



**B A P E N**  
Advancing Clinical Nutrition

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## **Annual BANS Report, 2011**

### **Artificial Nutrition Support in the UK 2000 - 2010**

**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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# **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](http://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) who had been updated during that 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) who had been updated during that year.

Outcome

This is the status of the patient at the end of a 12 month reporting period.

Children

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

## Section 2

### Preface

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

The British Artificial Nutrition Survey (BANS) was established in 1996 and consolidated work previously undertaken by the Salford HPN register and the Parenteral and Enteral Nutrition Group (PENG) Home Enteral Tube Feeding (HETF) register. The BANS committee, which reflects the multidisciplinary nature of BAPEN, publishes an annual report that can be accessed on the BAPEN website. BANS relies on the voluntary contributions of health care professionals to report data on adults and children receiving long term enteral tube feeding or parenteral nutrition. The aims of BANS are:

- ❑ Monitor trends in artificial nutrition support (ANS)
- ❑ Track treatment outcomes
- ❑ Establish structure of ANS services
- ❑ Identify problems associated with the use/lack ANS
- ❑ Assess standards of care

BANS has been very successful at reporting trends in ANS over more than 10 years; detailed questionnaires have identified strengths and weaknesses in the structure of ANS services and highlighted regional variations in service provision. However the challenge posed by data governance laws (Health and Social Care Act 2006) and specifically the requirement for reporters to obtain consent from patients prior to submitting data to BANS resulted in enormous reductions in reporting rates. These problems were discussed in detail in the 2009 and 2010 BANS reports. The National Information Governance Board (NIGB) confirmed in 2010 that BANS reporters are no longer required to obtain consent from patients (a confirmatory letter from NIGB is available for all reporters to view at [www.e-bans.com](http://www.e-bans.com)) and this, coupled with the development of e-BANS, an electronic reporting tool, has resulted in a significant increase in reporting rates over the last year.

e-BANS was re-launched in July 2010 and we continue to update and develop the web-based reporting tool in response to feedback and requests from reporters. Section 9 of this report describes the encouraging increase in reporting rates we have seen over the last 12 months and lists reporting centres. However, the BANS committee are aware that many centres are yet to register with e-BANS. A particular area of concern in paediatric practice; only 17 paediatric HPN patients were reported to BANS during 2010 and therefore we have not published a paediatric HPN chapter this year as we felt this would not be representative of current practice. BANS are working closely with the British Society of Paediatric Gastroenterology Hepatology and Nutrition to develop the e-BANS system to support paediatric practice.

BANS is keen to develop closer links with reporters and conduct national surveys directed at specific areas of clinical nutrition practice. This year we have undertaken a survey of home enteral tube feeding in patients receiving radiotherapy for head and neck cancer; this was a collaborative project with a dietitian in Southampton.

The response rate was excellent and the results informative. Section 8 of this report describes the results and highlights that there are no national pathways for managing enteral tube feeding in patients with head and neck cancer; feeding practices and funding for dietitians vary widely across different cancer centres. BANS would like to undertake further surveys so please get in touch if you like to collaborate with us on a specific area of clinical practice.

The BANS committee are immensely grateful to all reporters who take time and effort to report their patients. We are confident that the future of BANS is secure and that this unique national survey will continue to make vital contributions to the planning and delivery of high quality nutritional care in the UK.

Dr Trevor Smith  
Chair of the BANS committee, November 2011.

## Section 3

### Executive Summary

Dr Trevor Smith

#### *Adult HETF*

1. Since 2009 new registrations of adults receiving home enteral tube feeding (HETF) increased by 5% to 3430 in 2010. Point and period prevalence increased by 36% and 21% respectively. The number of new reporting centres decreased to 121 in 2010 (-18%).
2. The number of new registrations per million of the population was 55 in the UK; it was remarkably higher in Northern Ireland (112) and the Isle of Man (167) than in the other UK constituent countries.
3. The proportion of newly registered HETF patients with cancer (predominantly head and neck cancer) continues to gradually increase (from 25% in 2000 to 39% in 2010).
4. Most (63%) HETF new registrations in 2010 were aged over 60 years, with 41% over 70 years (decreased by 11% from 2000).
5. From 2000 to 2010, there was an increase in patients who were fully active (from 17% to 40%); independently living (from 21% to 40%); and living in their own home (from 56% to 69%).
6. The two main reasons for patients registered with BANS starting HETF were 'swallowing disorders' (65%) and 'to improve nutritional status' (27%).
7. Gastrostomy was the primary route of feeding (75%), as it has been over the last ten years.
8. Home care companies supplied 86% of newly registered adult HETF patients in 2010, a decrease of 3% compared with 2009.
9. At the end of the year, 71% of the patients continued on HETF, 6% returned to oral feeding and 12% of the patients died (predominantly due to the underlying disease).

#### *Children's HETF*

1. In 2010, 448 new children were registered and 1336 were updated (period prevalence). Despite the shortfall of data this is a large cohort of representative patients.
2. In 2007, 137 centres registered new children; by 2010 this had dropped by 60% to 55.
3. The decline of reporting centres was seen across all UK constituent countries, showing a fall in new registrations over a 10 year period: England (-60%), Scotland (-86%), Northern Ireland (-50%), Wales (- 85%).
4. In 2010, 69% of all newly registered children were less than 2 years old and 80% were 5 years or under. The overall trend over 10 years is that more children are receiving HETF at a younger age.
5. Over the period 2000 to 2010, the proportion of new children with cancer requiring HETF fluctuated between 6.2% and 11%, whilst the number with CNS & mental health conditions (30%) and non-malignant GI disorders (~14%) were relatively stable.



6. The 'other conditions' category, which includes congenital cardiac conditions, respiratory disease and faltering growth, (conditions that correspond with the higher percentage of younger children registered) increased to 49%.
7. During 2010, 63% of new registrations were fed via a naso-gastric tube - this in stark contrast to just 17% of adults being fed this way.
8. In 2010 only 2 out of 448 new children registered lived elsewhere other than their own home thus indicating that home is a viable discharge location for children receiving HETF.
9. By 2010 the use of Home Care Companies to provide feeds and equipment to new children had grown to 88% from only 62% in 2000.
10. Of the 1336 children reported on e- bans during 2010, 1148 (86%) continued on home enteral feeding, 74 (5.5%) returned to oral feeding, 23 (2%) died and 57 (5%) were lost to follow up or transferred to other centres.

### **Adult HPN**

1. New adult HPN registrations increased during 2010 – 228 patients compared to 148 in 2009 and 157 in 2008. Point and period prevalence increased to 523 and 624 cases respectively. This represents a significant increase in reporting rates following the difficulties that were encountered with consent during 2008 and 2009 (described in 2009 and 2010 BANS reports).
2. The number of centres registering new patients reduced from 27 in 2009 to 21 in 2010; the number of centres updating existing patients reduced from 35 in 2009 to 25 in 2010. These data suggest that fewer centres are managing larger number of HPN patients.
3. The reported UK HPN point prevalence was 8.40 per million and period prevalence 10.02 per million. These are significant lower than data reported in 2007 (although higher than 2009) and are due to under-reporting rather than a true reduction in HPN prevalence. These data therefore need to be interpreted very cautiously.
4. New registrations in England during 2010 increased to 196 patients (125 patients in 2009); new patient registrations grew by 69% compared to 2007 and 133% compared to 2006. Point and period prevalence increased to 413 and 506 patients respectively.
5. New registrations in Scotland increased to 16 patients (6 patients in 2009). Point and period prevalence increased to 59 and 67 patients respectively.
6. Welsh point and period prevalence was 23 patients; only 7 new HPN patients were reported to BANS. These low figures are due to significant under-reporting rather than an actual low prevalence of HPN in Wales.
7. Reporting in Northern Ireland has improved considerably and should be considered complete. The point and period prevalence were both 15.56 per million population.
8. The modal age for adult HPN is 51 – 60 years of age.
9. Short bowel syndrome remains the main reason for HPN (54.4% new cases; 58.9% established cases).
10. Crohns disease, small bowel ischaemia and pseudo-obstruction remain the major indications for new registrations (18.4%, 9.7% and 11% respectively) and established cases (29.3%, 15.3% and 15.1%). A substantial heterogeneous group including complex surgical problems accounts for 11.4% of new cases and 9.75% of point prevalence.

11. The percentage of newly registered patients initially placed in a nursing home has remained very small (1.1% and 0.4% in 2000 and 2010 respectively) despite a rise to 10.1% in 2007. The vast majority of patients are discharged to their own home.
12. Although a minority of new cases are described as house or bed bound (5.8%), 60.1% are described as fully independent, the remainder requiring assistance with their HPN.
13. Venous access was via an external catheter in 98.7% and subcutaneous ports in 1.3%.
14. Commercial homecare companies provided for all new patients in 2010; their contribution to point prevalence has been steadily rising from 70.6% in 2000 to 94% in 2010.
15. 83.8% patients were still on HPN at the end of the year but only 7.5% had reverted to oral nutrition. 1.4% were in hospital, 3% were transferred to other centres (and no further outcome data were available) and the mortality rate was 6.6%.

### ***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 46.5% of the total estimated cases. This reflects the significant reduction in reporting since 2008, although there are encouraging signs of recovery since the re-launch of e-BANS in 2010.
3. For paediatric HPN, BANS surveys only 10% of UK cases; the numbers were too small to formally publish in this year's BANS report.
4. Adult HETF returns were 18% of estimated cases.
5. Paediatric HETF attracts only 7% of estimated cases.
6. The significant reduction in reporting rates continues to pose a challenge for BANS; e-BANS was re-launched in July 2010 without the need for patients to provide consent. This has been approved by the National Information Governance Board (NIGB) and will help secure BANS' future as the leading nutritional survey of its kind internationally.

### ***Home enteral tube feeding for Head & Neck cancer patients: A national survey.***

1. Only 18 Cancer Centres (51.4%) had specific Dietetic funding for HNC patients.
2. Dietetic funding for HNC patients varies from 0.3 WTE – 5.0 WTE per cancer centre.
3. In total only 15 Cancer Centres (42.8%) report HNC patients to BANS.
4. Just over half (51.4%) of Cancer Centres have a local pathway for enteral tube feeding HNC radiotherapy patients.
5. There is currently no national pathway for enteral tube feeding HNC radiotherapy patients.
6. 77.1% of Cancer Centres place a feeding tube prophylactically in HNC patients (1 Centre (2.9%) uses NG tubes, 9 (25.7%) use RIG tubes and 17 (48.6%) use PEG tubes).

7. The most common factors used to determine if patients will automatically require tube feeding were cancer site (34.3%), radiotherapy treatment field (45.7%) and those who become malnourished during treatment (37.1%).
8. Only 25.9% of Cancer Centres use MUST to identify malnutrition pre-treatment, 17.9% during treatment and 15.4% after treatment.
9. Other tools and parameters used to identify malnutrition risk include BMI, percentage weight loss, ability to swallow, a local nutrition screening tool, weight, biochemistry, Dietetic assessment, diet history and clinical judgement.

## Section 4

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

Dr Rebecca Stratton

#### 4.1 Patients and Reporting Centres

##### New Registrations, point and period prevalence

In 2010, there was a small, 5% increase in the number of new registered adult patients receiving HETF (n=3430) compared with 2009 (Table 4.1). Point prevalence (the number of adults recorded as still receiving HETF at the end of the year) increased by 36% to 5703 and period prevalence (the number recorded as receiving HETF during the year) increased by 21% to 8075 in 2010. This reflects reporters registering a backlog of patients who were commenced on HETF prior to 2010, when there were great difficulties registering patients due to the problems of consent described in previous reports (2008 and 2009). It is encouraging that reporting rates are now increasing given that consent is no longer required.

##### Reporting centres

The number of reporting centres decreased in 2010 (-18%), however, the number of patients registered per reporting centre increased from 22 in 2009 to 28 in 2010 (the highest figure in the previous ten years). The continued decline in reporting centres can be partly explained by the aggregation of reporting centres as hospitals are joining into larger trusts; these figures also suggest that individual centres are reporting a more complete data set aided by the ease of use of the eBANS reporting tool.

**Table 4.1: Number of new adult HETF registrations, point and period prevalence, and reporting centres from 2008 – 2010 in the UK**

	2008	2009	2010
<b>New Registrations</b>	<b>4326</b>	<b>3282</b>	<b>3430</b>
<i>Reporting Centres</i>	193	148	121
<b>Point Prevalence</b>	<b>5959</b>	<b>4192</b>	<b>5703</b>
<i>Reporting Centres</i>	205	161	138
<b>Period Prevalence</b>	<b>10690</b>	<b>6704</b>	<b>8075</b>
<i>Reporting Centres</i>	205	185	148

##### Constituent UK countries

In 2010, there was an upward trend in new registrations for adult HETF patients compared to 2009 in England (6%), Scotland (31%) and Northern Ireland (4%),

whilst there was a decrease in Wales (42%). In addition, both point and period prevalence were increased in all countries, with the exception of Wales. The number of reporting centres decreased in all countries except for Northern Ireland.

New registrations for the Isle of Man increased to 14 patients in 2010. Point and period prevalence increased by 100% and 120% respectively, within this one reporting centre.

#### 4.2 New adult HETF registrations per million of the UK population

New registrations, point and period prevalence per million of the population are calculated using the mid-point annual population data for 2010 (Table 4.2). The number of new adult HETF registrations per million of the UK population was 55. New registrations per million were higher in Northern Ireland (112) and the Isle of Man (167) than in the other countries. For 2010, point and period prevalence per million of the population were lowest in England (83 and 118 respectively) and highest in Northern Ireland (213 and 354 respectively), although the BANS committee recognise that there is considerable under-reporting and therefore these data need to be interpreted very cautiously.

**Table 4.2: Number of new adult HETF registrations, point and period prevalence per million of the population in constituent UK countries in 2010**

	Registrations per million population in 2010			Mid 2010 population*
	New Registrations per million	Point Prevalence per million	Period Prevalence per million	millions
England	53	83	118	52,234
Scotland	61	115	143	5,222
N. Ireland	112	213	354	1,799
Wales	46	128	163	3,006
Isle of Man	167	167	282	0,084
UK	55	92	130	62,262

\*Source: Office for National Statistics

#### 4.3 Clinical conditions of adult HETF patients 2000 – 2010

Patient diagnoses are grouped into 4 main categories: cancer; central nervous system (CNS) and mental health; non-malignant gastrointestinal (GI) disorders; and other conditions. Figure 4.3 (A) illustrates the number of new registrations by clinical condition from 2000-2010.

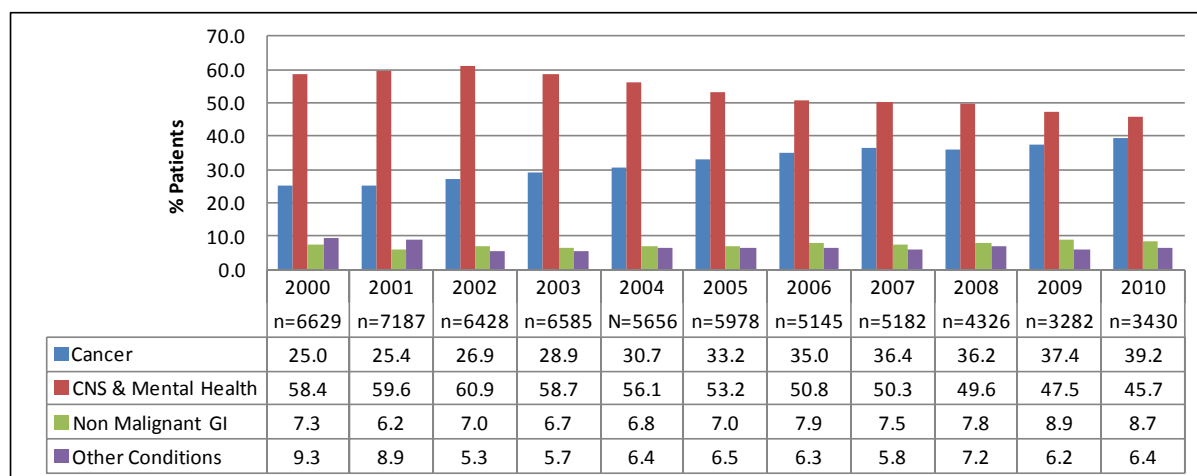
The main diagnoses for newly registered adult patients receiving HETF in 2010 grouped by four categories are listed below:

##### **Cancer (n=1346)**

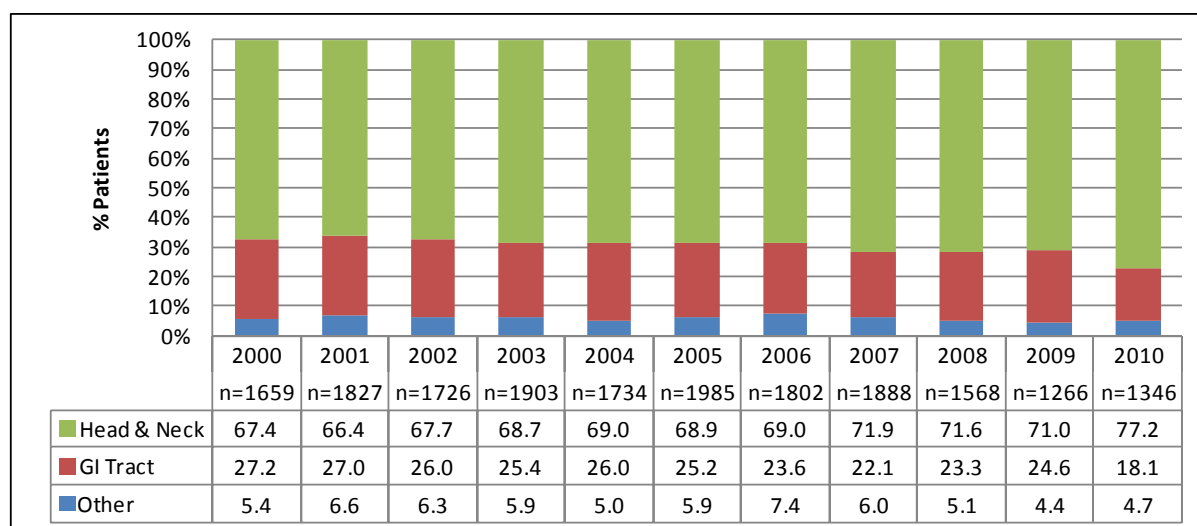
The proportion of new registrations with cancer receiving HETF has gradually increased from 25% in 2000 to 39% in 2010.

- Head and neck cancer accounted for 77% of new HETF registrations with cancer in 2010, a proportion that has increased gradually over the years (was 67% in 2000). For more information see figure 4.3 (B) and section 4.7.
- GI cancer, including oesophageal and gastric cancer, accounted for 18% of new HETF registrations in 2010, which has decreased from 27% in 2000.
- Other types of cancer (5%) accounted for a small proportion of the new registrations with cancer (haematology (1%); miscellaneous (4%)).

**Figure 4.3 (A): Clinical conditions of newly registered adult HETF patients from 2000-2010**



**Figure 4.3 (B): Breakdown of cancer types for new adult HETF registrations (2000-2010)**



**Central nervous system and mental health (n=1566):** the proportion of new adult HETF registrations with CNS and mental health conditions has gradually decreased from 58% in 2000 to 46% in 2010.

- Vascular disorders contributed to 43% of all CNS & mental health conditions in 2010 (compared to 60% in 2000) of which cerebrovascular diseases (41%) were the main diagnostic type.

- 32% of new registrants in this diagnostic group in 2010 had degenerative disorders such as motor neurone disease (12%), multiple sclerosis (8%) and Parkinson's disease (6%)
- There were a variety of other conditions that affected a smaller proportion of new registrants in this diagnostic category including: brain injury (8%); other CNS conditions (7%); congenital disorders (5%); neurological disorders (2%); cerebral tumour (1%); learning difficulties (1%); mental health problems (2%).

### Non-malignant gastro-intestinal (n=300)

The proportion of new registrations with non-malignant gastro-intestinal tract conditions receiving HETF was 9% in 2010 and has remained stable over the past ten years. These included the following: oesophageal/stomach disorders (41%); gut disorders (27%); hepatobiliary (8%); other GI diseases (19%).

### Other Conditions (n=218)

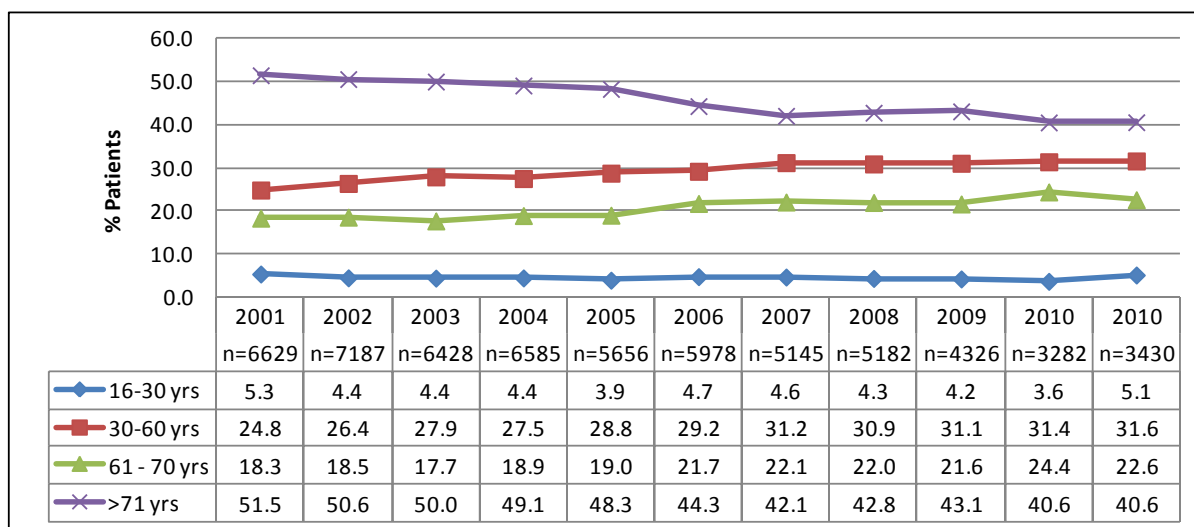
The proportion of new registrations with other conditions receiving HETF was 6% in 2010 and has remained stable over the past ten years. These included the following: respiratory disease (28%); cardiac disease (7%); renal disease (7%); miscellaneous or unnamed conditions (52%).

## 4.4 Age, level of activity, dependency and location of adult HETF patients

### Age

The majority of newly registered patients (63%) receiving HETF in 2010 were over 60 years (Figure 4.4 (A)) although the proportion aged between 31 and 60 years has increased by 7% since 2000. A possible explanation for the decreasing proportion of the oldest patients and the increasing proportion of the younger patients could be the change in the clinical conditions of patients newly registered with BANS (e.g. increase in the proportion of head and neck cancer patients; reduction in the proportion of CVA (cerebrovascular accident) patients).

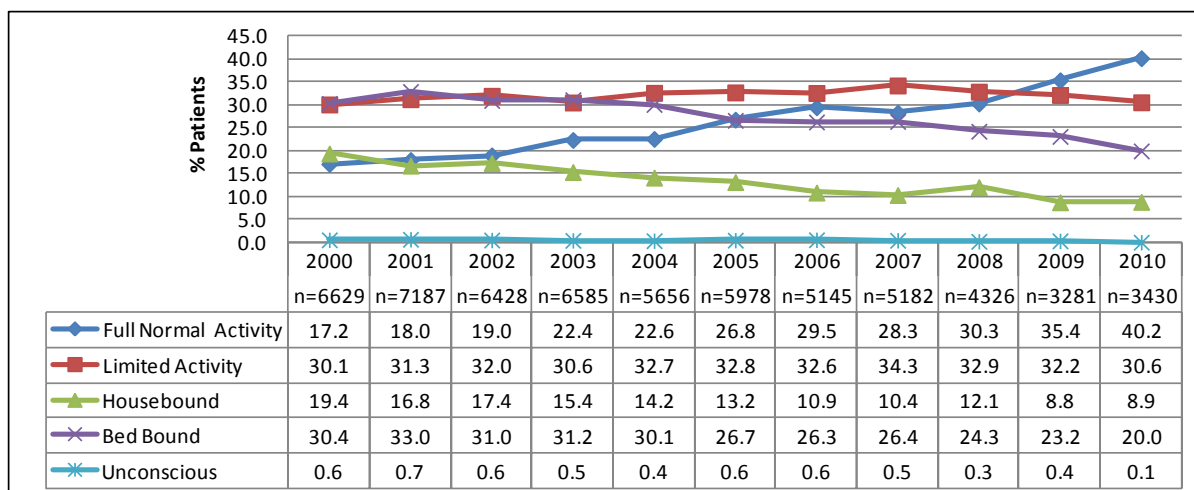
**Figure 4.4 (A): New adult HETF registrations (%) within age bands (2000-2010)**



## Level of activity

The number of patients on HETF and newly registered with BANS who were fully active has increased from 17% in 2000 to 40% in 2010, with an increase of 10% over the last two years. The number of patients with limited activity remained between 30 and 35% and the numbers of newly registered patients who are bed bound and those who are housebound have both decreased by 10% since 2000. See figure 4.4 (B).

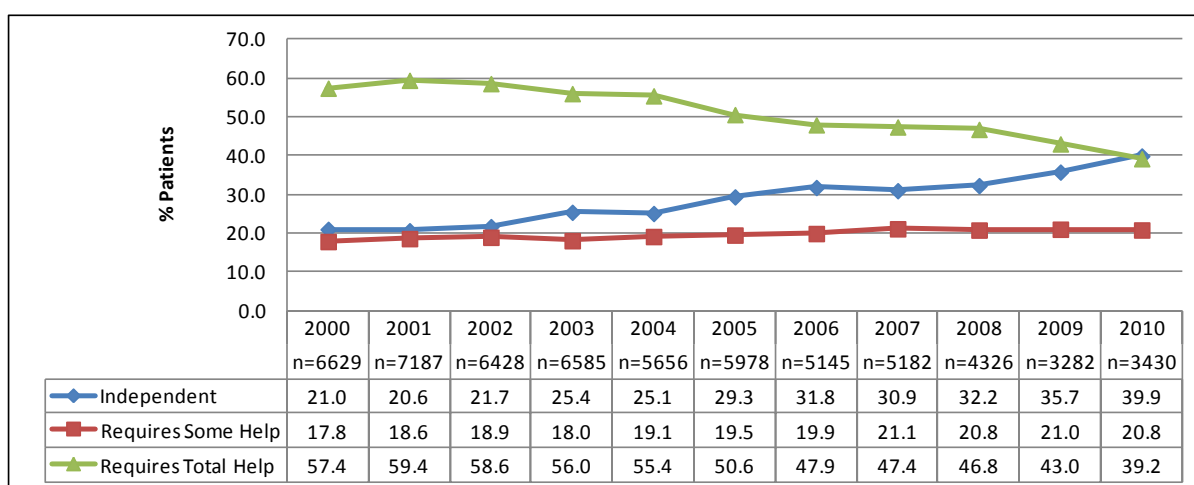
**Figure 4.4 (B): Activity levels (%) of new adult HETF patients registered 2000-2010**



## Dependency

The level of dependency in new HETF patients has reduced over the years. In 2000, 21% of new patients lived independently and 57% required total help. Data in 2010 showed an increase in patients who lived independently (40%), outnumbering the proportion of patients who required total help (39%). See figure 4.4 (C).

**Figure 4.4 (C): Dependency levels (%) of new adult HETF patients registered 2000-2010**





The level of dependency was greater in existing patients on HETF registered with BANS (a higher proportion (49%) required total help) compared with newly registered patients.

## **Location**

The majority of newly registered patients on HETF lived in their own home (increase from 56% in 2000 to 69% in 2010). Less than one third (29%) of the patients lived in nursing homes or received residential care, which dropped from 40% in 2000. There was only a small difference in the location of patients between new registrations and existing patients in 2010.

## **4.5 Reason for feeding, feeding routes and delivery of supplies for adult HETF patients**

### **Reason for feeding**

The two main reasons for patients starting HETF were: 'swallowing disorders' (65%) and 'to improve nutritional status' (27%). There has been a gradual change in these two categories over the last ten years: the number of patients with swallowing disorders has decreased by 8% and the number of patients fed to improve their nutritional status has increased by 7%. These changes may be a reflection of the changing clinical conditions of patients registered with BANS, i.e. an increased proportion of patients with cancer and a decreased proportion of patients with CVA. The remaining indications for feeding were mainly GI problems such as obstruction, malabsorption and short bowel syndrome.

### **Feeding routes**

Gastrostomy was the primary route of feeding for HETF patients as it has been over the last ten years. In 2010, 75% of the HETF patients were fed by gastrostomy. Other routes of feeding continued to be less common (jejunostomy 5%; nasogastric tube 17%). Feeding by naso-duodenal or naso-jejunal tube occurred in 4% of the patients.

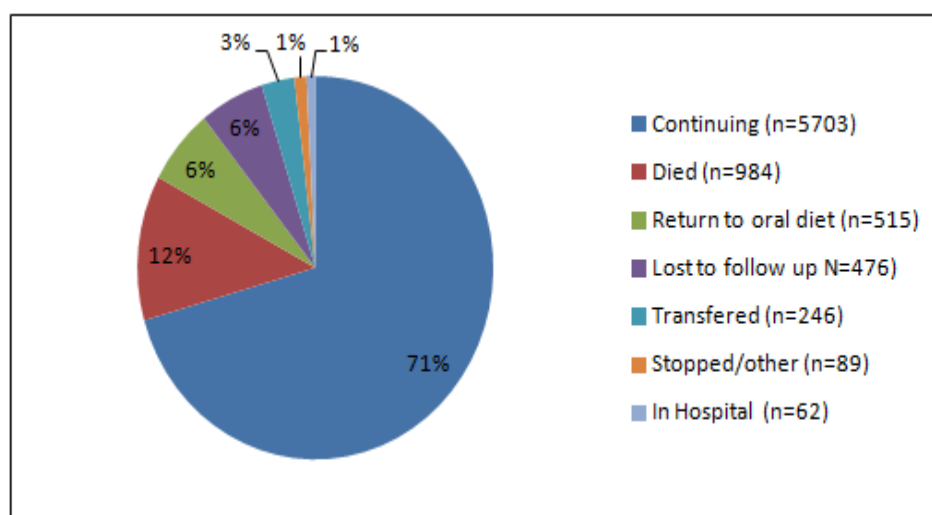
### **Delivery of Supplies**

Home care companies supplied 86% of new patients on HETF registered with BANS in 2010, a decrease of 3% compared with 2009. For 6% of the new patients it was unknown how they obtained their supplies.

#### 4.6 Outcomes for adults receiving HETF during 2010

The outcomes for patients in 2010 are based on period prevalence data. 71% of the patients continued on HETF and 6% returned to oral feeding. 12% of the patients died (92% due to underlying disease) and 1% stopped for other reasons (withdrawn or refused); see figure 4.6. Only 1% of patients were admitted to hospital, 3% were transferred to other sites and 6% were lost to follow-up.

**Figure 4.6: Outcomes for adult HETF patients during 2010**



#### 4.7 New adult HETF registrations to BANS with head and neck cancer

##### Incidence

Data from the Oxford Cancer Intelligence Unit and the National Cancer Intelligence Network 2006 shows the prevalence of head and neck cancer to be increasing, mortality decreasing and survival rates improving year on year. The incidence of new cases of head and neck cancer between October 2009 and November 2010 was estimated at 6747 as reported in the DAHNO (Data for Head and Neck Oncology) report 2010 ([www.ic.nhs.uk/canceraudits](http://www.ic.nhs.uk/canceraudits)). DAHNO also reported that 26% (n=1754) of patients had dietetic records.

##### Adults receiving HETF with head and neck cancer registered with BANS

- In 2010 the number of new registrants with head and neck cancer has increased (1039 patients versus 872 in 2009) contributing to 77% of all new cancer patients registered in 2010.
- Newly registered patients with head and neck cancer tended to be younger than the HETF population as a whole (63% versus 41% were aged 50-71), with about a quarter aged over 71 years (versus 41% for all adult HETF).
- Reasons for feeding in this patient group were swallowing disorders and improving nutritional status (62% and 30% respectively), which is similar to the overall adult HETF population.
- 76% of patients in this group were fully active, which is greater than the overall adult HETF population newly registered with BANS (40%).

- 75% of this group were independent of help, which is markedly higher than the overall HETF proportion (40%). About one fifth of this patient group required some help, which is very similar to the overall HETF population but the total percentage of patients requiring total help was significantly lower (4%) compared to the overall figure for HETF patients (39%).
- 96% of new head and neck cancer patients were living in their own home compared to 69% of the overall adult HETF population registered with BANS; only 3% required nursing home care compared to 27% of the whole adult HETF population.
- The primary route for feeding in this group was gastrostomy (71%) followed by nasogastric feeding (23%). These figures are similar to the overall adult HETF population (gastrostomy 75%, nasogastric 17%)

### **Outcomes during 2010**

The outcomes for patients in 2010 registered with BANS with head and neck cancer were based on period prevalence data. Most (68%) of patients continued on HETF and 14% returned to oral feeding (versus 6% for the overall HETF population). 10% of the patients died (90% due to underlying disease) and 1% stopped for other reasons (withdrawn or refused). Less than 1% of the patients were admitted to hospital, 3% were transferred to other sites and 3% were lost to follow-up.

### **Key Points**

- The number of individuals diagnosed with head and neck cancer is increasing and this is reflected in the number of newly registered patients with BANS who are receiving HETF.
- This group are generally younger, more independent and free living than the overall BANS registrants due to the nature of the condition, which can be less disabling than some disorders including CVA.

*Acknowledgements: Vicky Hutchings and Jolien Hofstede*

## Section 5

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

Amanda Hirst

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

Figure 5.1 shows the number of new registrations, point and period prevalence for 2008 – 2010. In 2010, 448 new children were registered and 1336 were updated (period prevalence). Despite the large reduction in numbers for all three categories seen in previous years (discussed in section 2) it is encouraging to see a similar number of children registered and an increase in the updating of existing patients.

**Table 5.1: No. of children registered as receiving HETF in UK for 2008-2010 (new, point and period prevalence), with no. reporting centres**

	2008	2009	2010
<b>New Registrations</b>	<b>694</b>	<b>482</b>	<b>448</b>
<i>Reporting Centres</i>	<i>87</i>	<i>70</i>	<i>55</i>
<b>Point Prevalence</b>	<b>1476</b>	<b>998</b>	<b>1148</b>
<i>Reporting Centres</i>	<i>108</i>	<i>80</i>	<i>71</i>
<b>Period Prevalence</b>	<b>2256</b>	<b>1317</b>	<b>1336</b>
<i>Reporting Centres</i>	<i>131</i>	<i>98</i>	<i>80</i>

Whilst the BANS Committee accept that the Children's HETF data are not complete, there are still a large number of centres reporting data on a total of more than 1300 children which in itself is significant to comment on. However, anecdotal reports from dietitians involved in home enteral tube feeding confirm that a large number of children being discharged on enteral feeds are not recorded on e-bans. The challenge for e-bans is to:

- Engage reporters and staff involved in caring for this group of children to review their practice, to adopt and implement e-bans as part of patients' electronic registration and review process
- Capture activity in such specialist paediatric areas as renal, oncology and gastroenterology.

This is all within the context and appreciation of the escalating volume of data to be collated associated with increasing number of children being discharged on HETF whilst staffing levels are becoming increasingly lean leading to individuals prioritising between essential and desirable data collection.

## 5.2 Reporting Centres

In 2007, 137 centres registered new children. In 2010 this had dropped by 60% to 55. The potential explanations for this decline are:

1. Hospitals joining into larger trusts resulting in units amalgamating their registering centres.
2. There was a decline in reporting as the need for consent was introduced to register patients and these units can be re-engaged now that the need for consent has been removed.
3. Reporters need to make the transition and familiarise themselves with the new paperless e-bans system.

### Constituent Countries:

The decline of reporting centres was seen across all UK constituent countries, showing a fall in new registrations over a 10 year period: England (-60%), Scotland (-86%), Northern Ireland (-50%), Wales (-85%). See Table 5.2.

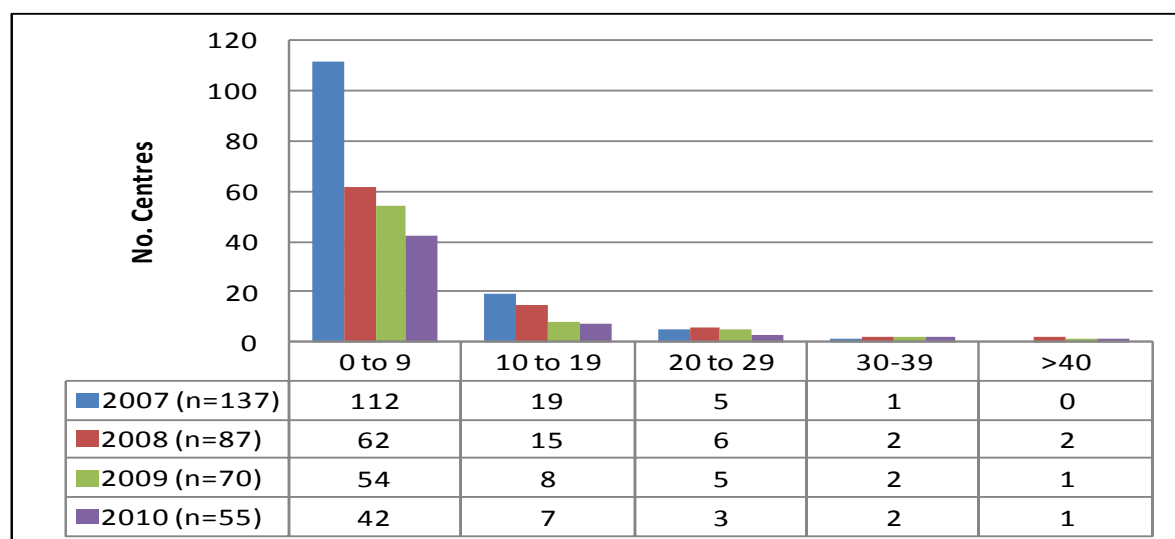
**Table 5.2: no. of centres reporting new children in UK constituent countries (2000-2010)**

	2000	2002	2004	2006	2008	2010
ENGLAND	120	145	111	95	72	47
SCOTLAND	14	12	10	11	3	2
N.IRELAND	8	5	7	5	9	4
WALES	13	8	8	5	3	2
UK total	155	170	136	116	87	55

### Number of children registered per centre:

Nine or fewer new children were registered by 77% (n=42) of centres, of which 29% (n=12) registered just one child. Despite the decline in reporting there was a similar distribution to previous years (Figure 5.2 (B)).

**Figure 5.2 (B): Reporting centres by number of new children (2007-2010)**



### 5.3 Paediatric HETF Diagnoses

Figure 5.3 shows the percentage of new registrations in 2010 grouped into 4 categories: cancer, central nervous system (CNS) & mental health, non-malignant gastrointestinal (GI) and other conditions. Table 5.3 illustrates the type of diagnoses that fall within the 4 categories.

**Figure 5.3: main paediatric HETF diagnostic categories (% of new registrations), 2000-2010**



Over the period 2000 to 2010, from the new registration data reported, the proportion of new children with cancer requiring HETF fluctuates from 6.2% to 11% whereas CNS & mental health has been fairly stable at 30% over the same 10 year period.

There was little change in the proportion of the non-malignant GI (~14%) but other conditions increased to 49%. This category includes congenital cardiac conditions, respiratory disease plus faltering growth, all conditions that correspond with the higher percentage of younger children registered (see section 5.4).

Over all 4 categories, reporters registered 119 children as 'other', unable to fit their condition into one of the category sub divisions. Many rare disorders present in children, too many to give or warrant their own category, however 'other conditions' listed are reviewed and the diagnostic categories updated to fit demand. Where a child fits into several categories the condition affecting their nutrition should be chosen and where possible allocated into the closest category to avoid large numbers being added to 'other than listed'. More work is required to select descriptions or generic conditions to help encompass all diagnoses to assist reporters easily register their patients.

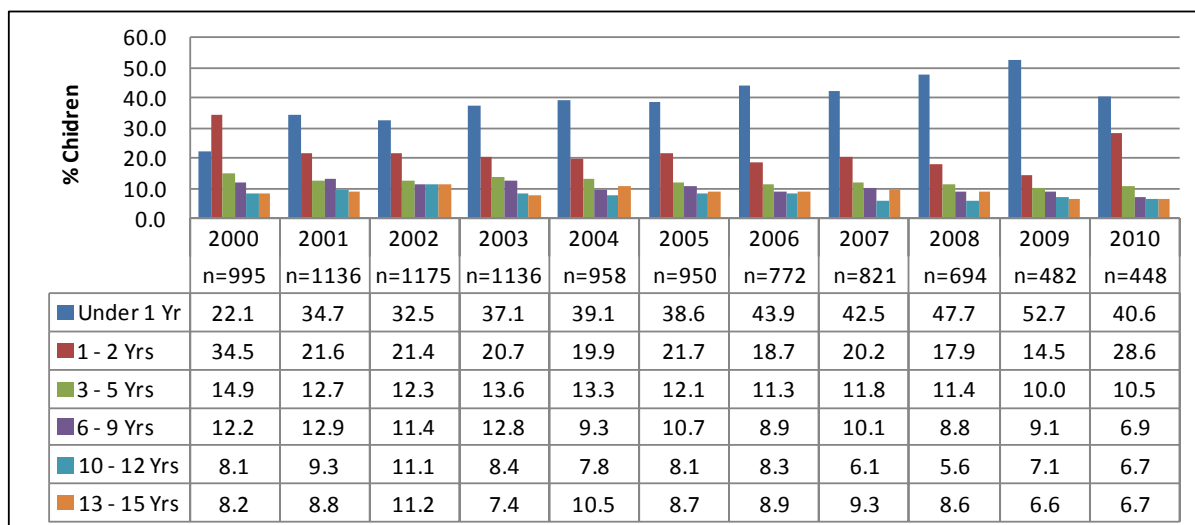
**Table 5.3: HETF Diagnoses of 448 new children registered in 2010**

<b>CANCER</b>	<b>27</b>	<b>CNS &amp; MENTAL HEALTH</b>	<b>139</b>
GI Cancer - oesophageal	6	Brain Injury Cerebral trauma / Hypoxic brain injury	9
Haematology lymphoma / Leukaemia	6	<b>Congenital</b>	<b>88</b>
Head and Neck	5	Cerebral Palsy	48
Other Cancers elsewhere than stated	10	Congenital malformation	23
		Congenital Handicap	10
		Down's Syndrome	7
		<b>Degenerative</b>	<b>4</b>
		<b>Mental Health</b> Prader willi syndrome	<b>1</b>
		<b>Neurological</b> Epilepsy/ atropy	<b>13</b>
		<b>Tumour</b> Cerebral tumour	<b>3</b>
		<b>Vascular</b> Cerebrovascular disease	<b>2</b>
		<b>Other CNS</b>	<b>19</b>
		<b>OTHER CONDITIONS</b>	<b>220</b>
		<b>Cardiac</b> congenital heart disease/ other disease	<b>39</b>
		<b>Inborn Errors of Metabolism</b>	<b>18</b>
		<b>Renal Disease</b>	<b>10</b>
		<b>Respiratory</b>	<b>35</b>
		Cystic Fibrosis	8
		Other respiratory disease	22
		Premature/Chronic Lung Disease	5
		<b>Miscellaneous - total</b>	<b>118</b>
		Auto Immune Diseases	4
		Faltering Growth	22
		Failure to thrive	26
		Other un-named	66
<b>GI - NON MALIGNANT</b>	<b>62</b>		
<b>Gut - total</b>	<b>24</b>		
Autoimmune enteropathy	1		
Congenital enteropathies	1		
Crohn's Disease	11		
Gastroschisis	1		
Idiopathic intractable diarrhoea (infancy)	2		
Post-necrotising enterocolitis	4		
Pseudo-obstruction/motility disorders	3		
Ulcerative colitis	1		
<b>Head &amp; Neck</b> CLAP / surgery / pharyngeal	<b>5</b>		
<b>Hepatobiliary/Pancreas</b> liver disease/ pancreatitis	<b>3</b>		
<b>Oesophageal/Stomach</b>	<b>24</b>		
Dysphagia of unknown cause	5		
Gastro-oesophageal reflux	12		
Oesophageal Strictures (benign)	3		
Other Oesophageal Disease (achalasia, fistula)	1		
<b>Surgery - total</b> Short gut/bowel syndrome	<b>3</b>		
<b>Other GI disease - total</b>	<b>3</b>		

#### 5.4 Age distribution

Figure 5.4 shows age distribution of new registrations from 2000 – 2010. In 2010, 69% of all newly registered children were less than 2 years old and 80% were 5 years or under. There is considerable flux between these two groups over the 10 year period but the overall trend is that children are being fed at a younger age. This demonstrates the need for enteral feeds in this young age group to provide complete or supplementary nutrition to achieve desirable growth.

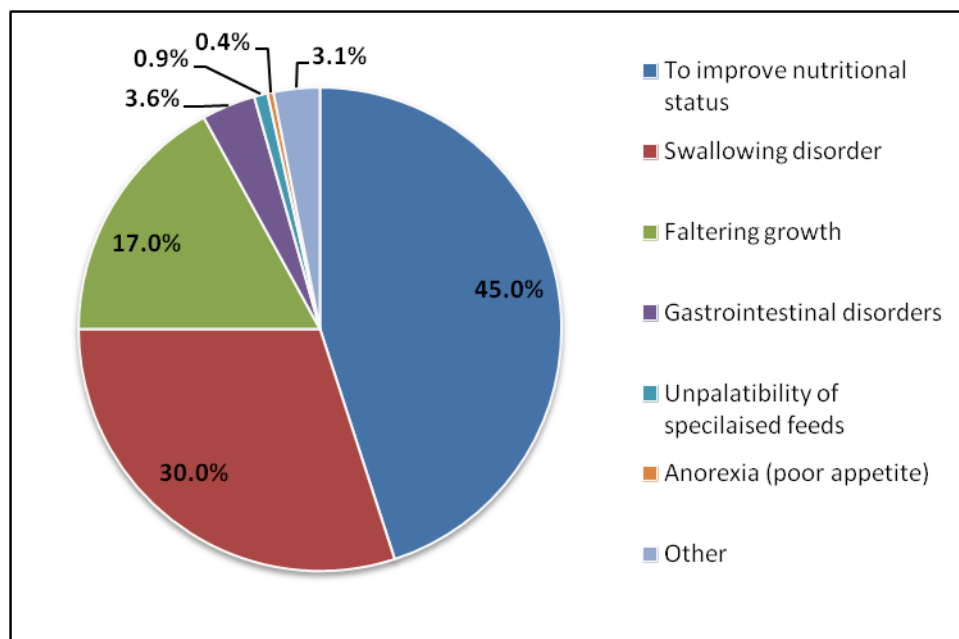
**Figure 5.4: Age distribution (%) of new paediatric HETF registrations (2000 – 2010)**



### 5.5 Reason for feeding & feeding routes

The main reasons for feeding new children in 2010 were: to improve nutritional status (45%); swallowing difficulties (30%); faltering growth (17%) gastrointestinal disorders (3.6%) (including: *fistula* (0.2%), *short bowel* (1.1%), *malabsorption* (1.6%) and *obstruction* (0.7%)), unpalatability of specialised feeds (0.9%), anorexia (0.4%) and 'other' (3.1%). See figure 5.5 (A).

**Figure 5.5(A): Reason for feeding (%) – new registrations 2010**



Since 2000 the proportion of new children requiring HETF to 'improve nutritional status' has continued to rise to almost 50% in contrast to the group described as 'faltering growth' dropping to just 17% of children. These data, coupled with the data

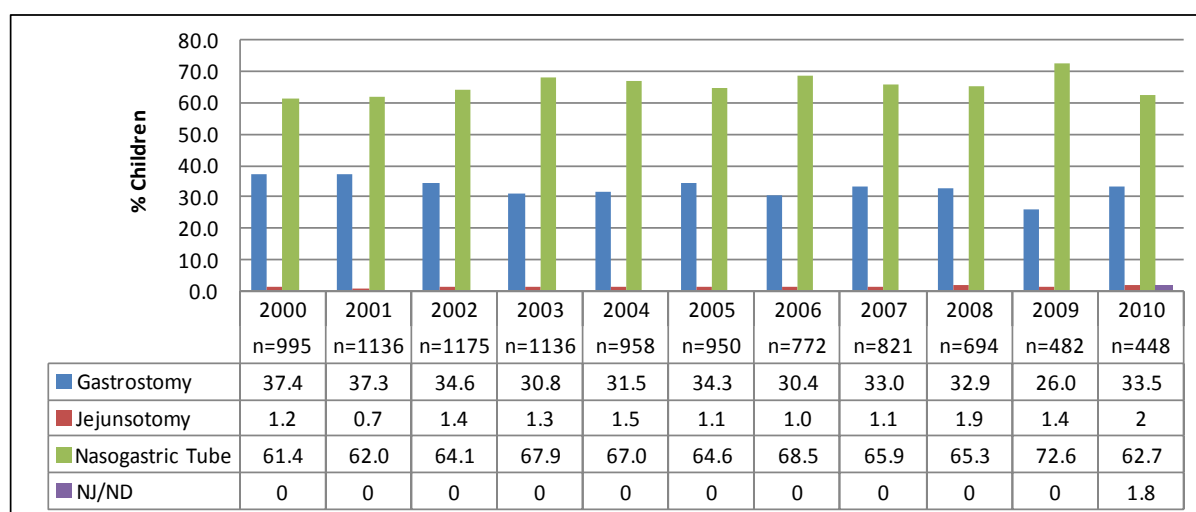


discussed in section 5.4, show active nutritional support at an early age is reducing the risk of poor nutritional intake and 'faltering growth', again supporting pro-active nutritional support rather than allowing growth to be compromised.

Swallowing disorder has remained fairly consistent above 20% which is likely to encompass many of the children with cerebral palsy having an unsafe swallow within a CNS diagnosis category, but also conditions within the GI non-malignant category such as dysphagia and structural abnormalities of upper GI tract.

During 2010, 63% of new registrations were fed via a naso-gastric tube (Figure 5.5 (B)). This is in stark contrast to just 17% of adults being fed this way. The use of naso-gastric tube feeding is an accepted and routinely used method to offer fluids and nutrition in children. 80% of new registrations were under 5 years of age, therefore linking frequent use of naso-gastric feeding in very young children, many returning to oral feeding. Gastrostomy feeding accounted for a third of all cases and is used preferentially for patients with an unsafe swallow requiring longer term feeding or for oral or oesophageal malformations preventing or compromising oral feeding.

**Figure 5.5 (B): Feeding routes (%) – new children 2000-2010**



There continues to be a small percentage of children fed into jejunum. This is not always seen as an ideal option as nutrition and fluids need to be given slowly often over many hours during which time the child is attached to a feeding pump that may have a negative impact. Naso-jejunal tube feeding can buy time until other options are considered, in contrast to jejunostomy feeding that may have resulted due to the failure of other methods of enteral feeding.

### 5.6 Location of patients and delivery of supplies

In 2010 only 2 out of 448 new children registered were documented to live in a location other than their own home, indicating home is a viable discharge location for children receiving HETF. This is in contrast to the adult HETF population of whom 27% live in nursing homes and only 69% live in their own homes. Many of the children requiring HETF have other complex medical needs that require supportive or full time nursing care. The contrast appears to be that children are kept within in

their own home and care is provided by family members, carers and nursing services within the home.

In 2010 Homecare companies were involved with families in 88% of new cases. The use of home care companies has grown since 2000 when only 62% of new patients used this service. The increasing number of individuals receiving HEFT has necessitated organised efficient services to provide the volume and wide range of products required for children to be safely fed at home

### ***5.7 Outcomes for children receiving HETF during 2010***

Of the 1336 children reported on e-bans during 2010, 1148 (86%) continued on home enteral feeding and 74 (5.5%) returned to oral feeding. 2% died and 5% were lost to follow up or transferred to other centres. Overall the data provide a successful picture of the role of HETF in children. It allows continuity of care predominantly in the family home until, for some, oral feeding is achieved.

## Section 6

### Adult Home Parenteral Nutrition (HPN)

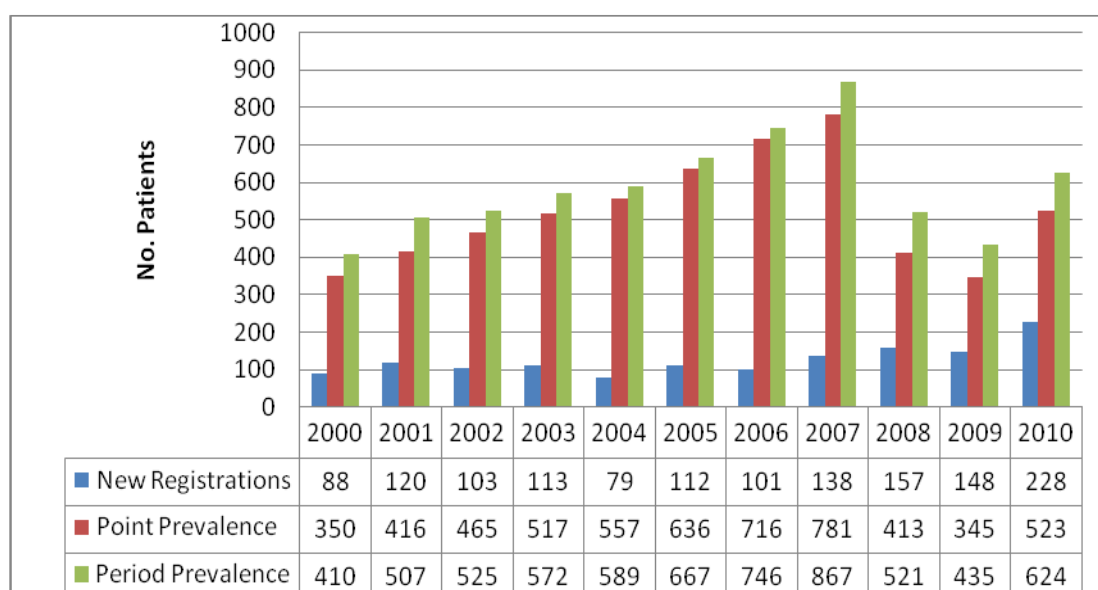
Dr Trevor Smith

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

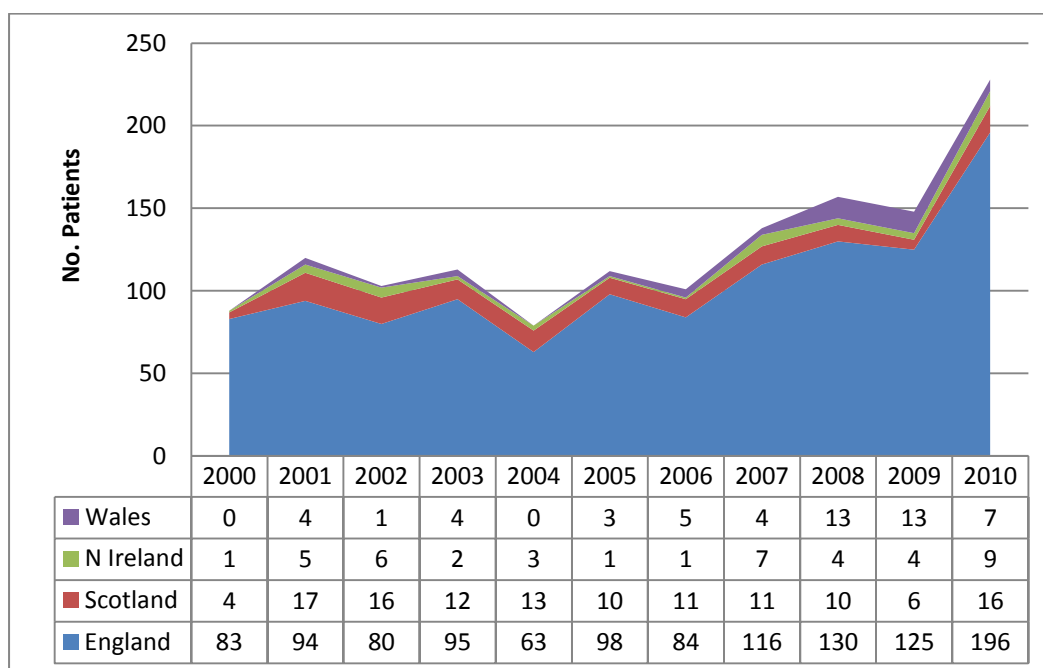
228 new adult HPN patients were registered with BANS during 2010, compared with 148 in 2009 and 157 in 2008. Prior to 2007 there had been a long period stability at around 100 new cases per year but over the last 4 years there has been a significant increase in registrations (see figure 6.1A). Increasing numbers of registrations in England account for most of the growth in HPN cases. New registrations in Scotland have increased although this may reflect registration of patients who were not reported to BANS in 2009, when there was a significant fall in the number of new registrations. New HPN cases in Wales reported to BANS have reduced although the BANS committee are aware that there is considerable under-reporting from the Welsh HPN network (personal communication from Dr Barney Hawthorne). Nine new patients were registered from Northern Ireland which is the largest number reported to BANS from Northern Ireland to date; this partly reflects the development intestinal failure services in Belfast and the appointment of specialist staff who report patients to BANS (see figure 6.1B).

The reporting of HPN prevalence data to BANS increased significantly during 2010; the resolution of the issue of patient consent, with the accompanying fall in reporting rates as described in the 2008 and 2009 BANS reports, has had a beneficial effect on reporting rates (see figures 6.1 A and C). However the reported point prevalence of HPN during 2010 was 523 patients which still represent a significant short fall in national reporting (see section 7 for independently acquired HPN data from homecare companies).

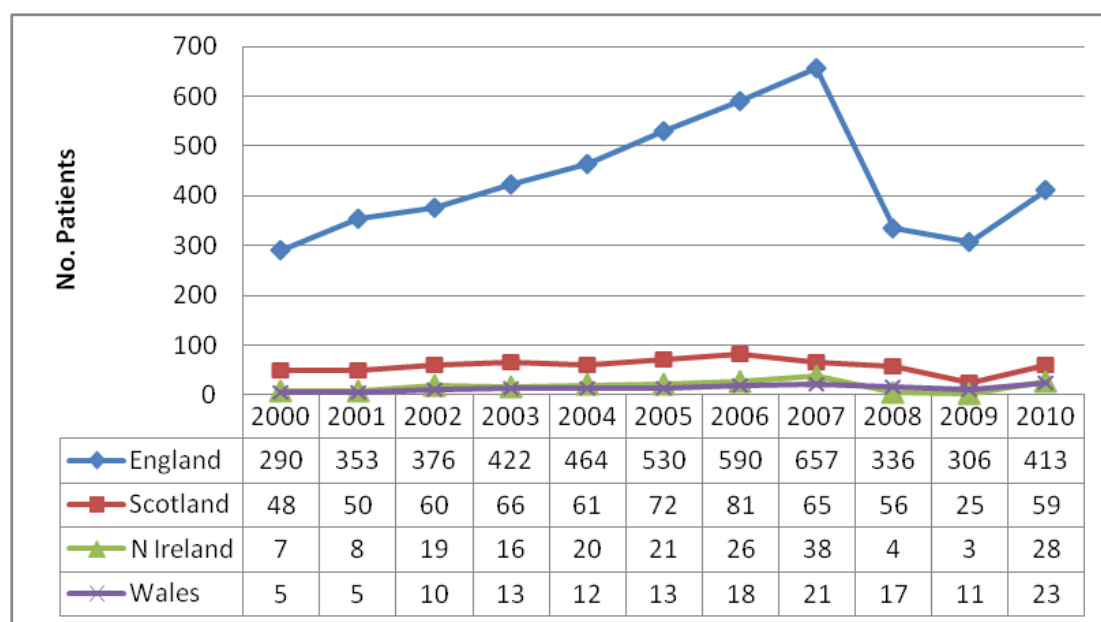
**Figure 6.1(A): Number of new registrations, point prevalence and period prevalence of HPN in UK, 2000 -2010**



**Figure 6.1 (B): New HPN registrations in constituent countries of UK, 2000 – 2010**



**Figure 6.1 (C): HPN point prevalence in constituent countries of UK, 2000 – 2010**



Expressed in terms of population size, the prevalence of new HPN cases was 3.66 per million of the UK population, with a period prevalence of 10 cases per million. Although reporting of new HPN patients has increased, with significant improvements in the reporting of prevalence data, the BANS committee recognise that there is considerable under-reporting and therefore these data need to be interpreted very cautiously.

**Table 6.1: HPN prevalence per million population\* in UK and home countries in 2010 (2007 in brackets)**

	<b>New</b>	<b>Point prevalence</b>	<b>Period prevalence</b>
<b>UK**</b>	<b>3.66 (2.3)</b>	<b>8.40 (13.1)</b>	<b>10.02 (14.5)</b>
England	3.75 (2.3)	7.91 (13.1)	9.77 (14.5)
Scotland	3.06 (2.0)	11.30 (15.1)	12.83 (16.1)
Wales	2.33 (1.4)	7.65 (7.1)	7.65 (7.5)
N. Ireland	5.00 (4.1)	15.56 (22.2)	15.56 (22.8)

\*Sources: Population estimates, 2010: Office for National Statistics,

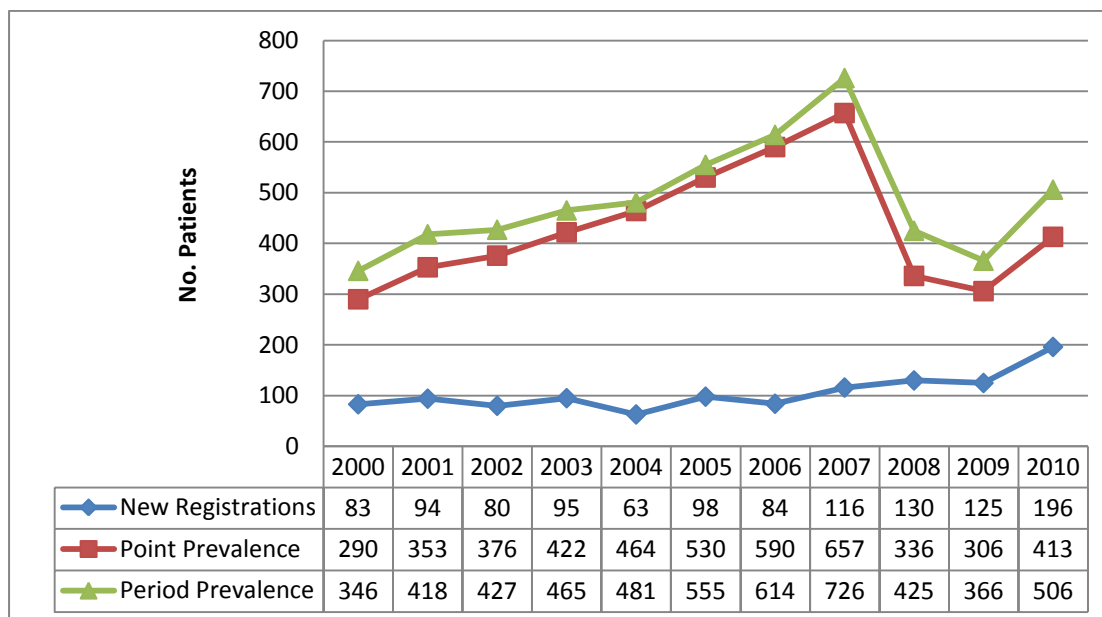
[www.statistics.gov.uk](http://www.statistics.gov.uk)

(Population UK 62,262,000; England 52,234,000; Scotland 5,222,000; Wales 3,006,000; N Ireland 1,799,000).

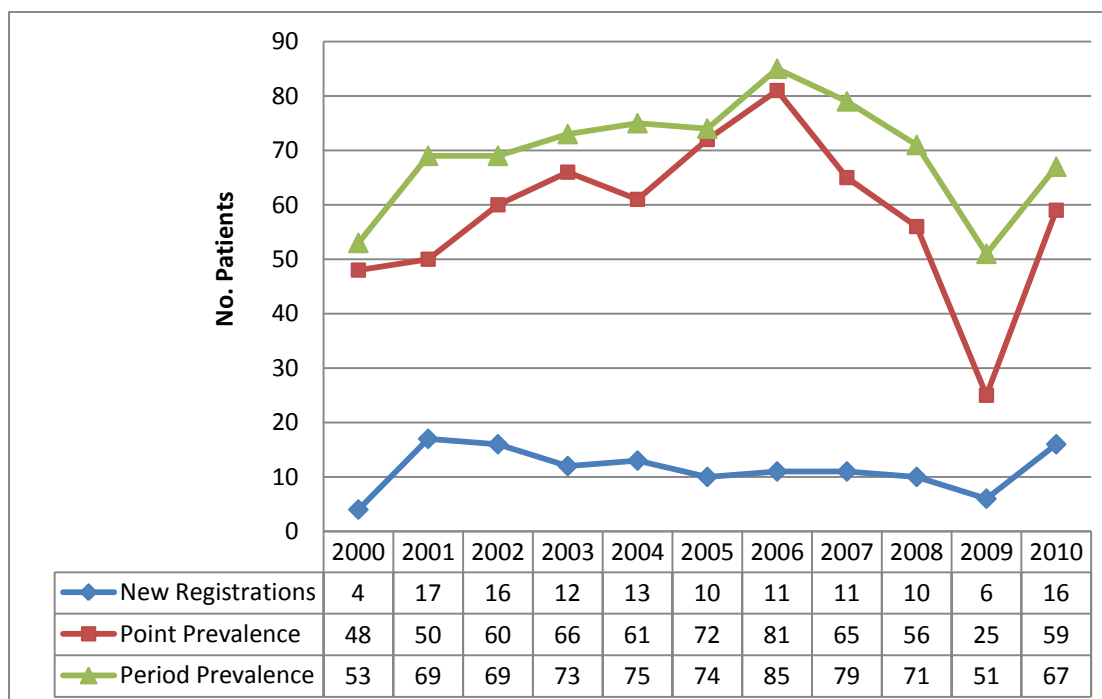
Trends for new registrations and both point and prevalence data are illustrated for UK constituent countries below (see figures 6.1 D-G).

- New registrations in England increased to 196 during 2010 which represents an increase of 57% compared to 2009. This is likely to be as a result of both an expansion in the numbers of patients being treated with HPN and the delayed registration of patients to BANS due to the difficulties relating to patient consent in 2007 – 2009. Encouragingly there was 35% increase in the reporting of prevalence data (see figure 6.1D).
- Scottish data are reported via the Scottish Managed Clinical Network and have shown a prolonged period of stability. The fall in the numbers of patients reported to BANS during 2009 recovered to their previous levels in 2010, although there are some centres that don't report all HPN patients to BANS (see figure 6.1E).
- The numbers of patients reported to BANS from Wales are small and are the result of under-reporting rather than an actual low prevalence of HPN. The total number of HPN patients in Wales is approximately 60 (personal communication from Dr Barney Hawthorne); BANS hope to improve regional reporting rates through UK constituent country representation on the BANS committee (see figure 6.1F).
- Reporting from N. Ireland has improved considerably and should be considered as complete (see figure 6.1G).

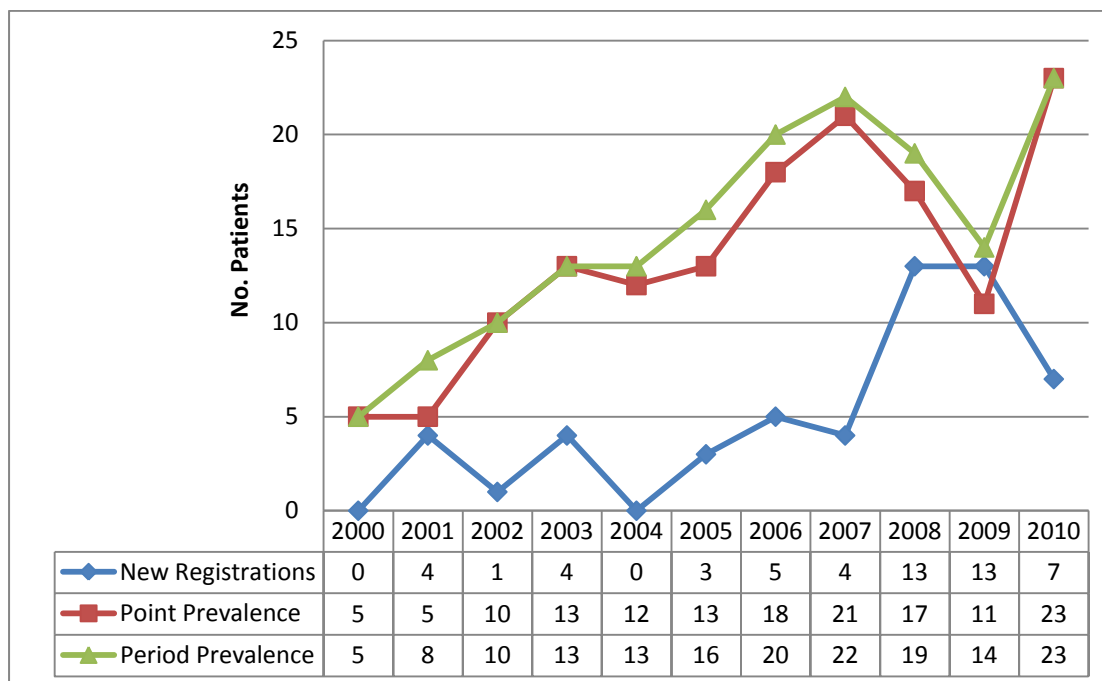
**Figure 6.1 (D): Trends in HPN in England, 2000 – 2010**



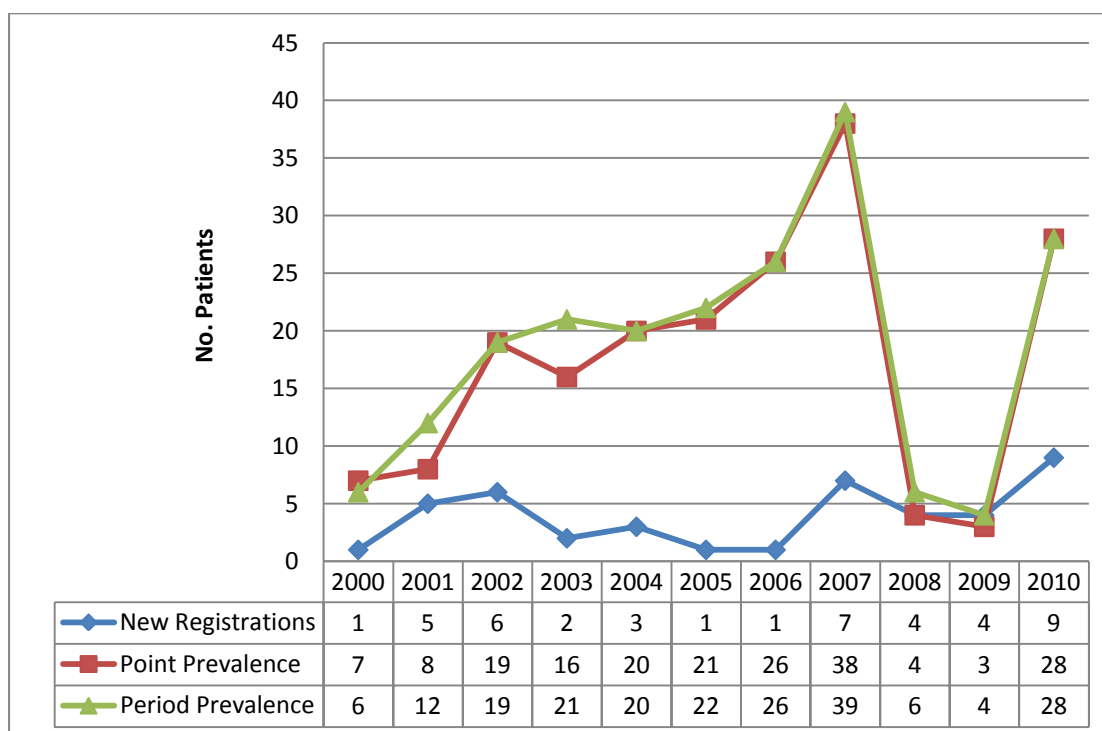
**Figure 6.1 (E): Trends in HPN in Scotland, 2000 – 2010**



**Figure 6.1 (F): Trends in HPN in Wales, 2000 – 2010**



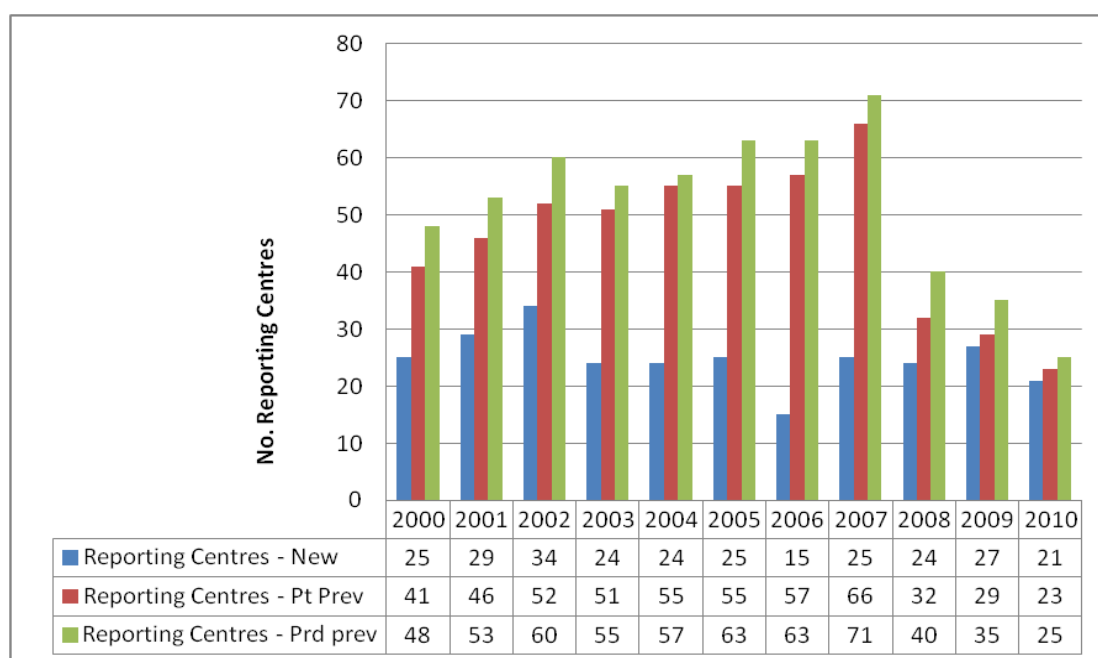
**Figure 6.1(G): Trends in HPN in N Ireland, 2000 – 2010**



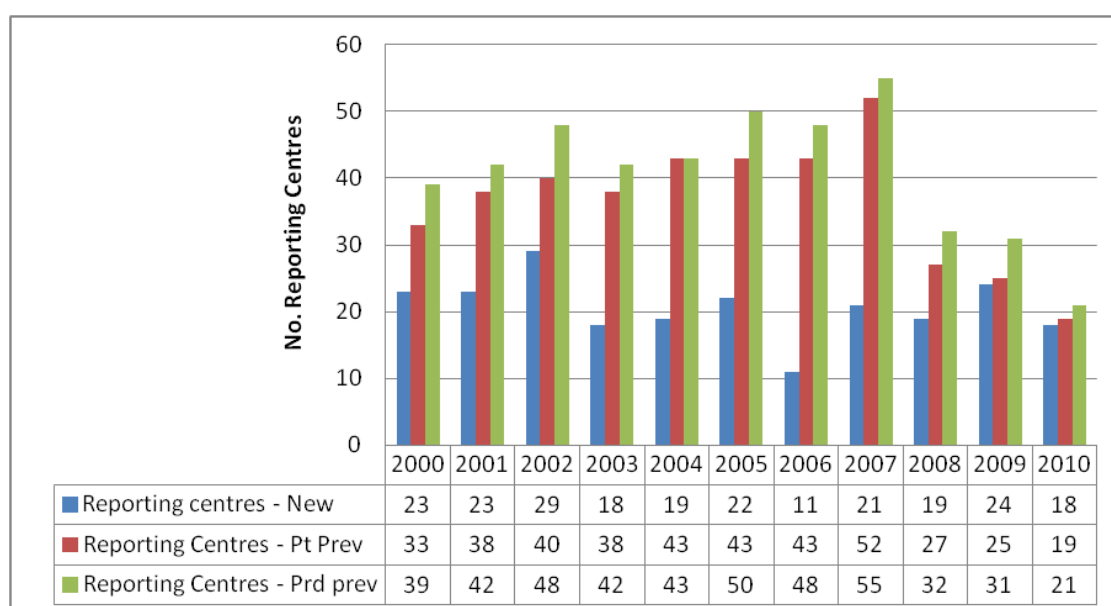
## 6.2 Reporting Centres

21 centres registered new patients to BANS during 2010 which is a reduction in 6 centres compared to 2009; the majority of these centres were located in England. Point and period prevalence data were reported by 23 and 25 centres respectively, representing a reduction compared to previous years (see figures 6.2A and B). These data suggest that fewer centres are managing larger numbers of HPN patients, although it is also recognised that some centres may not be reporting to BANS.

**Figure 6.2 (A): Numbers of adult HPN reporting centres in UK for new registrations, point prevalence and period prevalence, 2000 – 2010**



**Figure 6.2 (B): Numbers of adult HPN reporting centres in England for new registrations, point prevalence and period prevalence, 2000 – 2010**

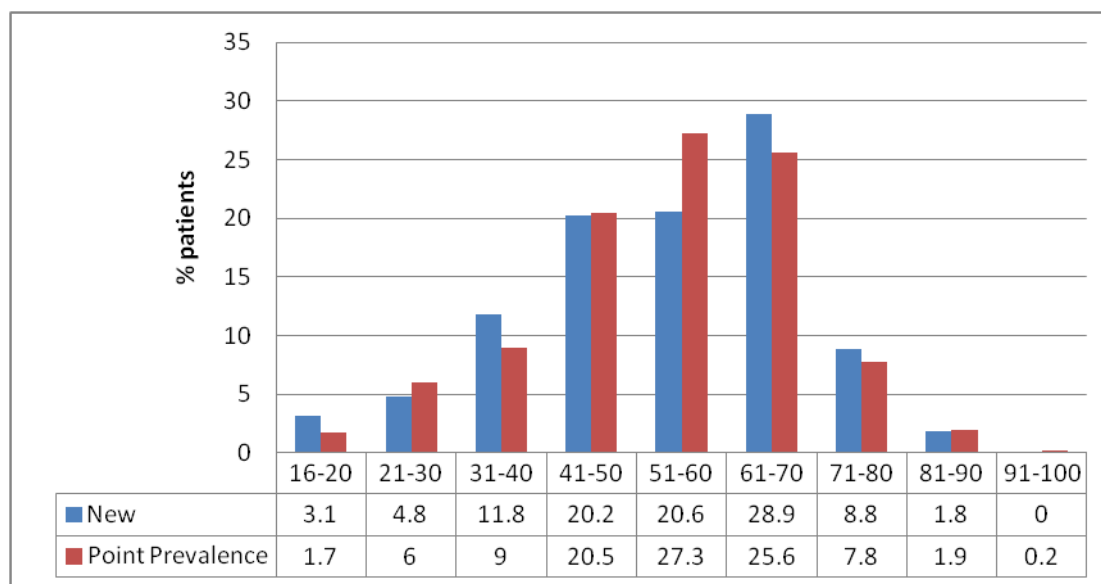




### 6.3 Age distribution

The vast majority of new and established HPN patients are under 71 years of age; more than two thirds of patients are between 41 and 70 years of age. These data are illustrated in figure 6.3.

**Figure 6.3: Age distribution of adult HPN in the UK for new registrations and point prevalence (percentages), 2010**



### 6.4 Reasons for HPN

Short bowel syndrome remains the commonest indication for new HPN patients (54.4%). Fistula is cited as the main reason in 17.1%, malabsorption in 13.6%, gastrointestinal obstruction in 9.6%, "to improve nutrition" in 2.2%, and swallowing difficulties in 0.4%. Short bowel syndrome is also the main reason for HPN in established patients (58.9%). See table 6.4.

**Table 6.4: Reasons for adult HPN, 2000 and 2010**

	% New		% Point prevalence	
	2000	2010	2000	2010
Short bowel	40.9	54.4	61.4	58.9
Fistula	17.0	17.1	6.0	9.6
Malabsorption	12.5	13.6	14.6	13.8
Obstruction	9.1	9.6	6.3	9.0
To improve nutrition	11.4	2.2	4.8	2.9
Swallowing disorder	5.7	0.4	2.3	1.1
Other	3.4	2.7	4.6	4.7

## 6.5 Diagnoses and HPN

Crohn's disease remains the leading diagnosis for adults established on HPN (point prevalence 29.3%); Crohn's disease also represents the commonest reason for new HPN registration to BANS (18.4%) (See tables 6.5A and B). Mesenteric vascular disease (ischaemia) and pseudo-obstruction are the other major diagnostic categories leading to HPN dependence, accounting for 9.7% and 11% of new registrations respectively. The proportion of patients in 2010 with vascular disease fell in comparison to previous years; the point prevalence in 2010 was 15.3% and 18.8% in 2009 (see table 6.5 C). This may be due to normal variation within the population, although this is the smallest proportion of HPN patients with vascular disease recorded by BANS over the last 11 years. Incomplete reporting will also impact on the validity of the data but it is encouraging that reporting rates increased in 2010. A growing number of patients are treated with HPN due to severe gastrointestinal pseudo-obstruction, with a point prevalence of 79 patients in 2010, which is 15.1% of the HPN cohort (see table 6.5D).

Cancer, of all types, accounted for 14% of new HPN registrations which is very similar to previous years although higher than the lowest recorded figure of 9.5% in 2009. Gastrointestinal cancers accounted for 7% of new registrations; 7.8% of established HPN patients (point prevalence) had a primary diagnosis of malignant disease. The proportion of newly registered patients with 'other gastrointestinal' diagnoses, which includes surgical complications, fell to 11.4% in 2010, compared to 20.1% in 2009. The point prevalence fell from 14.2% in 2009 to 9.75% in 2010 (See Tables 6.5 A & B).

**Table 6.5 (A): Diagnostic categories of adult HPN, 2000 and 2010**

	% New registrations		% Point prevalence	
	2000	2010	2000	2010
Crohns	25.0	18.4	34.3	29.3
Ulcerative colitis	3.4	2.3	2.9	3.2
Ischaemia*	14.8	9.7	17.7	15.3
Radiation enteritis	5.7	3.9	5.1	3.8
Pseudo-obstruction	4.5	11.0	9.1	15.1
Other...including Surgical complications	6.8	11.4	11.1	9.75
Cancer**	17.0	14.0	5.7	7.8
Total	81.8	86.8	90.9	92.7
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 – 2010**

Crohns disease											
Patients	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Numbers	120	131	147	156	160	175	196	213	117	105	153
%	34.3	31.5	31.6	30.2	28.7	27.5	27.4	27.3	28.3	30.4	29.3

**Table 6.5 (C): Point prevalence of mesenteric vascular disease 2000 – 2010**

Patients	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Numbers	62	82	89	90	103	122	139	156	76	65	80
%	17.7	19.7	19.1	17.4	18.5	19.2	19.4	20	18.4	18.8	15.3

**Table 6.5 (D): Point prevalence of Pseudo-obstruction 2000 – 2010**

Patients	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010
Numbers	32	41	43	55	59	66	71	78	56	44	79
%	9.1	9.9	9.2	10.6	10.6	10.4	9.1	10.0	13.6	12.8	15.1

## **6.6 Location, ability to manage and activity level of HPN patients, 2010**

The percentage of new registrations placed initially in a nursing home has remained very small (1.1% in 2000 and 0.4% in 2010). 97.4% of patients were discharged to their own home, with 2.2% discharged to unspecified locations. Amongst established patients (point prevalence), the number in nursing homes was 0.5% in 2010 compared to 2.3% in 2009 and 0.7% in 2008; 99% of patients lived in their own homes. Newly discharged patients described as independent increased to 60.1% in 2010, compared to 52% in 2009 and 53.5% in 2008. Independence levels improve following discharge in established patients with 71% described as fully independent. Approximately 40% of new registrations require “some help” or “total help” but only 29% of established cases require such help. These figures are mirrored by activity data; 68% of new cases and 70.3% of established cases are described as fully active. Limited activity (new 28.5%; point prevalence 27.3%) and house or bed bound (3.5% and 2.3%) account for the remainder.

### **6.7 Access route and administration of adult HPN, 2010**

Venous access was via an external catheter in 98.7% and subcutaneous ports in 1.3% of newly registered patients.

Commercial homecare companies provided for all new patients in 2010; their contribution to point prevalence has been steadily rising from 70.6% in 2000 to 94% in 2010. This suggests that the greater contribution to new patients is being carried through to established patients.

### **6.8 Outcomes for patients receiving HPN during 2010**

624 patients received HPN and were registered with BANS during 2010 (period prevalence); 83.8% were still on HPN at the end of the year but only 7.5% had reverted to oral nutrition. 1.4% were in hospital and the mortality rate was 6.6%. HPN was withdrawn in one patient.

## Section 7

### Independently acquired data compared with BANS reported data.

**Dr Janet Baxter**

Since 2005, it has been the committee's decision to verify the numbers of patient provided with HAN, by comparing data obtained from the home care companies (HCCs) who supply HETF and HPN to patients in the UK with that provided by BANS reporters. This is collected by asking each of the companies to provide the point prevalence data. Once aggregated, the data are compared with those provided by BANS reporters. This means that the shortfall of patients reported to BANS can be estimated and therefore provides a more accurate reflection of the numbers of patients receiving artificial nutrition support at home.

The table 7.1 below shows the point prevalence at December 2010 of UK patients compared with the 2010 point prevalence reported to BANS as well as the estimated shortfall.

**Table 7.1: Point prevalence of HAN – HCC acquired, from 2010 BANS data with estimated shortfall**

2010 data	HETF		HPN	
	ADULT	PAED	ADULT	PAED
Total number supplied by HCCs	26 660	14 526	991	152
Point prevalence (BANS)	5 703	1148	523	16
% use for HCCs from BANS	83.9	85.5	93.9	100
HCC number known to BANS	4782	982	491	16
Estimated point prevalence	31 795	16 982	1055	152
Estimated % shortfall	82.1	93.2	53.5	89.5

When registering a patient with BANS, the reporter documents whether a home care company delivers the artificial nutrition. Table 7.2 details the percentage of patients supported by HCCs.

**Table 7.2: Use of home care companies – BANS data, 2010**

	New (%)	Point prevalence (%)
Adult HETF	85.7	83.9
Paediatric HETF	88.2	85.5
Adult HPN	99.6	93.9
Paediatric HPN	100	100

### *The use of HAN according to independently acquired data*

The data in this section of the BANS Report has been collected routinely for several years and is an important method for the validation of BANS data. Table 7.3 shows year on year comparisons since this data collection began. Six years of independently acquired data illustrates the true growth of HAN in the UK since 2005. It should be noted that this data does not include information from N. Ireland, as HAN is provided direct from the NHS rather than commercial sources.

**Table 7.3 Growth of HAN, according to independently acquired data**

Year	HETF		HPN	
	ADULT	PAEDIATRIC	ADULT	PAEDIATRIC
2005	24 129	11 753	735	134
2006	24 551	10 978	757	141
2007	26 886	11 958	865	161
2008	26 166	12 273	856	128
2009	25 777	12 234	941	134
<b>2010</b>	<b>31 776</b>	<b>16 986</b>	<b>1055</b>	<b>152</b>

In six years there has been a significant rise in HAN. HETF provided to adult patients has grown by 28% and by 41.5% to children. Provision of HPN has increased by 43% for adults. In contrast the growth of paediatric HPN is less marked – 13% in six years. This is important data to take into consideration for service planning.

## Section 8

# Home Enteral Tube Feeding in Adult Head & Neck Cancer Patients: A National Survey

**Sarah Sharp,**

Head and Neck Cancer Dietitian, Southampton University Hospital

### **8.1 Nutrition and Head and Neck Cancer**

It is well recognised that most patients with head and neck cancer (HNC) have problems with eating and drinking and a substantial proportion have to cope with tube feeding, especially during radiotherapy treatment (Nguyen et al 2006; 2004). Historically, patients requiring artificial nutrition during radiotherapy for HNC have been enterally fed via a prophylactic gastrostomy tube (Wiggenraad et al. 2007; Nguyen et al. 2006). However, there is a growing wealth of evidence to show that nasogastric feeding may be as or more effective for these patients (Corry et al 2008; Clavel et al 2011). A national survey was therefore conducted in conjunction with the British Artificial Nutrition Survey to establish the prevalence of different methods of enteral feeding used for patients receiving radiotherapy for HNC across the UK.

### **8.2 Survey Design**

An online survey was developed using 'Survey Monkey', which is an online questionnaire tool. This method makes the survey easy to circulate and complete, hopefully encouraging a high response rate. The questionnaire was designed to answer the following questions:

- ❑ What is the prevalence of dietetic provision for HNC patients receiving radiotherapy?
- ❑ How are HNC patients that require tube feeding identified?
- ❑ What type of enteral feeding tubes do the majority of HNC patients have placed?
- ❑ Are the majority of tubes prophylactic or reactive?
- ❑ How is malnutrition identified before, during and after radiotherapy treatment in HNC patients?

58 Hospitals with radiotherapy departments across the UK were identified using the 2010 Cancer UK radiotherapy work force review (Cancer UK). The dietetic department at each hospital was contacted by phone in order to obtain a contact name and email address for the lead cancer Dietitian or radiotherapy Dietitian. The questionnaire was circulated by email to the Dietitians identified.

### **8.3 Survey Response Rate:**

The questionnaire was circulated to 58 Dietitians who were given 2 months to complete the online questionnaire. A reminder email was sent out 2 weeks before the closing date. 35 out of 58 Dietitians responded giving an overall response rate of 60%.

#### 8.4 Number of HNC cancer patients treated with radiotherapy at each centre

The number of HNC patients treated with radiotherapy at each cancer centre varied greatly from 25 to over 100 patients per year as shown in the table 8.4

**Table 8.4: Annual number of patients with head and neck cancer treated with radiotherapy (RT) at each cancer centre**

Number of HNC patients treated with RT per year	Number of Cancer Centres responding	
	n	(%)
25 - 50	2	(5.7%)
51 - 75	6	(17.1%)
76 - 100	6	(17.1%)
>100	16	(45.7%)
Unknown	5	(14.3%)
Total	35	

#### 8.5 Dietetic funding for HNC Patients

Only 18 Cancer Centres (51.4%) who responded had specific dietetic funding to support HNC patients. All but one Cancer Centre without specific dietetic funding for HNC patients stated that these patients are seen as part of a generic Cancer Dietetic caseload.

Four Cancer Centres (11.4%) had specific dietetic assistant funding for HNC patients, with 11 Cancer Centres (31.4%) having some support from a generic dietetic assistant post. Dietetic assistant's roles varied and included general paperwork, enteral feeding pump training, information gathering and phone calls.

A staggering 27 respondents (77%) felt that they had inadequate dietetic funding to adequately manage HNC patients. 17 respondents (48.5%) had put in a formal request for extra funding. At the time of the survey none had been successful in obtaining the extra funding.

The dietetic funding for HNC patients varies widely even in Cancer Centres of a similar size. Table 8.5 shows that Cancer Centres with radiotherapy departments treating over 100 HNC patients a year have dietetic funding of between 0.5 whole time equivalent (WTE) and 5.0 WTE.

**Table 8.5: Comparison of whole time equivalent (wte) dietitians treating patients undergoing RT across a range of centres**

Average no. patients/centre/yr	WTE Dietitians										No. responses
	0.3	0.5	0.6	1.0	1.4	1.6	1.8	2	4	5	
25-50	1	-	-	-	-	-	-	-	-	-	1
51-75	-	-	2	1	-	-	-	-	-	-	3
76-100	-	-	1	3	-	-	-	-	-	-	4
>100	-	1	1	2	1	1	1	1	1	1	10
Total no. centres	1	1	4	6	1	1	1	1	1	1	18



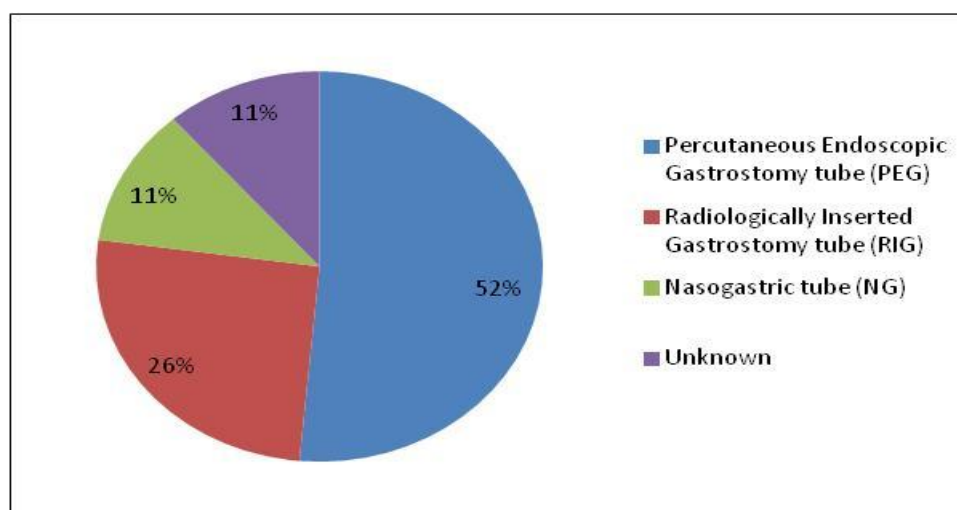
## 8.6 BANS and HNC patients

Only 11 respondents (31.4%) report their HNC patients who are discharged into the community with enteral tube feeding to BANS. Reasons for not reporting included lack of time, problems with data input, confidentiality and poor staffing levels. However, four Cancer Centres report that their HETF patients are followed up by the community team, therefore BANS is filled in by the community team. This gives a total of 42.8% of respondents who complete BANS on HNC patients.

## 8.7 HETF during HNC Radiotherapy

Just over half (51.4%) of the Cancer Centres have a local pathway for enteral tube feeding in HNC patients undergoing radiotherapy. There is currently no national pathway for enteral feeding in HNC radiotherapy patients and local pathways vary immensely as shown in figure 8.7 and tables 8.7 (A-C).

**Figure 8.7: Most common type of enteral nutrition used for head and neck RT patients in individual cancer centres**



Over three quarters (77.1%) of Cancer Centres place a feeding tube prophylactically in patients who receive enteral feeding during radiotherapy treatment. Of the 77.1% who place prophylactic tubes, one Centre (2.9%) uses NG tubes, 9 (25.7%) use RIG tubes and 17 (48.6%) use PEG tubes.

**Table 8.7 (A): Criteria used to identify HNC radiotherapy patients who automatically require enteral tube feeding during treatment**  
(respondents were allowed to select more than one option)

Criteria	%
All patients receiving radiotherapy	2.9
All patients receiving surgery and radiotherapy	8.6
All patients receiving chemotherapy and radiotherapy	14.3
All patients receiving surgery, chemotherapy and radiotherapy	11.4
Those who are malnourished or nutritionally at risk pre treatment	22.9
Those who became malnourished during treatment	37.1
According to cancer site	34.3
According to radiotherapy treatment field	45.7
According to cancer staging	25.7
Other	22.9

The most common factors used to determine if patients will automatically require tube feeding were cancer site (34.3%), radiotherapy treatment field (45.7%) and those who become malnourished during treatment (37.1%).

**Table 8.7(B): Reasons given for HNC patients automatically requiring enteral tube feeding**

Patient categories	Examples given
All patients receiving surgery & RT	Major surgery before radiotherapy
All patients receiving chemo-RT (CRT)	All oropharynx patients having CRT
Those who are malnourished or nutritionally at risk pre treatment or during treatment	BMI < 20kg/m <sup>2</sup> Weight loss > 10% Difficulty eating At risk of aspiration
According to cancer site	Oral cavity, Floor of mouth Base of tongue +/- free flap Tonsil, Oropharynx ,Hypopharynx Nasopharynx Unknown head and neck primary
According to radiotherapy treatment field	Bilateral treatment fields Large treatment field
According to cancer staging	T3 o T4 tumour If the cancer is large Presence of neck nodes Extracapsular spread
Other	Patients on insulin Poor wound healing before treatment Those who are NBM Poor performance status Age (e.g. older patients more at risk) Lack of social support

**Table 8.7 (C): artificial nutrition and palliative patients with HNC**

% palliative care patients receiving artificial nutritional support (n=29 centres)	Centres n (%)
0%	2 (6.9%)
<5%	9 (31%)
5-10%	10 (34.5%)
11-20%	7 (24.1%)
21-30%	1 (3.4%)
>30%	0

The percentage of palliative artificially fed patients varies greatly across Cancer Centres as shown in table 8.7 (C). A number of comments were made about some patients having radical treatment at initiation of tube feeding, but becoming palliative while still being tube fed, which may have led to the wide variation.

## 8.8. Identifying Malnutrition in Head and Neck Cancer Patients

Tools and parameters used for identifying malnutrition risk pre, during and post treatment include BMI, percentage weight loss, ability to swallow, a local nutrition screening tool, weight, bloods, Malnutrition Universal Screening Tool (MUST), Dietetic assessment, diet history and clinical judgement.

**Table 8.8 (A): % of cancer centres that stated MUST was used to identify malnutrition at different stages of treatment**

Stage of treatment	responses	Cancer centres using MUST n (%)
Pre-treatment	(n = 27)	7 (25.9%)*
During treatment	(n = 28)	5 (17.9%)
After treatment	(n = 26)	4 (15.4%)

\*One centre uses a locally adapted version of MUST

**Table 8.8 (B): Frequency of nutritional assessment during treatment**

Frequency of nutritional assessment during treatment (n = 27)	Centres n (%)
Less than weekly	5 (18.5%)
Weekly	16 (59.3%)
At least weekly / twice weekly	5 (18.5%)
Other	1 (3.7%)

### 8.8 Key points

- ❑ Only 18 Cancer Centres (51.4%) had specific Dietetic funding for HNC patients.
- ❑ Dietetic funding for HNC patients varies from 0.3 WTE – 5.0 WTE per cancer centre.
- ❑ In total only 15 Cancer Centres (42.8%) report HNC patients to BANS.
- ❑ Just over half (51.4%) of Cancer Centres have a local pathway for enteral tube feeding HNC radiotherapy patients
- ❑ There is currently no national pathway for enteral tube feeding HNC radiotherapy patients
- ❑ 77.1% of Cancer Centres place a feeding tube prophylactically in HNC patients (1 Centre (2.9%) uses NG tubes, 9 (25.7%) use RIG tubes and 17 (48.6%) use PEG tubes)
- ❑ The most common factors used to determine if patients will automatically require tube feeding were cancer site (34.3%), radiotherapy treatment field (45.7%) and those who become malnourished during treatment (37.1%).
- ❑ Only 25.9% of Cancer Centres use MUST to identify malnutrition pre-treatment, 17.9% during treatment and 15.4% after treatment.
- ❑ Other tools and parameters used to identify malnutrition risk include BMI, percentage weight loss, ability to swallow, a local nutrition screening tool, weight, biochemistry, Dietetic assessment, diet history and clinical judgement.

## 8.9 References

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[www.canceruk.net/rtservices/rtworkforce2010/](http://www.canceruk.net/rtservices/rtworkforce2010/) accessed 18/5/11

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## Section 9

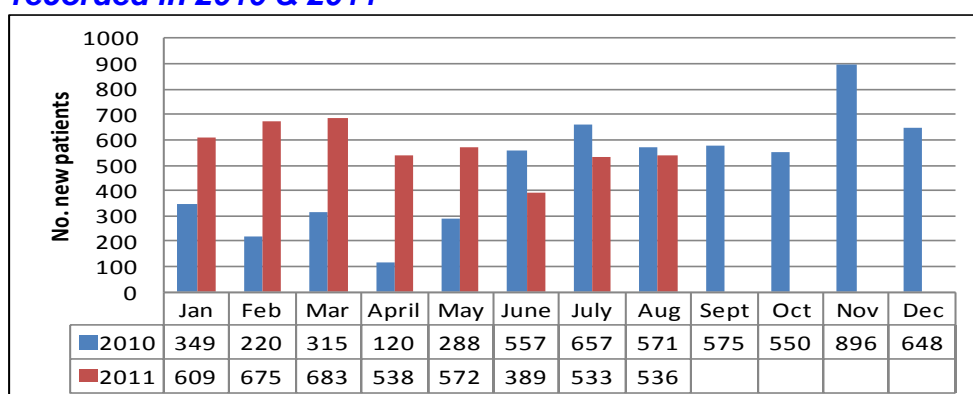
### e-BANS updated

Ann Micklewright

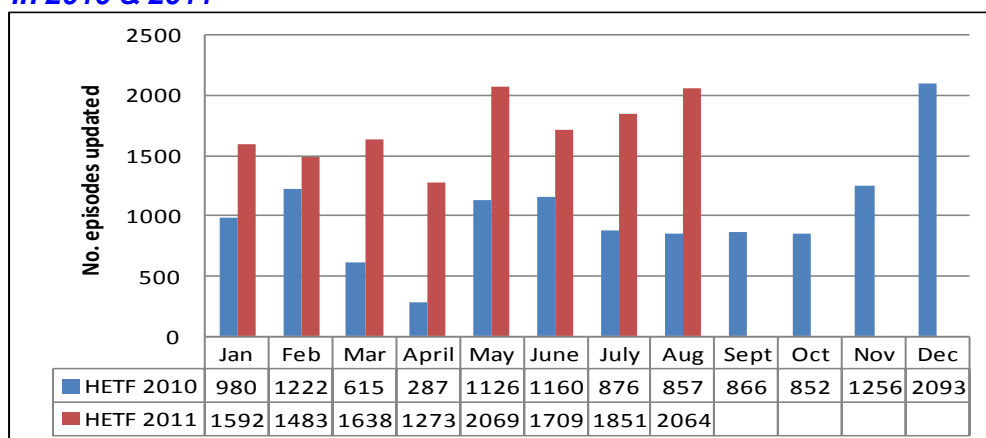
#### 9.1 Reporting activity

The 2009 and 2010 Annual BANS Reports discussed in detail the reduction in the number of reporting centres submitting data and postulated reasons for this decline: in particular, the time constraints preventing reporters obtaining informed patient consent and submitting data in paper format. To overcome these obstacles an electronic system, e-BANS was introduced in July 2010 which allows reporters to enter non-consented data using a fast and effective process. Following an active publicity campaign reporting to BANS is gradually improving. Figures 9.1 – 9.3 show a monthly comparison for both new and existing patients (episodes) from January to August 2011 with those recorded in 2010. New registrations (HETF & HPN combined) increased from June 2010 onwards with an unexplained dip in June 2011 (figure 9.1). Updates for existing HETF patients started to increase in June 2010 reaching 2000 per month by August 2011 (figure 9.2). HPN updates (figure 9.3) which improved dramatically in August 2010 were maintained in 2011.

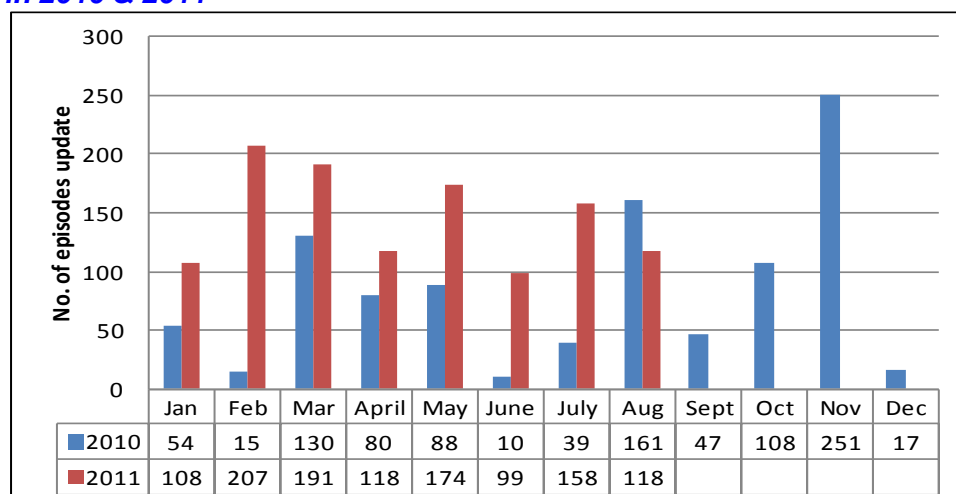
**Figure 9.1: comparison of the number of new patient (HETF & HPN) recorded in 2010 & 2011**



**Figure 9.2: comparison of the number of existing HETF patients updated in 2010 & 2011**

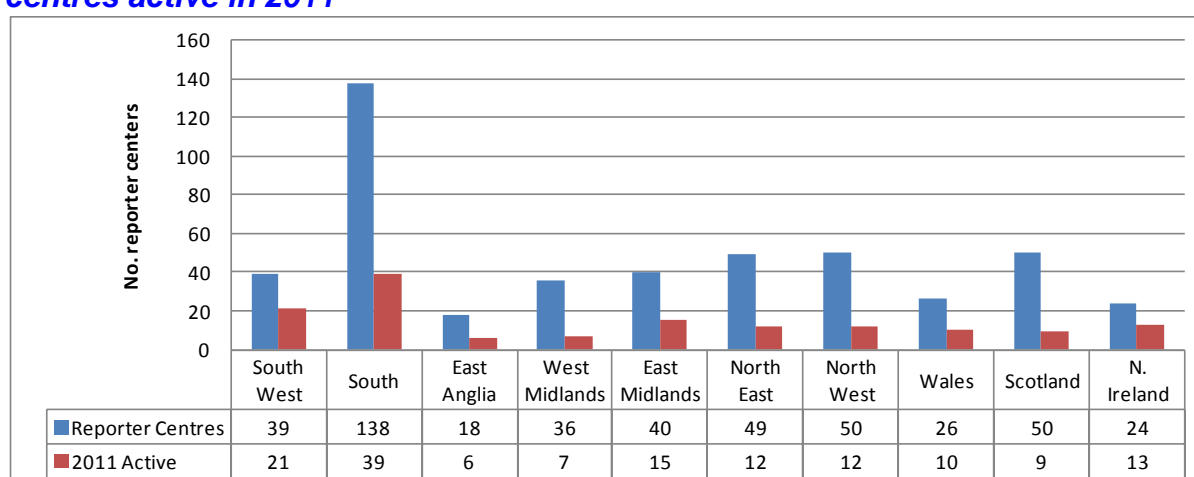


**Figure 9.3: comparison of the no. existing HPN patients updated in 2010 & 2011**



Whilst these data are extremely encouraging, there is no room for complacency. Figure 10.4 shows the number of organisations registered with BANS and the number who actually reported in 2011. Those organisations who reported patients during the first 6 months of 2011 are listed in table 9.1

**Figure 9.4: number BANS reporting centres in each region highlighting centres active in 2011**



## 9.2 Barriers preventing organisations from reporting

Despite the introductions of e-BANS and the removal of the requirement for consent a large number of organisations registered with BANS have stopped reporting whilst others fail to engage. An HETF focus group held in April 2011 identified the following barriers which they felt prevented organisations from reporting:

- Resources: low staffing levels and poor funding for HETF dietitians and support staff; extra documentation (duplicating other databases)
- Historical experience: consent issues; paper process: adult focus – not paediatric friendly, failure to produce useful local reports; unable to do it properly & fully so better not to do it
- BANS is not mandatory resulting in the lack of a local process and/or management championing making BANS a low priority

- Poor BANS PR resulting in lack of knowledge of what BANS can do

Whilst BANS can do little to improve departmental resources it aims to do more to raise the profile of e-BANS, dispel the negative impact of the historical experience through improved communications and regional/local championing and promote e-BANS as the unique national survey which can:

- Inform patient care: nationally, regionally and locally
- Raise awareness of patient trends: highlighting inequalities and informing standard setting
- Help develop business cases
- Inform the commissioning process

In 2012 BANS will be renewing its efforts to recruit more centres by targeting specific groups. For example: only 11 (31%) head and neck cancer dietitians responding to Sarah Sharpe's survey (see section 8) reported to BANS despite the fact that HETF is expanding rapidly in groups of patients within this cancer site. DAHNO 2011, the sixth national report on Head and Neck Oncology (accessible at [www.ic.nhs.uk/canceraudits](http://www.ic.nhs.uk/canceraudits)), when discussing its shortfalls in data submission states:

*'All healthcare professionals have a responsibility to perform audit to demonstrate the care provided is of a high quality. Medical Directors, Directors of Nursing and AHP Leads should seek assurance that head and neck professionals and head and neck teams are contributing to national audit as well as acting upon the results in this report'*

Acknowledgement:

The BANS committee wish to acknowledge all the reporting centres (table 9.1 below) who have submitted patient data, thus ensuring the sustainability e-BANS, and the input of the HETF Focus Group.

**Table 9.1: organisations reporting to e-BANS (January-June 2011)**

City (A-L)	User No/s	Organisation	City (L-Y)	User No/s	Organisation
Addenbrookes	255	Addenbrookes Hospital	Llandough	283	Llandough Hospital
Aylesbury	419	Manor House	London	103/346	Royal London Hospital
Basildon	231/417	Basildon Hospital	London	472	National Hospital for Neurology
Basingstoke	452	North Hampshire Hospital	Londonderry	105/490/491	Shantallow Health Centre
Bassetlaw	165	Bassetlaw District Hospital	Manchester	66	Wythenshawe Hospital
Bath	495	Royal United Hospital	Mid Glamorgan	110	St Tydfils Hospital
Belfast	237	Belfast City Hospital	Nelson	323	East Lancashire PCT
Belfast	262	Royal Belfast Hospital	Newcastle upon Tyne	8	Newcastle Upon Tyne General Hospital
Belfast	263	The Ulster Hospital	Newcastle upon Tyne	475	Freeman Hospital
Belfast	273	Royal Victoria Hospital	Newtownabbey	212	Whiteabbey Hospital
Belfast	326	Mater Hospital Trust	North Shields	10/11	North Tyneside General Hospital
Birmingham	177	Birmingham Heartlands Hospital	Norwich	489	Norfolk & Norwich University Hospital
Birmingham	338	Princess Diana Children's Hospital	Nottingham	81/168/494	Nottingham University Hospital
Bishop Auckland	142	Bishop Auckland, District Hospital	Nuneaton	102	George Eliot Hospital
Bristol	423 to 429	Bristol Royal Infirmary	Orkney	54	Balfour Hospital
Bury St Edmunds	22	West Suffolk Hospital	Orpington	291	Kent Community Dietetic Service
Camberley	122	Frimley Park Hospital	Oxford	314	John Radcliffe Hospital
Camberwell	404	Home Enteral Nutrition Team	Poole	287	Parkstone Health Centre
Cambridge	456	Addenbrookes NHS Trust	Poole	377	Poole Hospital
Cardiff	279	Velindre NHS Trust	Port Talbot	191	Port Talbot Hospital
Cardiff	384	University Hospital of Wales	Portadown	504	Craigavon Area Hospital
Carlisle	100	Cumberland Infirmary	Portsmouth	2	Queen Alexandra Hospital
Carshalton	315	Primary Care Dietetic Service	Prescot	127	Prescot Primary Care Resource Centre
Chelmsford	21	Broomfield Hospital	Preston	304	St Mary's Health Centre
Chertsey	265	St Peters Hospital	Rhyl	120	Glan Clwyd Hospital
Chester	203	Countess of Chester Hospital	Rochdale	459	Rochdale Infirmary
Chichester	210	St Richard's Hospital	Romford	240	Queens Hospital
Chigwell	77	Hainault Health Centre	Rotheram	137	Oakwood Hall
Chippenham	174	Chippenham Community Hospital	Runcorn	18	Halton General Hospital
Christchurch	264	Christchurch Hospital	Sale	135	Bodmin Road Health Centre
Coleraine	26	Coleraine Hospital	Salisbury	67	Salisbury District Hospital
Consett	285	Shotley Bridge Hospital	Scarborough	136	Scarborough Hospital
Croydon	19	Croydon University Hospital	Scunthorpe	160	Scunthorpe General Hospital
Cumbria	25	West Cumberland Hospital	Sheffield	213/389	Royal Hallamshire Hospital
Derby	186	Derby City General Hospital	Southampton	405	Southampton General Hospital
Derby	187	Derbyshire Royal Infirmary	Southampton	15	Royal South Hants Hospital
Derby	441	Derby City General Hospital (Children's)	St Albans	52	St Albans City Hospital
Dorchester	216	Dorset County Hospital	Stevenage	133	Lister Hospital
Dumfries	107	Dumfries & Galloway Royal Infirmary	Stourbridge	198	Stourbridge Health & Social Care Centre
Dundee	260/370	Ninewells Hospital & Medical School	Sunderland	457	Sunderland Royal Hospital
Dunstable	134	Dunstable Health Centre	Swansea	400	Singleton Hospital
Edinburgh	476	Royal Edinburgh Hospital	Swindon	51	The Great Western Hospital
Enniskillen	333	Erne Hospital	Tayside	375	Strathmartine Centre
Epping	113	St Margaret's Hospital	Tonypandy	48	Llwynpia Hospital
Exeter	485	Royal Devon & Exeter NHS Trust	Torquay	175	Torbay Hospital
Glasgow	398	Pollock Health Centre	Truro	252	Royal Cornwall Hospital
Guildford	38	Royal Surrey County Hospital	Truro	460	Royal Cornwall Hospital
Gwent	479	Royal Gwent Hospital	Uxbridge	202	Uxbridge Hospital
Harrogate	232	Harrogate District Hospital	Walsall	392	Manor Hospital
Harrow	256	N P H & St Marks NHS Trust	Watford	139	Watford General Hospital
Hereford	27	Hereford County Hospital	Wells	454	Somerset Community Dietetics
Hertfordshire	106	QE2 Hospital	West Bromwich	290	Sandwell District General Hospital
High Wycombe	289	Wycombe General Hospital	Westcliffe-On-Sea	91	Southend Hospital
Inverness	159	Raigmore Hospital	Whiston	494	Whiston Hospital
Ipswich	47	Ipswich Hospital	Whitstable	394	Whitstable & Tankerton Hospital
Isle of Man	438	Nobles Hospital	Windsor	386	King Edward VII Hospital
Isle of Wight	118	St Mary's Hospital	Wrexham	432	North East Wales Trust
Leeds	167	Leeds General Infirmary	Yeovil	58	Yeovil District Hospital
Leicester	267/268	Leicester Royal Infirmary	Unknown	266	Victoria House Dietetics
Leicestershire	23	Leicestershire Nutrition & Dietetics			
Lincoln	437	Lincoln County Hospital			



## Section 10

### The BANS Committee, 2010-11

#### BAPEN - Constituent Group Representatives.

- ❑ Dr Trevor Smith, BANS Chair, Consultant Gastroenterologist, BAPEN Medical
- ❑ Ann Micklewright, Dietitian, (Hon Sec) Parenteral and Enteral Nutrition Group (PENG) of the British Dietetic Association
- ❑ John Kennedy, Nutrition Nurse Specialist (Adult), National Nutrition Nurse Group (NNG)
- ❑ Carolyn Wheatley, HPN Patient, Chair of Patients on Intravenous and Nasogastric Nutrition Treatment (PINNT)
- ❑ Sarah Zeraschi, Pharmacist, British Pharmacists Nutrition Group (BPNG)
- ❑ Carole Glencorse, Dietitian, Main Industry Group (Abbott)

#### UK – Constituent Country Representatives

- ❑ Amanda Hirst, Paediatric Dietitian, Paediatric Group, BDA (England)
- ❑ Karen Henderson, HETF Dietitian, (Scotland)
- ❑ Sarah Jane Hughes, Chief Dietitian, (N.Ireland)
- ❑ Liz Pascoe, Senior Head & Neck Dietitian, (Wales)

#### Others:

- ❑ Janet Baxter, Dietitian and Manager, Scottish Managed Clinical HPN Network, Scottish Representative on BAPEN (ESPEN HANS group representative)
- ❑ Rebecca Stratton, Research Member (Clinical Nutrition Group)
- ❑ Henry Gowan, Administrator, British Intestinal Failure Register (BIFS)
- ❑ Phil Scot-Townsend, Technical Manager, Streets-Heaver Healthcare Computing

#### Ex Officio

- ❑ Prof. Marinos Elia, Consultant Physician & Professor of Clinical Nutrition and Metabolism, Nutrition Society. Founder Member
- ❑ Dr Barry Jones, Past Chair

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