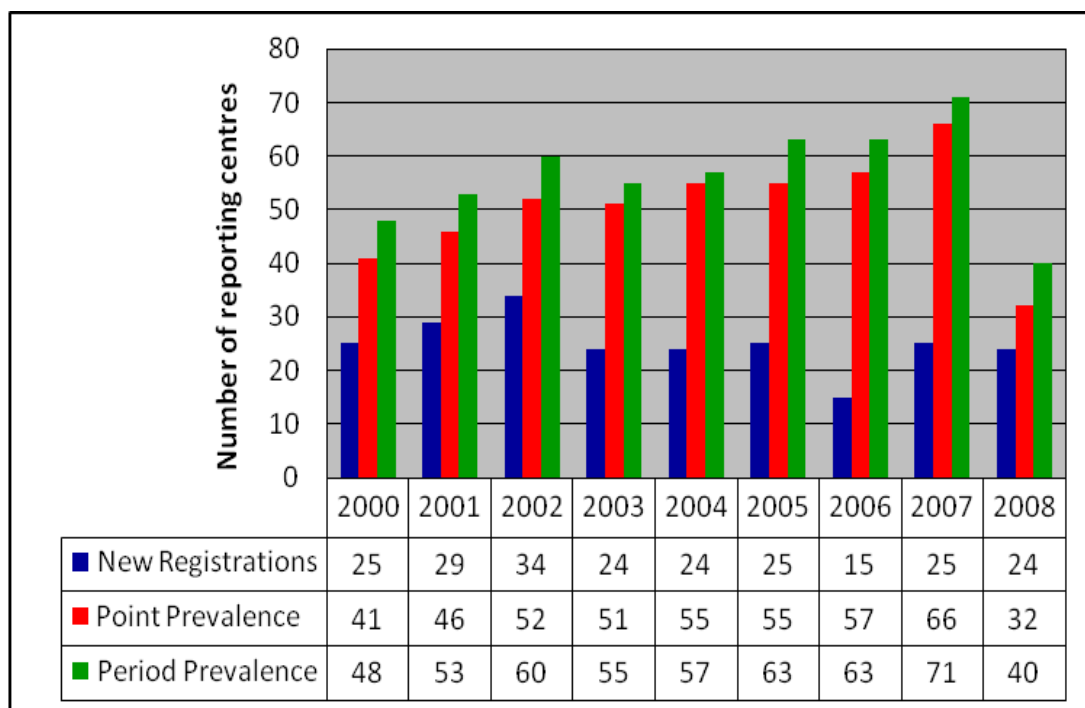
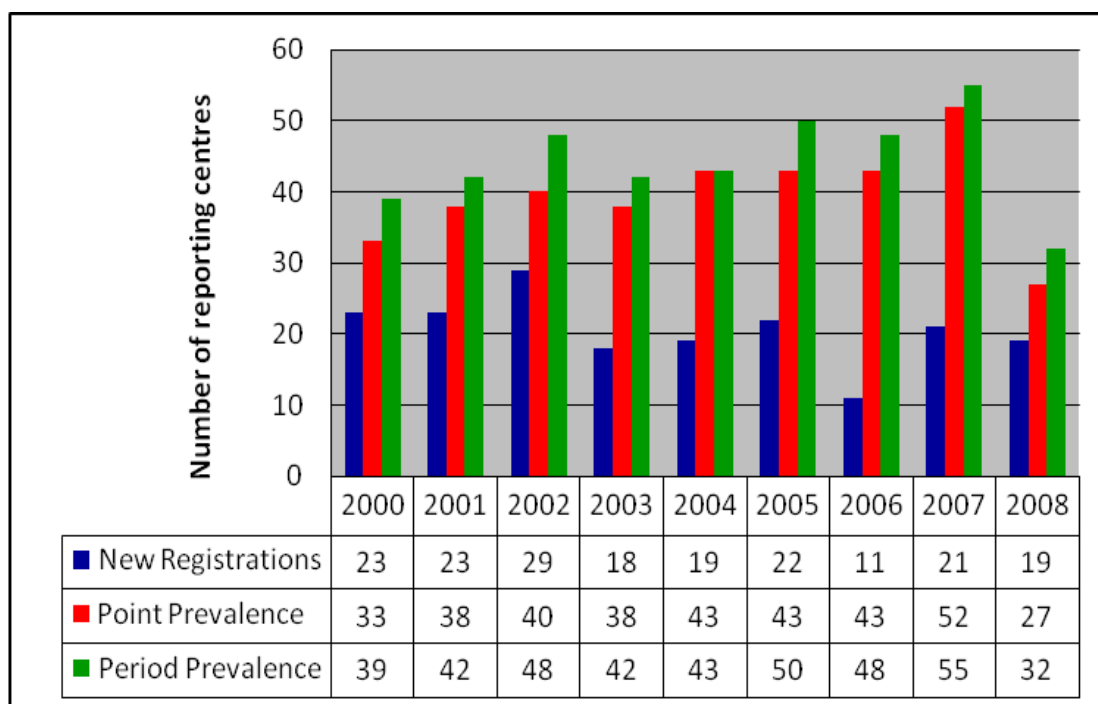


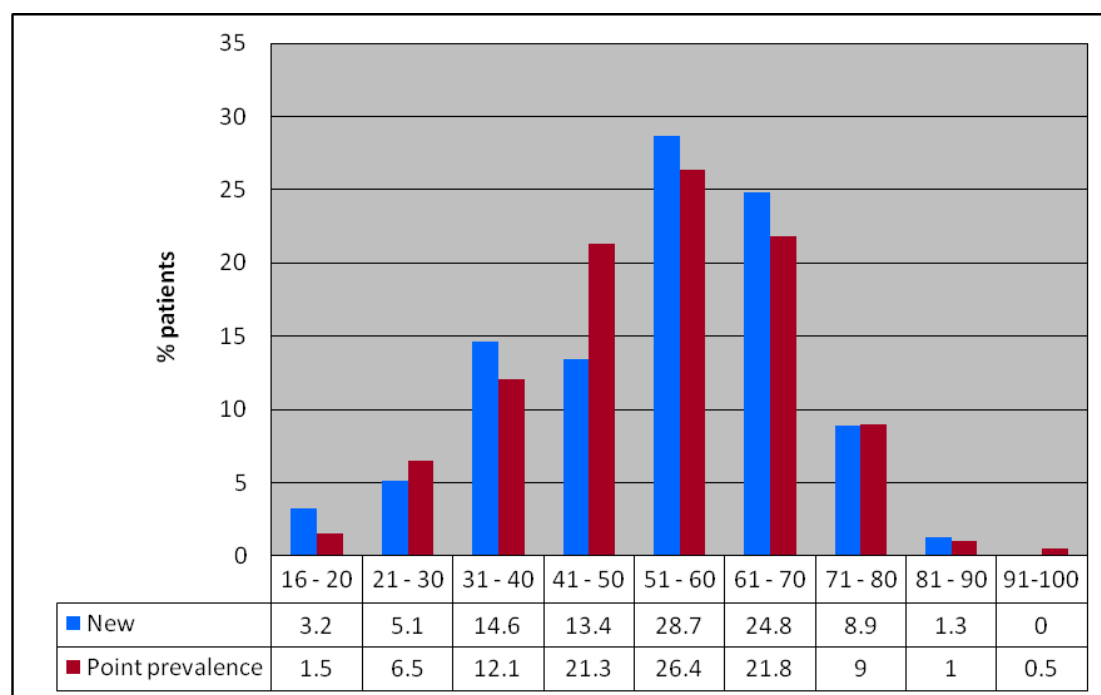
Figure 6.2 (B): Numbers of adult HPN reporting centres in England for new registrations, point prevalence and period prevalence, 2000 – 2008



6.3 Age distribution

There is a unimodal peak of 51 – 60 years of age, with a majority of patients under the age of 70 years for both new and established HPN in adults (*Figure 6.3*).

Figure 6.3: Age distribution of Adult HPN in UK for new registrations and point prevalence, 2008



6.4 Reasons for HPN

Short bowel syndrome remains the commonest indication for new HPN patients (42.7%). Fistula is cited as the main reason in 18.5%, malabsorption in 12.1%, “to improve nutrition” in 5.7%, gastrointestinal obstruction in 8.9% and swallowing difficulties in 5.1%. Short bowel syndrome is also the main reason for HPN in established patients (55.7%). (*Figure 6.4*)

Table 6.4: Reasons for Adult HPN, 2000 and 2008

	% New		% Point prevalence	
	2000	2008	2000	2008
Fistula	17.0	18.5	6.0	9.9
Obstruction	9.1	8.9	6.3	7.7
Malabsorption	12.5	12.1	14.6	14.5
Short bowel	40.9	42.7	61.4	55.7
To improve nutrition	11.4	5.7	4.9	4.1
Swallowing disorder	5.7	5.1	2.3	2.2
Other	3.4	7.0	4.6	5.9

6.5 Diagnoses and HPN

Crohns remains the leading diagnosis for adults on established HPN (point prevalence 28.3%) but this figure is slowly falling (34.3% in 2000). By comparison, new registrations for Crohns disease have fallen to 17.2% in 2008 compared to 25% in 2000. Cancer, of all types including leukaemias, account for 15.3% of new registrations, but only 6.7% of point prevalence. Colonic and small bowel cancers account for 8.3% of new registrations. A growing number of patients are treated with HPN due to severe gastrointestinal pseudo-obstruction (point prevalence increased from 9.1% to 13.6% between 2000 and 2008). The proportion of newly registered patients with 'other gastrointestinal' diagnoses, which includes surgical complications, is increasing (6.8% in 2000 to 17.8% in 2008). However, the point prevalence has only increased by 2.2%, suggesting that many of these patients receive short term HPN. (Table 6.5 (A& B)).

Table 6.5 (A): Diagnostic categories of Adult HPN, 2000 and 2008

	% New registrations		% Point prevalence	
	2000	2008	2000	2008
Crohns	25.0	17.2	34.3	28.3
Ulcerative colitis	3.4	3.2	2.3	2.9
Ischaemia*	14.8	13.4	17.7	18.4
Radiation enteritis	5.7	4.5	5.1	4.6
Pseudo-obstruction	4.5	9.6	9.1	13.6
Systemic Sclerosis	3.4	3.2	2.9	3.4
Other...including				
Surgical complications	6.8	17.8	11.1	13.3
Benign strictures	5.7	1.9	4.0	1.5
Neurological conditions	5.7	0	1.7	0.5
Cancer**	16.8	15.3	5.8	6.7
Total	86.4	84.1	94.0	92.0
Gastrointestinal***				

*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

***Total gastrointestinal includes gastrointestinal cancers also included under "Cancer"

Table 6.5 (B): Point prevalence of Crohns disease 2000 – 2008

Crohns disease									
Patients	2000	2001	2002	2003	2004	2005	2006	2007	2008
Numbers	120	131	147	156	160	175	196	213	117
%	34.3	31.5	31.6	30.2	28.7	27.5	27.4	27.3	28.3

6.5 Location, Ability to Manage and Activity level

The percentage of new registrations placed initially in a nursing home has remained very small (1.1% and 0% in 2000 and 2008 respectively) despite a rise to 10.1% in 2007. 96.2% of patients were discharged to their own home, with only 1.3% discharged to residential care. Amongst established patients (point prevalence), the number in nursing homes fell to 0.7% with 97.6% in their own homes. Newly discharged patients described as independent have increased from 49.3% (2007) to 53.5% (2008). Independence levels improve following discharge in established patients with 72.9% described as independent. Approximately 46% of new registrations require "some help" or "total help" but only 26% of established cases require such help. These figures are mirrored by activity data. Thus, 59.2% of new cases and 65.9% of established cases are described as fully active. Limited activity (new 36.3%; point prevalence 31.7%), house or bed bound (4.4% and 2.1%) account for the remainder.

6.6 Access route and Administration of Adult HPN, 2008

Venous access was via an external catheter in 91.7% and subcutaneous ports in 8.3%.

Commercial homecare companies provided for all new patients in 2008; their contribution to point prevalence has been steadily rising from 70.6% in 2000 to 90.3% in 2008. This suggests that the greater contribution to new patients is being carried through to established patients.

Section 7

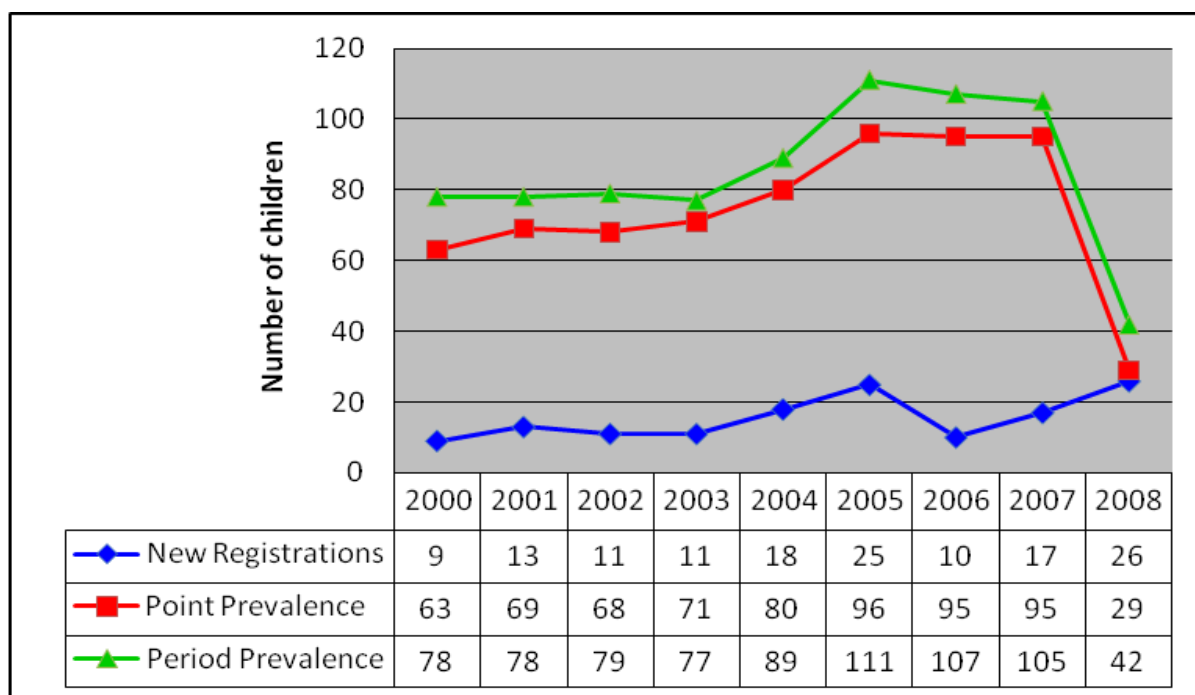
Home Parenteral Nutrition (HPN) in children

Dr Janet Baxter and Dr Trevor Smith

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

The number of new registrations of children on HPN (26) in 2008 has risen since 2007 (17); Over the last year, point and period prevalence have fallen from 95 to 29 (-69%) and 105 to 42 (-60%) respectively (*figure 7.1*). This reduction partly reflects the general difficulties encountered by reporters with regard to obtaining consent prior to registering and updating patients described in earlier chapters.

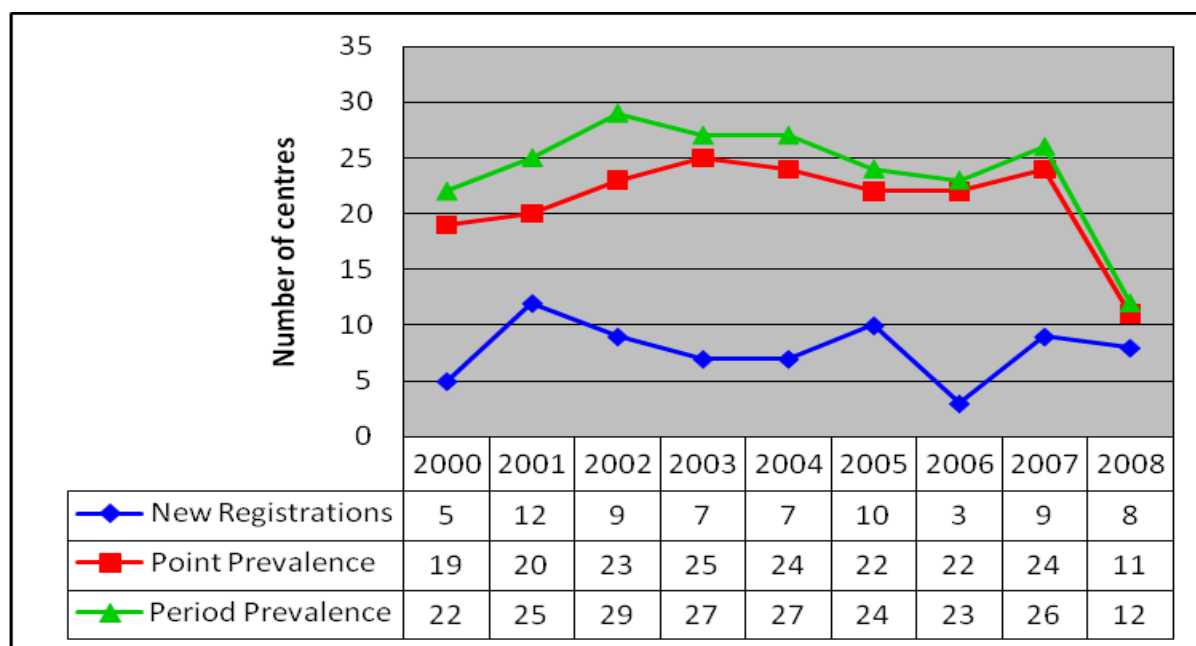
Figure 7.1: New Registrations, point and period prevalence of children receiving HPN, 2000-2008



7.2 Reporting Centres

Eight centres reported new HPN patients in 2008 (Figure 7.2) with the number of centres reporting prevalence data falling to 12. The highest number of centres ever reporting to BANS was 29 in 2002, so there are several centres not reporting data to BANS, which unfortunately mirrors practice in adult HPN and HETF (see sections 4 – 6).

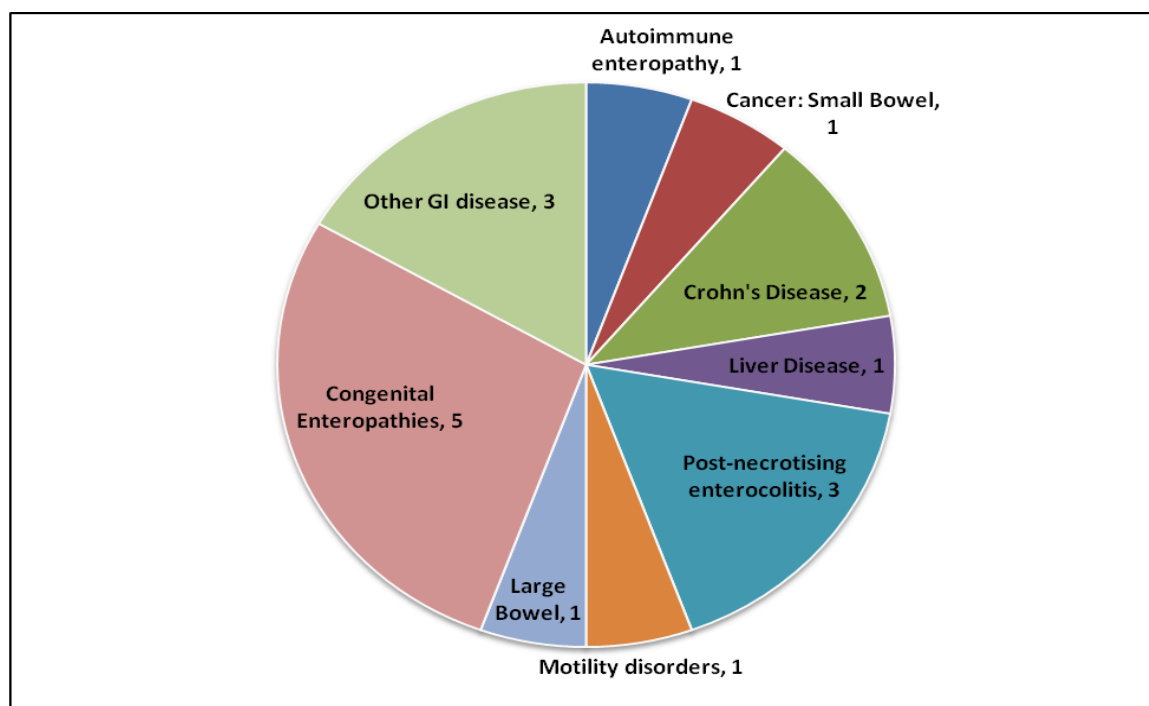
Figure 7.2: Numbers of HPN reporting Centres for children, 2000-2008



7.3 Age, Diagnoses and Reason for Feeding

Of the 26 new registrations in 2008, 22 (85%) were under the age of 3 years; 69% of established patients were under the age of 3 years. Point Prevalence data by diagnosis in 2008 showed 18 (62%) children were suffering from a gastrointestinal disorder (figure 7.3). Others suffer with cardiac disease (3%), neurological disease (21%), or one of a number of ‘miscellaneous’ disorders (14%)

Figure 7.3: Point Prevalence of HPN in 2008: number of children with a gastrointestinal diagnosis



Short bowel syndrome is a major indication for HPN (new 31% and point prevalence 24%), however the amount of HPN provided to children 'to improve nutritional status' has risen significantly (new 50%, point prevalence 48%) whilst 'malabsorption' as an indication has fallen (new 11.5%, point prevalence 17%). (See Table 7.3)

Table 7.3: Reasons for feeding in 2008

	New %	Point Prevalence %
GIT Obstruction	4	7
Malabsorption	11.5	17
To Improve Nutritional Status	50	48
Short Bowel	31	24
Other Than Listed	3.5	4

7.4 Location & Activity Levels in 2008

The majority (92%) of new registrants lived in their own home; 35% had full normal activity, 54% reported limited activity and 11% were bed bound.

93% of established patients (point prevalence) lived at home; full normal activity was maintained by 31% and limited activity by 59%, with 10% described as bed bound.

7.5 Delivery of HPN in 2008

88% of new children (23) received their feed via an external catheter and 12% (3) via a subcutaneous port. 21% of established patients (point prevalence) obtained vascular access by subcutaneous port.

Home care companies delivered to 92% of newly registered children and 93% of those already established.

Section 8

Independently acquired data compared with BANS reported data

Janet Baxter

For several years we have obtained independent data from the commercial homecare companies (CHCs) who supply nutritional support to patients at home. The data is provided by each company and aggregated. This allows estimation of the shortfall of patients reported to BANS, therefore a more accurate estimate of total numbers of patients receiving artificial nutritional support at home in the UK.

The Table below shows the point prevalence (February 2009) of UK patients receiving nutritional support from the HCC compared with the 2008 point prevalence reported to BANS and the estimated shortfall.

Table 8.1: The point prevalence of patients receiving HPN compared with the 2008 BANS point prevalence and the estimated shortfall.

2008 data	HETF		HPN	
	ADULT	PAED	ADULT	PAED
Total number supplied by CHCs	20933	9536	773	119
Pt prevalence (BANS)	5959	1476	413	29
% Use of CHCs from BANS	80.0	77.7	90.3	93
CHC number known to BANS	4767	1147	373	27
Estimated point prevalence	26166	12273	856	128
Estimated % shortfall	77.2%	88%	52%	77%

When completing the data entry, BANS reporters are asked to provide information as to whether home care companies are used or not. Table 8.2 details the percentage of patients supported by the HCC.

Table 8.2: Use of Commercial Homecare Companies – BANS data, 2008.

	New (%)	Point prevalence (%)
Adult HETF	88	80
Paediatric HETF	83	77.7
Adult HPN	100	90.3
Paediatric HPN	92	93

Section 9

Consent and e-BANS: an update

Dr Trevor Smith & Ann Micklewright



In the 2007 and 2008 reports 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) 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. As outlined throughout this report it is now clear that the process of consent has been an enormous challenge for reporters for a variety of reasons and has seriously threatened the future of BANS. This has been recognised by the National Information Governance Board (NIGB), who have taken over from PIAG (January 2009), and BANS are working closely with them to develop an 'exit strategy' which will involve the collection of pseudonymised data without the need to obtain consent. This work is on-going and we hope will be concluded in February 2010.

BANS agreed with PIAG/NIGB 2 years ago to move to an electronic reporting system. e-BANS has been very well received, although the committee are aware that many reporters continue to report to BANS in writing, using the yellow forms. BANS are working with Streets-Heaver to explore ways in which reporters can be supported using e-BANS and the proposed removal of consent early in 2010 will be a significant benefit. BANS have been planning to end the paper reporting system for some time but have delayed this whilst liaising with NIGB. These plans do however need to move forward and we are therefore planning to change to the exclusive use of electronic reporting from April 2010. BANS are no longer able to issue new copies of the yellow forms but will accept any existing forms up to the end of March 2010.

TO GET STARTED:

- Reporters can obtain their logon and password details by contacting: Geoff.Cooke@streets-heaver.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.
- More extensive diagnostic lists have been developed and grouped into categories to reduce the use of the 'other' category and to facilitate easier searching. (Figures 9.1 (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 9.1 (A): e-BANS Adult HETF primary diagnoses

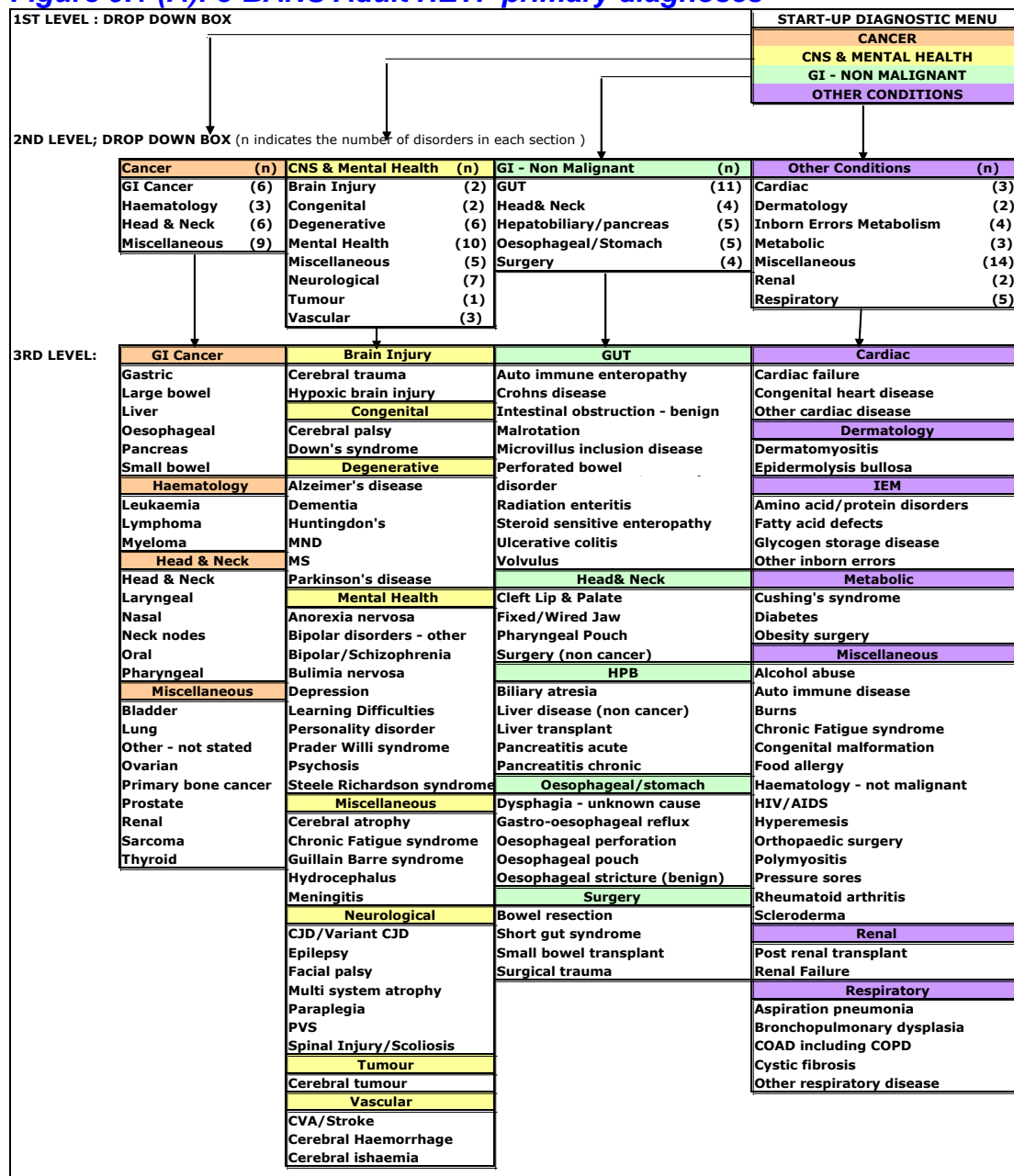


Figure 9.2 (B): e- BANS adult HPN primary diagnoses

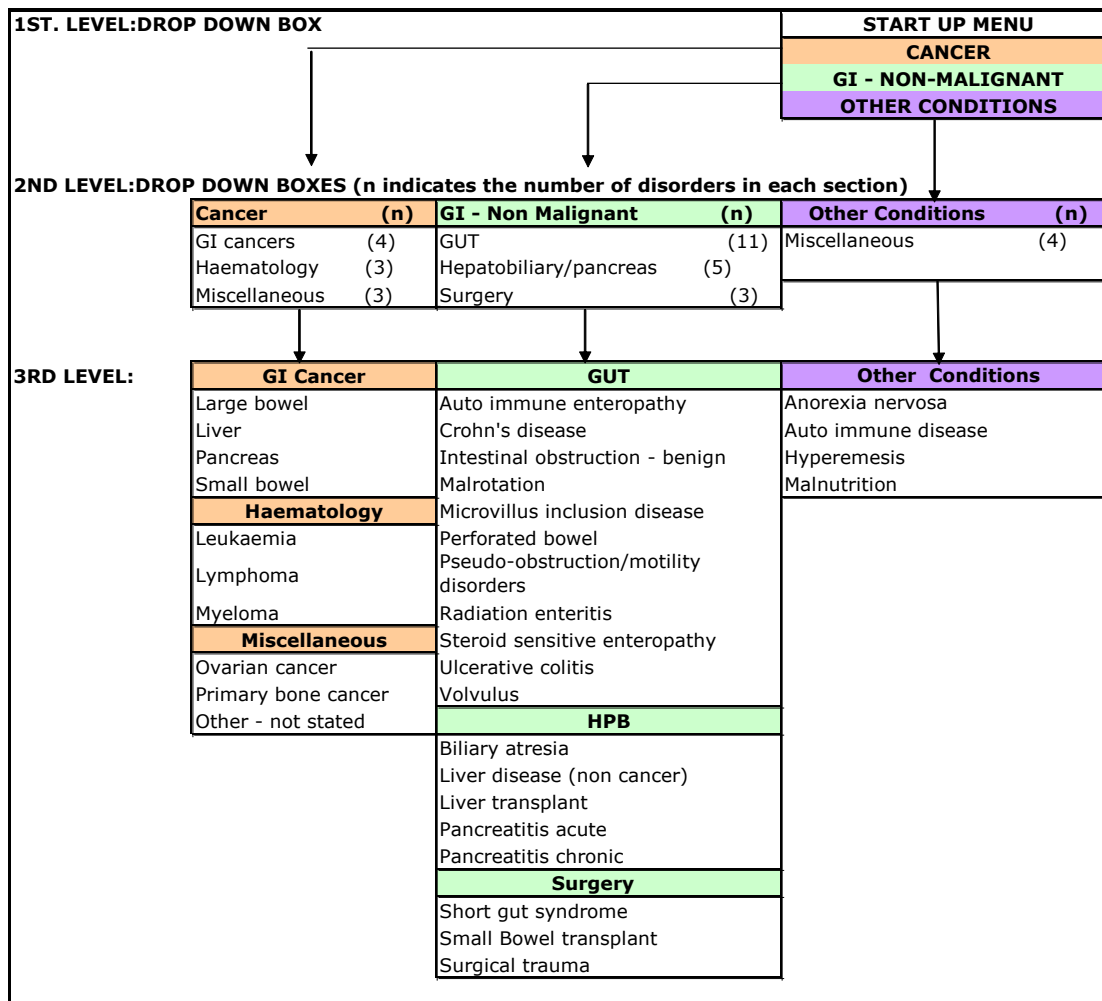


Figure 9.2 (C): e-BANS children's primary diagnoses (HPN & HETF)

1ST LEVEL: DROP DOWN BOX				START-UP MENU
				CANCER
				CNS & MENTAL HEALTH
				GI - NON MALIGNANT
				OTHER CONDITIONS
2ND LEVEL DROP DOWN BOXES (n indicates the number of disorders in each section)				
Cancer (n)	CNS & Mental Health (n)	GI - Non Malignant (n)	Other Conditions (n)	
GI Cancer (6)	Brain Injury (2)	GUT (15)	Cardiac (3)	
Head & Neck (4)	Congenital (2)	Head& Neck (4)	Inborn errors (IEM) (4)	
Haematology (6)	Mental Health (6)	Hepatobiliary/pancreas (5)	Dermatology (1)	
Miscellaneous (6)	Miscellaneous (5)	Oesophageal/Stomach (5)	Metabolic (2)	
	Neurological (4)	Surgery (4)	Miscellaneous (12)	
	Tumour (2)		Renal (2)	
	Vascular (3)		Respiratory (4)	
3RD LEVEL:				
GI Cancer	Brain Injury	GUT	Cardiac	
Oesophageal	Cerebral trauma	Auto immune enteropathy	Cardiac failure	
Gastric	Hypoxic brain injury	Crohn's disease	Congenital heart disease	
Small bowel	Congenital	Gastrochisis	Other cardiac disease	
Large bowel	Cerebral palsy	Idiopathic intractable diarrhoea	Dermatology	
Liver	Down's syndrome	Intestinal obstruction - benign	Epidermolysis bullosa	
Pancreas	Mental Health	Malrotation	IEM	
Haematology	Anorexia nervosa	Microvillus inclusion disease	Amino acid/protein disorders	
Leukaemia	Bipolar/Schizophrenia	Necrotising enterocolitis	Fatty acid defects	
Lymphoma	Bulimia nervosa	Perforated bowel	Glycogen storage disease	
Myeloma	Depression	Pseudo-obstruction/motility disorders	Other inborn errors	
Head & Neck	Learning Difficulties	Radiation enteritis	Metabolic	
Oral	Prader Willi syndrome	Steroid sensitive enteropathy	Diabetes	
Nasal	Miscellaneous	enteropathies	Obesity surgery	
Pharyngeal	Cerebral atrophy	Ulcerative colitis	Miscellaneous	
Laryngeal	Chronic fatigue syndrome	Volvulus	Auto immune disease	
Head & Neck	Guilliam Barre syndrome	Head& Neck	Burns	
Neck nodes	Hydrocephalus	Cleft Lip & Palate	Congenital malformation	
Miscellaneous	Meningitis	Fixed/Wired Jaw	Dr George syndrome	
Bladder	Neurological	Pharyngeal Pouch	Faltering growth	
Lung	Epilepsy	Surgery (non cancer)	Food allergy	
Primary bone cancer	Multi system atrophy	HPB	HIV/AIDS	
Renal	Paraplegia	Biliary atresia	Noonan's syndrome	
Sarcoma	Spinal Injury/Scoliosis	Liver disease (non cancer)	Orthopaedic surgery	
Other - not stated	Tumour	Liver transplant	Polymyositis	
	Cerebral tumour	Pancreatitis acute	Rheumatoid arthritis	
	Neuroblastoma	Pancreatitis chronic	Russel Silver disease	
	Vascular	Oesophageal/ stomach	Renal	
	Cerebral haemorrhage	Dysphagia - unknown cause	Renal failure	
	Cerebral ishaemia	Gastro-oesophageal reflux	Post renal transplant	
	CVA/Stroke	Oesophageal perforation	Respiratory	
		Oesophageal pouch	Aspiration pneumonia	
		Oesophageal stricture (benign)	Cystic fibrosis	
		Surgery	Premature/chronic lung disease	
		Bowel resection	Other respiratory disease	
		Short gut syndrome		
		Small Bowel transplant		
		Surgical disasters		

Section 10

References

M Cullinane M, Gray AJG, & Hargraves CMK et al. 2004 *Scoping our practice*. NCPOD. London

Data Protection Act. 1998 *Chapter 29*

www.opsi.gov.uk/acts/acts1998/ukpga_19980029

Health & Social Care Act. www.hmso.gov.uk/acts/acts/2001/20010015.htm

Cancer research 2005 *Persons-number of new cases of cancer diagnosed, by site, UK 2005*. www.info.cancerresearchuk.org/cancerstats/incidence/site/index

A Strategic Framework for intestinal failure and HPN services for adults in England. www.nscteam.org.uk/ifstrategy.htm.

Jones B, Micklewright A, Hirst A et al. Annual BANS Report, 2008, Artificial Nutrition Support in the UK, 2000 – 2007. BAPEN 2008. www.bapen.org.uk

Section 11

The BANS Committee, 2009

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