



Annual BANS Report, 2010

Artificial Nutrition Support in the UK 2000 - 2009

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: 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 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 the last 10 years; reporting rates have been validated from anonymised data provided by nutrition companies. Detailed questionnaires have identified strengths and weaknesses in the structure of ANS services and highlighted regional variations in service provision. BANS data demonstrating inequity of access to home parenteral nutrition (HPN) services in England were instrumental in the development of the Strategic Framework for Intestinal Failure and Home Parenteral Nutrition Services for Adults in England.

BANS is registered through BAPEN under the data protection act. To avoid duplication of reported patients, reporters have been requested to supply only the patients' initials, date of birth, gender and the first part of their postcode. In 2006 BANS were required to apply for section 60 support of the Health and Social Care Act through the Patient Information Advisory Group (PIAG). This is designed to protect patients from inappropriate use of medical records and ensures that data collected are anonymised, pseudonymised or obtained with full consent of the patient or parent. BANS were legally obliged to comply with this legislation and therefore introduced a mechanism for reporters to obtain informed consent or assent from patients.

This process was an enormous challenge for reporters, particularly for those trying to update large numbers of HETF patients with chronic neurological disease, who were unable to provide consent. The time involved to obtain assent was also prohibitive for healthcare professionals who already had a very busy work schedule. Unfortunately this has had a significant effect on reporting rates, with a 37% reduction in new registrations for HETF, a 72% reduction in reporting of existing HETF patients and significantly fewer centres contributing to BANS. Similar problems have occurred with the updating of HPN patients. The reporting of

Paediatric data is a particular concern and I am delighted that we are now collaborating with the British Intestinal Failure Survey (for children). Henry Gowan, who manages BIFS, has joined the BANS committee and has contributed data to this report.

The BANS committee have worked closely with PIAG and their replacement group (National Information Governance Board (NIGB)) and have developed an 'exit strategy' that will not require reporters to obtain consent from patients. There have been some relatively small, but important changes to the patient code and reporters are now requested to submit the first part of the post code, year of birth and last 4 digits of the NHS/CHI number. These data produce a pseudonymised code and NIGB have provided written confirmation that reporters are not required to obtain consent (this letter is available for all reporters to view at www.e-bans.com).

The submissions to PIAG/NIGB over the last 4 years have run in parallel with the development and introduction of electronic reporting through e-BANS. We have received very positive feedback from reporters using the website and have updated the reporting tool following several meetings with reporters at BAPEN conference and elsewhere. Recognising the problems encountered by reporters with consent over recent years, BANS has now been re-launched with a new and updated website: www.e-bans.com.

BANS have undertaken a number of national surveys examining individual aspects of artificial nutrition support over the years, including the provision of services for Home Enteral Feeding in 2003. This survey showed a number of shortcomings and has been repeated in a modified format this year. Unfortunately the response rate was poor, but nevertheless similar problems around inadequate staffing and a non standard clinical, financial and management infrastructure have been identified. The assessment and development of standards of care for Home Enteral Feeding will be a core activity for BANS over the next few years.

BANS has been through an extended period of change and we are now confident that e-BANS is fit for purpose. This unique national survey has made some vital contributions to the planning and delivery of high quality nutritional care in the UK; the contributions of reporters are key to past and future success and the BANS committee are very grateful to all reporters for their ongoing support.

Dr Trevor Smith
Chair of the BANS committee, December 2010

Section 3

Executive summary

Dr Trevor Smith

Adult HETF

1. New registrations have fallen from a high of 7187 in 2001 to 3282 in 2009 (24% reduction from 2008). Point and period prevalence data have fallen significantly to 4192 and 6704 patients respectively (30% and 37% reductions from 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. The number of new registrations per million of the UK population was 53.
4. An average centre reports and updates data on 36 patients per year; however this is limited by significant reductions in reporting rates.
5. Cancer continues to account for an increasing proportion of new HETF registrations – increasing from 25% in 2000 to 37.4% in 2009. 96% of new cancer registrations were diagnosed with head and neck or oesophageal cancer.
6. Neurological disorders account for 47.5% of new cases. Cerebrovascular accident is the commonest neurological diagnosis requiring HETF. Dementia continues to decline as an indication for HETF (3% of neurological/degenerative disorders).
7. Adult HETF patients are predominantly older in age with 65% >60 years old.
8. 68% of patients live in their own homes. There has been a gradual rise in the proportion of new patients who live independently from 21% in 2000 to 36% in 2009 and a drop in those requiring 'total help' from 57% to 43%.
9. Nasogastric tube feeding accounts for 17.5% of new cases (slowly increasing use) with Gastrostomy being by far the commonest route of administration (75%).
10. Commercial homecare companies support 89% of new cases and 87% of established patients.
11. 62% of patients were still receiving HETF at the end of the year; 16 died, predominantly from their underlying disease process.

Paediatric HETF

1. 482 patients were registered with BANS – a 30% reduction from 2008. The new patient data was the lowest recorded since 2000. There were significant reductions in the reporting of point (-32%) and period (-42%) prevalence data in 2009.
2. Requirement to obtain consent or assent is the main explanation for the reduction in reporting rates (communications from BANS reporters).
3. Centres reporting new patients fell from 137 in 2007 to 70 in 2009, a decline of 49%. The number of centres updating existing patients fell dramatically by 67% (point prevalence) and 61% (period prevalence).

4. The number of new registrations per centre in 2009 ranged from 1 – 49. Nine or fewer new children were registered by 77% (54 centres), of which 34% (24 centres) registered only one child each.
5. The main reasons for feeding for new children in 2009 were: to improve nutritional status (46%); failure to thrive (23%); swallowing difficulties (21%); gastrointestinal disorders (4%) and a miscellaneous group (6%).
6. The underlying diagnostic categories were: Neurological 30.5%, Non-malignant GI disease 14.5%, cancer 10% and 'other conditions' 45%.
7. Feeding routes were similar to previous years for newly registered children, although there is a slowly increasing trend in the use of naso-gastric tube feeding: gastrostomy (26%), naso-gastric (72.6%), jejunostomy (1.4%)
8. The age distribution has changed significantly; in 2000 22% of the paediatric HETF population was under 1 year – this has increased to 53% in 2009.
9. 98.8% of children were discharged home.
10. Commercial homecare companies were involved in 86% of new cases compared to 62% of new cases in 2000.
11. 82% of children were still receiving HETF at the end of the year; 11% returned to oral feeding and 4% died.

Adult HPN

1. New registrations were stable in 2009 – 148 patients compared to 157 in 2008. Point and period prevalence fell to 345 and 435 cases respectively; this represents a 50% reduction compared to 2007 and demonstrates the negative impact of the requirement for reporters to obtain consent from patients during 2008 and 2009.
2. The number of centres registering new patients has remained stable at 27, but the number of centres updating existing patients has remained low at 35 (51% reduction compared to 2007).
3. As shown in BANS report 2005, there are still a significant number of centres managing small numbers of HPN patients.
4. The reported UK point prevalence was 5.6 per million and period prevalence 7.0. These are large reductions compared to 2007 and are due to under-reporting rather than a true reduction in HPN prevalence.
5. New registrations in England during 2009 (125 patients) were similar to 2008 (130 patients); new patient registrations grew by 8% compared to 2007 and 48% compared to 2006. Point and period prevalence fell to 306 and 366 patients respectively, a reduction of over 50% compared to 2007
6. Scottish point prevalence per million has reduced to 4.8 and period prevalence to 9.8 (2007: 15.1 and 16.1 respectively). This is due to under-reporting rather than a true reduction in HPN prevalence.
7. Welsh point prevalence per million has reduced to 3.7 and period prevalence to 4.7 (2007: 7.1 and 7.5 respectively). Registration of new patients has improved considerably with the development of a Welsh HPN network.
8. Northern Irish point prevalence per million has reduced significantly to 1.7 and period prevalence to 2.2 (2008: 22.2 and 22.8 respectively).
9. The modal age for adult HPN is 51 – 60 years of age.
10. 49% of new cases are aged 16 – 50.

11. Short bowel syndrome remains the main reason for HPN (41.2% new cases; 55.4% established cases)
12. Crohns disease and small bowel ischaemia remain the major indications for new registrations (21.6% and 18.9% respectively) and established cases (30.4% and 18.8%). A substantial heterogeneous group including complex surgical problems accounts for 20.1% of new cases and 14.2% 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 12.8% between 2000 and 2009).
13. The percentage of newly registered patients initially placed in a nursing home has remained very small (1.1% and 3.4% in 2000 and 2009 respectively) despite a rise to 10.1% in 2007. The vast majority of patients are discharged to their own home.
14. Although a minority of new cases are described as house or bed bound (6%), only 52% are described as fully independent, the remainder requiring assistance with their HPN.
15. Venous access was via an external catheter in 93.9% and subcutaneous ports in 6.1%.
16. Commercial homecare companies provided for all new patients in 2009; their contribution to point prevalence has been steadily rising from 70.6% in 2000 to 96.2% in 2009.
17. 83.4% patients were still on HPN at the end of the year but only 6.9% had reverted to oral nutrition. 2.1% were in hospital, 3% were transferred to other centres (and no further outcome data were available) and the mortality rate was 4.4%.

Paediatric HPN

1. 21 new children were registered with BANS during 2009, a 20% reduction on the previous year. During 2009 point and period prevalence have fallen to 43 and 48 cases respectively; this represents a more than 50% reduction compared to 2007 showing a similar trend to that of adult HPN.
2. The number of reporting centres has remained stable at 8. However the number of centres reporting prevalence data has fallen to 12 (-54% compared to 2007) - the committee are aware that some large centres do not report to BANS.
3. 77% of newly registered children were suffering from a non-malignant gastrointestinal disorder.
4. 14% of new cases were classified as 'miscellaneous' diagnosis. BANS has revised diagnostic categories for use with e-BANS so miscellaneous diagnoses should be exposed to greater clarity.
5. 86% of new children received their feed via an external catheter and 14% via a subcutaneous port.
6. Commercial homecare companies were involved in support of 95% 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 37% of the total estimated cases, which reflects the significant reduction in reporting rates over the last 2 years.
3. For paediatric HPN, BANS surveys 32% of UK cases.
4. Adult HETF returns were 16% of estimated cases.
5. Paediatric HETF attracts only 9% of estimated cases.
6. The significant reduction in reporting rates poses 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.

Provision of home enteral tube feeding: a national survey

1. A national electronic survey was conducted with the aim of reviewing the infrastructure of HETF services in 2009 from an organisational, clinical and financial perspective.
2. The response rate was poor; questionnaires were sent to 500 dietetic managers and PEN group dietitians. 76 Dietitians responded (15%), although only 60 entered data from 40 organisations.
3. A significant number of organisations did not record accurate data regarding the numbers and types of patients receiving HETF.
4. Dietitians and Nutrition nurses have important training roles for patients and carers; written information for patients was invariably available to backup training.
5. Almost 50% of organisations described inadequate staffing levels to support an expanding population of patients requiring HETF.
6. Most centres had developed local guidelines for managing HETF patients, although there was no standardised approach across the UK.
7. There was no standardised approach to managing budgets for HETF services; procurement of feeds and ancillary items was often fragmented, and there was uncertainty as to how an expanding population of patients should be funded.
8. Rates of reporting to BANS were low.

Section 4

Home Enteral Tube Feeding (HETF) in adults

Ann Micklewright

4.1 Patients and Reporting Centres

4.1.1 New Registrations

The highest recorded number of new patients registered with BANS was 7187 in 2001 after which time there was a gradual annual decline to 5182 in 2007, despite the number of reporting centres remained relatively similar (Table 4.1). However, in 2008 patient registrations and reporting centres decreased rapidly by 17% and 24% respectively. A further deterioration occurred in 2009 with both new registrations (-24%) and Reporting Centres (-23%) less than the previous year (Figure 4.1). The BANS committee are aware via direct feedback from reporters that these reductions are a direct result of the requirement for reporters to obtain consent from patients during 2008 and 2009.

Table 4.1: the number of new registrations, point and period prevalence and reporting centres from 2000-2009 in the UK

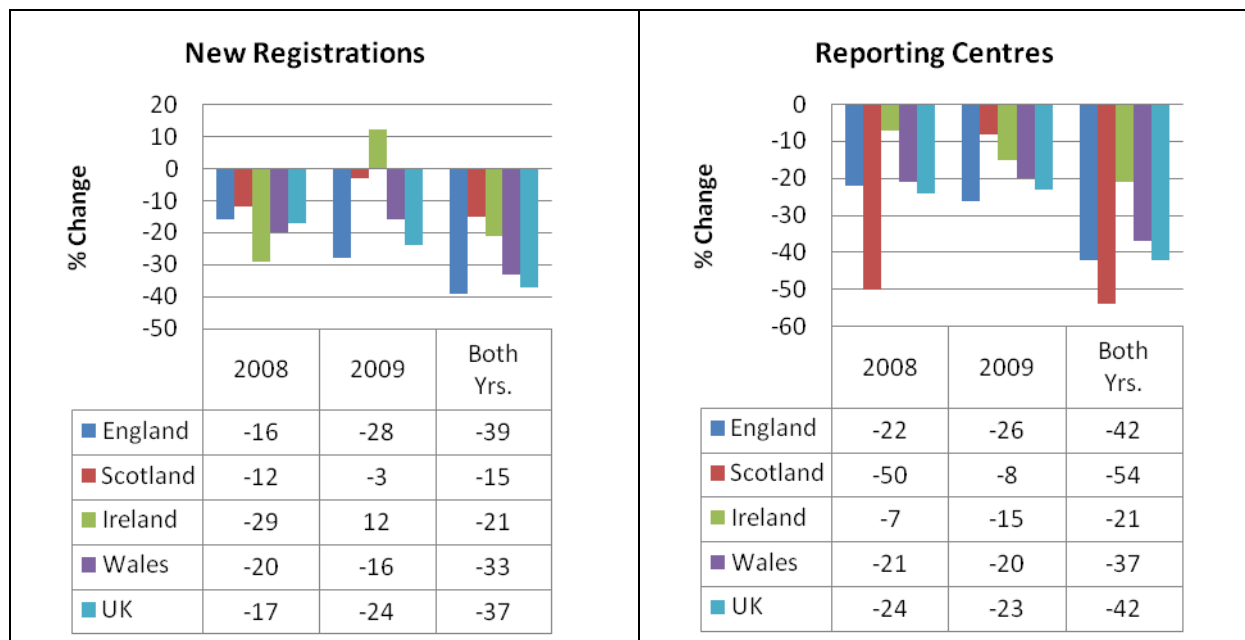
	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
New Registrations	6629	7187	6428	6585	5656	5978	5145	5182	4326	3282
<i>Reporting Centres</i>	275	280	264	251	252	257	216	254	193	148
Point Prevalence	11817	13742	15148	16890	18260	18686	19583	21858	5959	4192
<i>Reporting Centres</i>	311	318	319	319	323	333	340	357	205	161
Period Prevalence	15652	18376	19474	21028	21677	23095	23088	24203	10690	6704
<i>Reporting Centres</i>	319	331	331	325	327	340	347	367	205	185

The percentage reduction in both new registrations and reporting centres for the UK and its constituent countries for 2008 and 2009 and for both years together is shown in Figure 4.1. Overall since 2007 there has been a loss of 106 (-42%) reporting centres across the UK. Losses in: England 83 (-42%); Scotland 13 (-54%); N. Ireland 3 (-21%) and Wales (-37%).

This has had a devastating effect on new registrations. Only in N. Ireland was there an upward trend in 2009 when new registrations increased by 12% over the previous year. However, the average number of new patients per reporting centres was 22.2, slightly up on the previous year (20.4). In 2007 (before the consent issue affected

reporting) the number of centres reporting new patients was 254. If all of these centres had continued reporting, new registrations would be in excess of 5000.

Figure 4.1: % change in number of new registration and reporting centres in 2008 and 2009 in constituent UK countries



4.1.2 Point and Period Prevalence

The consent issue has also beleaguered the point and prevalence data as reporters who did not register new patients failed to update existing ones. Since 2007 BANS has held records for a large number of patients who have not been updated for one or more years. In 2008 the BANS Committee agreed that in future **only those patients who had been updated in the previous year** would be counted in the point and period prevalence data. Therefore the 2008 and 2009 data are noticeably lower than in previous years, making it difficult to draw conclusions about the number of patients receiving HETF in the UK at one point in time or during a calendar year. **In future any patients not updated during a reporting year will not be included in the prevalence data for that year.**

In 2009 only 161 centres updated 4192 patients (point prevalence) and 185 centres updated 6704 patients (period prevalence). This was a reduction of 44 (point prevalence) and 20 (period prevalence) centres updating patients compared to 2008.

Independent data suggest that the point prevalence for 2009 was 25,777 adults. This was data supplied by the Home Care Companies to which an additional 13% has been added to account for the patients that, according to BANS, are not supplied by a home care company (see section 8 for more details). Based on these figures the 2009 point prevalence was 417 patients on HETF per million of the UK population.

4.1.3 Reduction in reporting

The main reasons for the decrease in reporting for both new and existing patients were discussed in the 2009 Report and are outlined briefly below:

- Nutrition Companies who previously undertook a large proportion of new registrations withdrew due to confidentiality and consent issues.
- Reporters, mainly 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 altogether because of consent issues.

Key Points

The reduction in reporting for both new and existing patients is cause for concern. However there is still a considerable number of patients, both new and existing, for BANS to report upon.

A number of changes have been made to BANS to encourage existing and non-active reporters to provide data. Consequently BANS was re-launched in July 2010 with the following main features:

- **Consent is no longer required.**
- e-BANS is now live and enables reporters to register and update patients very easily.
- The possibility of Nutrition Companies registering new patients is being explored
- Only patients who have been updated 'in year' will be reported in the point and period prevalence data. Patients who are updated beyond the 12 month reporting period will be included in subsequent year's reports.

More detailed information may be found in section 9.

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

In the past BANS has reported on the number of patients per million of the population for the constituent countries of the UK. Table 4.2 shows data from 2007-2009. Figures have been calculated on mid-point annual population data from the Office for National Statistics, General Registry Office for Scotland and Northern Ireland Statistics and Research Agency. These data are given to show the reduction in registrations since 2007. It is likely that the 2007 data better reflects current practice.

Table 4.2: Number of new registrations per million/population in UK

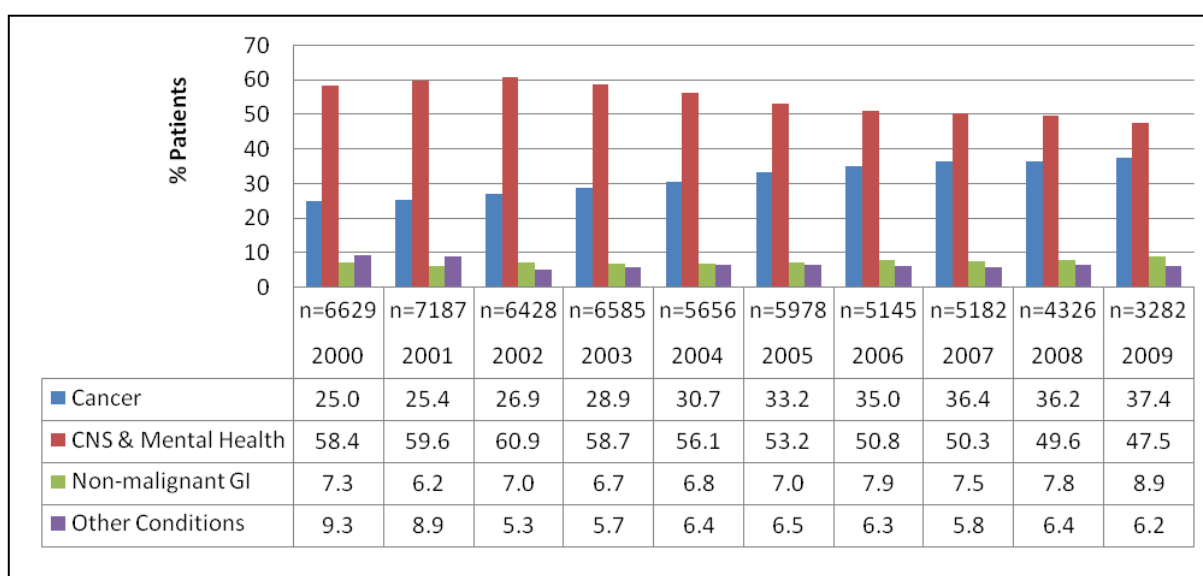
	New Registrations per million population			Mid 2009 population*
	2007	2008	2009	millions
England	86	71	50	51.810
Scotland	57	49	47	5.194
N.Ireland	142	98	108	1.789
Wales	119	94	79	29.999
UK	67	77	53	61.792

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

4.3 Clinical conditions

Patient diagnoses are grouped into 4 main clinical conditions: cancer; central nervous system (CNS) & mental health; non-malignant gastrointestinal (GI) disorders and other conditions. Figure 4.3 illustrates the number of new registrations by clinical condition from 2000-2009.

Figure 4.3: clinical conditions of new registrations 2000-2009



The main diagnoses for new patients in 2009 as percentage of appropriate clinical condition are listed below, whilst Table 4.3 lists all new registrations according to diagnosis.

Cancer (n- 1226)

- the incidence of cancer patients receiving HETF has gradually increased from 25% to 37.4% of new registrations since 2000.
- Head & Neck and oesophageal cancer contributed 71% & 25% of all new cancer registrations in 2009.

CNS & Mental Health (n=1560)

- ❑ Vascular disorders (42%): *predominantly cerebrovascular accident (CVA)*
- ❑ Other CNS condition (13%)
- ❑ Degenerative disorders (33%): *motor neurone disease (13%); multiple sclerosis (8%), Parkinson's disease (7%)*
- ❑ Brain injury, congenital disorders and cerebral tumour (10%): *5%, 3.5%, 1.5% respectively*
- ❑ Mental health (<2%): *mostly anorexia nervosa*

Non-malignant gastro-intestinal tract (n=291)

- ❑ Gut disorders (15%): *Crohns (7%); Pseudo-obstruction/motility disorders (5%), ulcerative colitis (1%); radiation enteritis (1%)*
- ❑ Hepatobiliary (5%): *liver (4%); pancreatic (1%)*
- ❑ Oesophageal/Stomach (36%): *Dysphagia of unknown cause (20%); other oesophageal disorders (achalasia, strictures, fistula (13%); gastro-oesophageal reflux (4%)*
- ❑ Other GI disease (44%)

Other Conditions (n=205)

- ❑ Respiratory disease (34%): *cystic fibrosis (12%); chronic obstructive airways disease (6%); other respiratory disorders (16%)*
- ❑ Miscellaneous conditions (58.9%): *auto immune disease, congenital malformation, HIV/Aids, polymyositis, scleroderma), >7%; renal (6%) other unnamed conditions (58%)*
Failure to thrive is a category usually associated with paediatrics rather than adults yet 7 new patients (age range 52-80yrs) were recorded with this condition, all were resident and nursing homes.

Key Points:

Since 2000 the number of new cancer patients receiving HETF has increased whilst those suffering from CNS disorders, particularly CVA has decreased

The number of patients with dementia reached its highest level (7% of CNS conditions in 2004) but had decreased to 3% by 2009. This may be due to improved patient selection following publications such as, 'Scoping our practice'. (NCEPOD, 2004).

The proportion of mental health patients is extremely low particularly for those with learning difficulties (LD). No patients were registered until 2008 when 5 patients were recorded and one further patient added in 2009. It seems likely that these patients are not being registered by mental health staff or are being registered according to more specific clinical diagnoses rather than LD.

Despite a major re-organisation of the diagnostic codes there are still a percentage registered as 'other'. Further work is being done to address this situation.

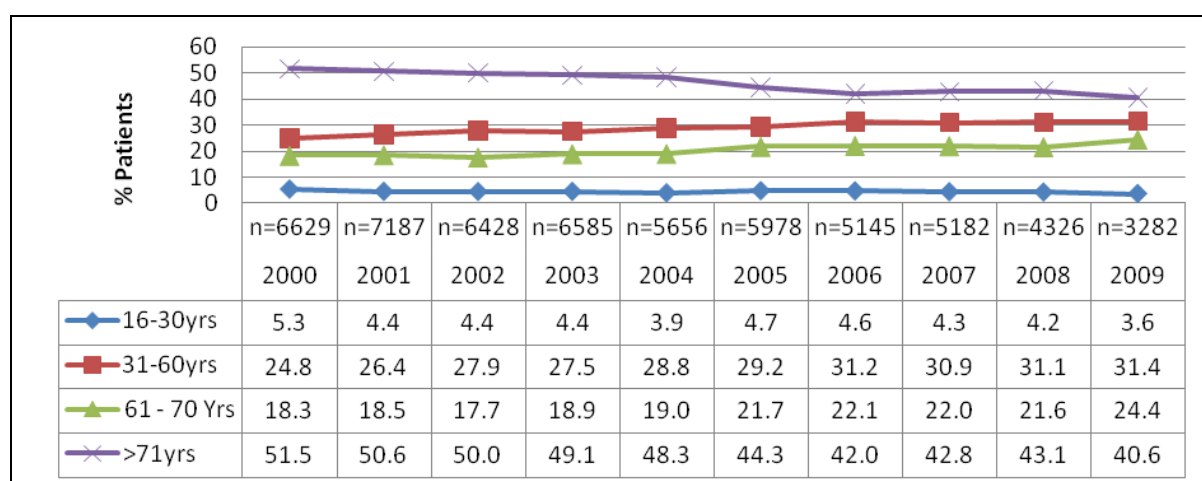
Table 4.3: diagnosis at registration in 2009

CANCER		CNS & MENTAL HEALTH		NON MALIGNANT GIT	
n=1226		n=1560		n=291	
GI Cancer n=301		Brain Injury n=79		Gut n=43	
Gastric	45	Cerebral Trauma	75	Benign intestinal strictures	1
Oesophageal	239	Hypoxic brain Injury	4	Crohn's Disease	20
Pancreatic	4	Congenital n=54		Post-necrotising enterocolitis	2
Small Bowel	6	Cerebral Palsy	36	Pseudo-obstruction/motility disorders	15
Cancer: Colonic	7	Down's syndrome	3	Radiation Enteritis	2
Cancer: GI Lymphoma	0	Congenital Handicap	15	Ulcerative Colitis	2
Haematology n=2		Degenerative n=516		Vascular Disease - ischaemic	
Leukaemia	2	Alzheimers	1	Hepatobiliary/Pancreas n=15	
Head and Neck n=872		Dementia	48	Biliary Atresia	1
Cancer: Head & Neck	673	Huntingdon's Chorea	30	Liver Disease	11
Cancer: Oropharyngeal (incl orolaryngeal)	183	Motor Neurone Disease	197	Chronic pancreatitis	3
laryngeal	2	Multiple Sclerosis	122	Oesophageal/Stomach n=104	
Oral	11	Muscular Dystrophy	9	Dysphagia of unknown cause	58
Pharyngeal	3	Parkinsons Disease	109	Gastro-oesophageal reflux	6
Miscellaneous n=51		Mental Health n=27		Oesophageal Perforation	1
Bladder	1	Learning Difficulties	1	Oesophageal Strictures (benign)	12
Elsewhere than stated	47	Anorexia Nervosa	26	Other Oesophagea (achalasia, fistula)	27
Lung	2	Miscellaneous Conditions n=208		Surgery n=1	
Ovarian	0	Cerebral Atrophy	2	Surgical Trauma	1
Thyroid	1	Chronic Fatigue Syndrome	2	Other GI disease n=128	
		Guillain Barre Syndrome	1	128	
		Other CNS	201	OTHER CONDITIONS	
		Hydrocephalus	1	n=205	
		Meningitis	1	Cardiac n=10	
		Neurological		Congenital Heart Disease	2
		Paraplegia	1	Other Cardiac Disease	8
		Spinal Injury	1	Inborn Errors of Metabolism n=5	
		Tumour n=25		Miscellaneous n=120	
		Cerebral Tumour	25	Auto Immune Diseases	1
		Vascular n=649		Failure to thrive	7
		Cerebral haemorrhage	1	Congenital Malformation	2
		CVA/Stroke	50	HIV/Aids	2
		Cerebrovascular Disease	598	Polymositis	1
				Scleroderma	1
				Renal Disease	6
				Other	100
				Respiratory n=70	
				Aspiration Pneumonia	1
				Bronchopulmonary dysphasia	0
				Chronic obstructive airways disease	12
				Cystic Fibrosis	24
				Other respiratory disease	33

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

Age: In 2000 almost 70% patients were over 60 years old at registration. By 2009 this had dropped to 65%. The period between 2000 and 2009 saw some changes in age distribution, most noticeably a reduction of 10% in the proportion of those over 71yrs and an increase (6%) of those between 60-70yrs. In the younger population there was a slight reduction (1.7%) in those between 16-30 yrs and an increase (6.6%) in those between 31-60 years. (Figure 4.4 A).

Figure 4.4 (A): Percentage of new registrations within age bands from 2000-2009



Level of activity: Figure 4.4 (B) shows the activity levels of all new patients at registration. Since 2000 there has been a gradual increase in those patients regarded as fully active rising from 17% to over 35% in 2009. Consequently, the percentage of patients who were housebound or bedbound dropped by 10.6% and 7.2% respectively. Less than 1% were unconscious.

Figure 4.4 (B): Activity status of new patients at registration 2000-2009

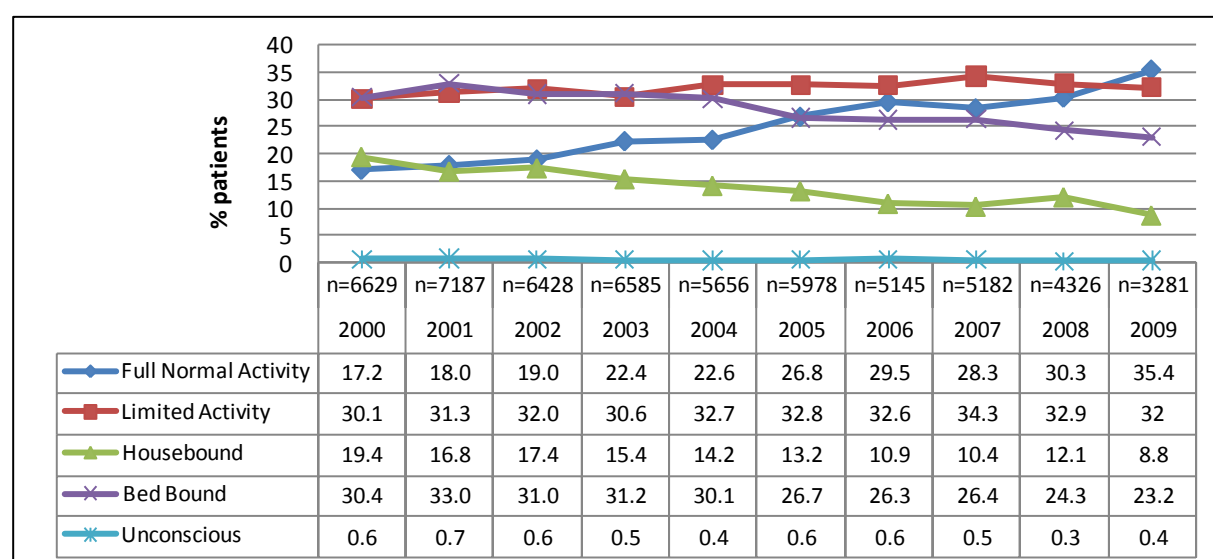
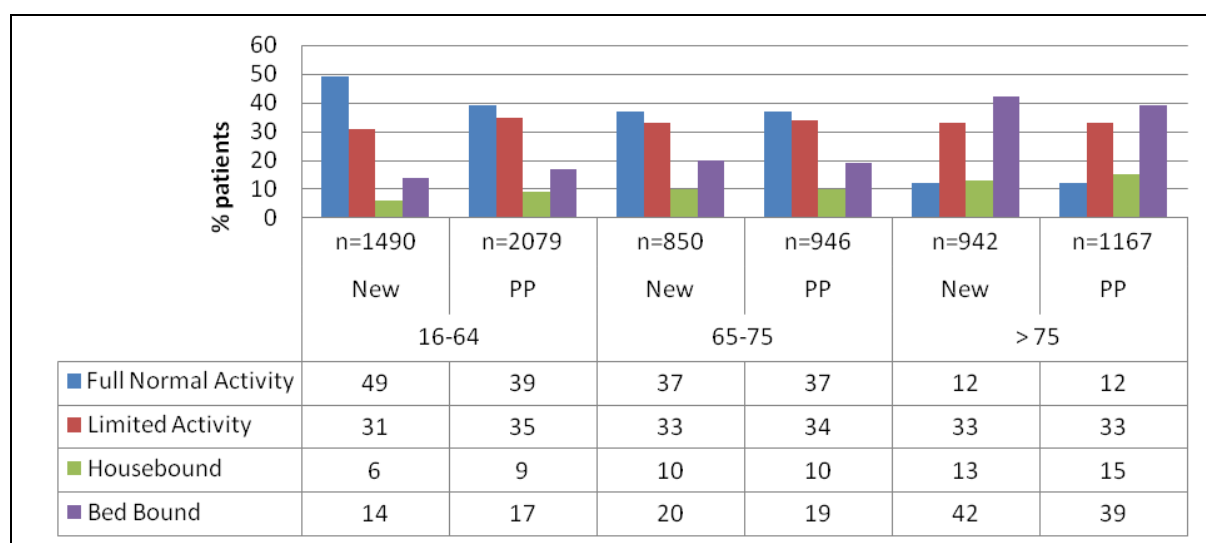


Figure 4.4 (C) shows the activity data for 2009 by age range for both new and existing patients. There is a noticeable difference between age groups: 49% of patients starting HETF aged between 16-64 years were regarded as fully active compared to 37% of those aged 65-75 years and 12% of those over 75 years. Around one third of all patients had limited activity levels. As age increased activity levels decreased in both housebound and bedbound categories.

Comparing new and existing patients in each age group there appears to be a deterioration in the 16-64 years group as HETF continues, little change in the 60-75 years and a slight (2%) improvement from bedbound to housebound status.

Figure 4.4 (C): Activity status of patients by age group in 2009 (percentage of new and point prevalence (PP) patients)

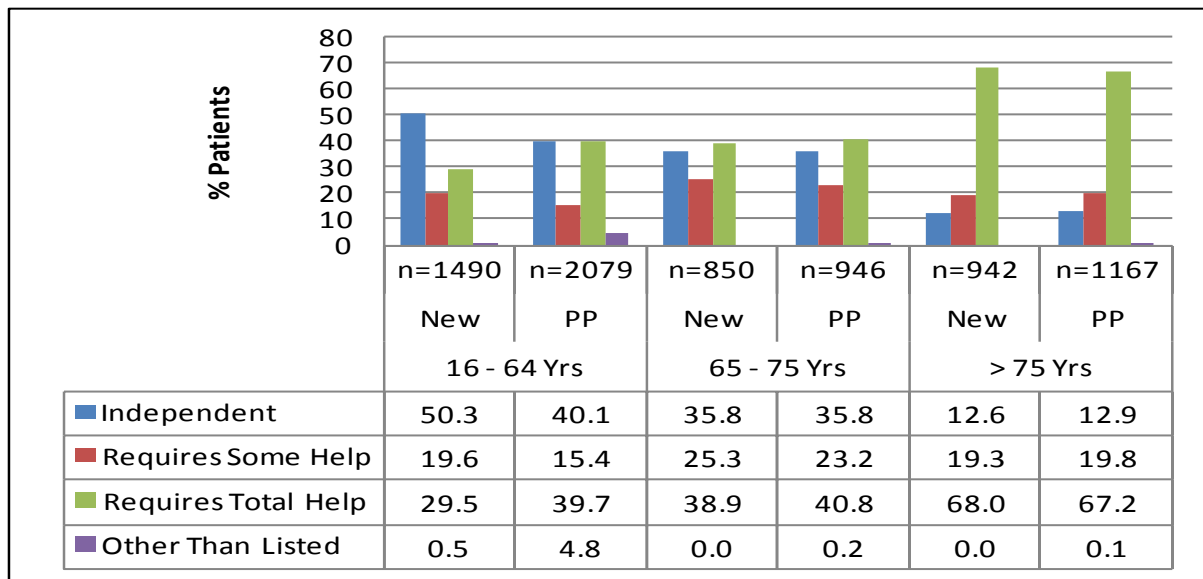


Dependency: There has been a gradual rise in the proportion of new patients who live independently from 21% in 2000 to 36% in 2009 and a drop in those requiring 'total help' from 57% to 43%.

The 2009 dependency data were broken down by age band for both new and existing (PP) patients. (Figure 4.4 D)

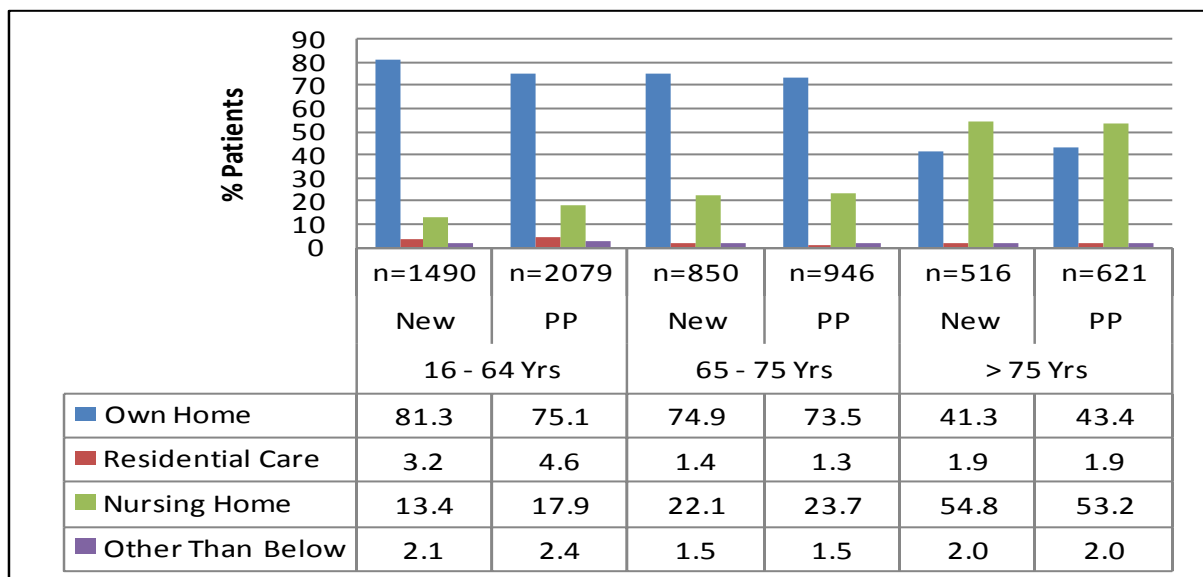
- **Age 16-64 yrs.:** 50% of new patients were independent, 20% required some help and 30% total help. However, dependency levels increased for existing patients with only 40% being independent, 15% requiring some help and 30% total help.
- **Age 65-75 yrs.:** 36% new patients were independent, 25% required total help and 39% total help. There were only small differences (~1-2%) between new and existing patients' dependency levels.
- **Age >75 yrs.:** > 13% new and existing patients were fully independent; 19-20% required some help and 60% total help.

Figure 4.4 (D): Dependency by age for new and existing patients (point prevalence (PP)) 2009



Location: Given the growing number of patients able to maintain full normal activities and their independence, it is not surprising that the number of new patients able to live at home has increased from 56% in 2000 to 68% in 2009. Only 27.5% required nursing home care* in 2009 compared to 41.5% in 2000. (* figures include 2.3% and 1.6% in residential care). Patients in nursing homes will be discussed in more detail later in this chapter.

Figure 4.4 (E): Location by age for new and existing patients (point prevalence (PP)) 2009



Again looking across the 3 age groups in 2009 (Figure 4.4 E):

- *Age 16-64yrs.:* 81% of new patients live at home with 3% in residential care and 13% in nursing homes. As discussed above existing patients become more dependant – 75% remain at home with 4% in residential care and 18% in nursing homes.
- *Age 65-75yrs.:* 75% new patients live at home, 1.4% in residential care and 22% in nursing homes. There is little difference with existing patients
- *Age >75yrs.:* 41% patients live at home, 2% in residential care and 55% in nursing homes. There is a small increase (<2%) in existing patients living at home with subsequent decrease in those in nursing homes.

Key points:

- One of the aims of BANS is to identify trends associated with provision of HETF. Clear associated trends are emerging in relation to the age of patients, clinical condition, activity, dependency and location. In 2009, more new patients were described as: fully active (18%), independent (17%), able to live in their own homes (12%) with 14% less required nursing home care than in 2000.
- The proportion of patients over the age of 70 has reduced due in part to fewer elderly patients presenting with CVA receiving HETF. These patients due to age and illness tend to be less active, more dependent and require nursing home treatment.

4.5 Reason for feeding, feeding routes and delivery of supplies

Reason for feeding: In 2000 the two primary reasons for patients starting HETF were: swallowing disorders (72%) and to improve nutritional status (19%). Over the subsequent nine years, swallowing disorders gradually decreased to 63%, with a corresponding increase to 29% for nutritional support. This changing picture is due in part to the reduction in patients with neurological conditions and an increase in those with cancers requiring HETF. The remaining indications were GI problems such as obstruction, malabsorption and short bowel syndrome (~6%).

Feeding routes: Figure 4.5 (A) identifies gastrostomy feeding as the principal feeding route. However, the use of naso-gastric tubes appears to have increased in 2009. Jejunostomy feeding has increased year on year from 3.6% in 2000 to 7.7% in 2009 probably due to improved placement techniques.

Figure 4.5 (B) shows the percentages of tubes used for patients with the 4 main clinical conditions in 2009 for both new and existing patients.

All tubes were used across a broad spectrum of diagnoses within each clinical condition category; the **main** diagnoses associated with each tube type are listed below, with a percentage in parenthesis for new and point prevalence registrations:

Gastrostomy: head & neck cancer including oropharyngeal (26%, 21%); CVA (24% both); motor neurone disease (5% both), multiple sclerosis (4%, 6%); Parkinson's disease (4% both)

Jejunostomy: head and neck cancer (9%, 8%); gastric cancer (11%, 7%), oesophageal cancer (40%, 37%); oesophageal (non malignant) (4%, 6%); obstruction/motility disorders (3% both); GI other than listed (15% both)

Nasogastric: head & neck cancer (30%, 24%); oesophageal cancer (11%, 8%); CVA (7% both), non-malignant oesophageal (6%), cerebral palsy (<1%, 5%)

Figure 4.5 (A): Feeding routes for new patients 2000-2009

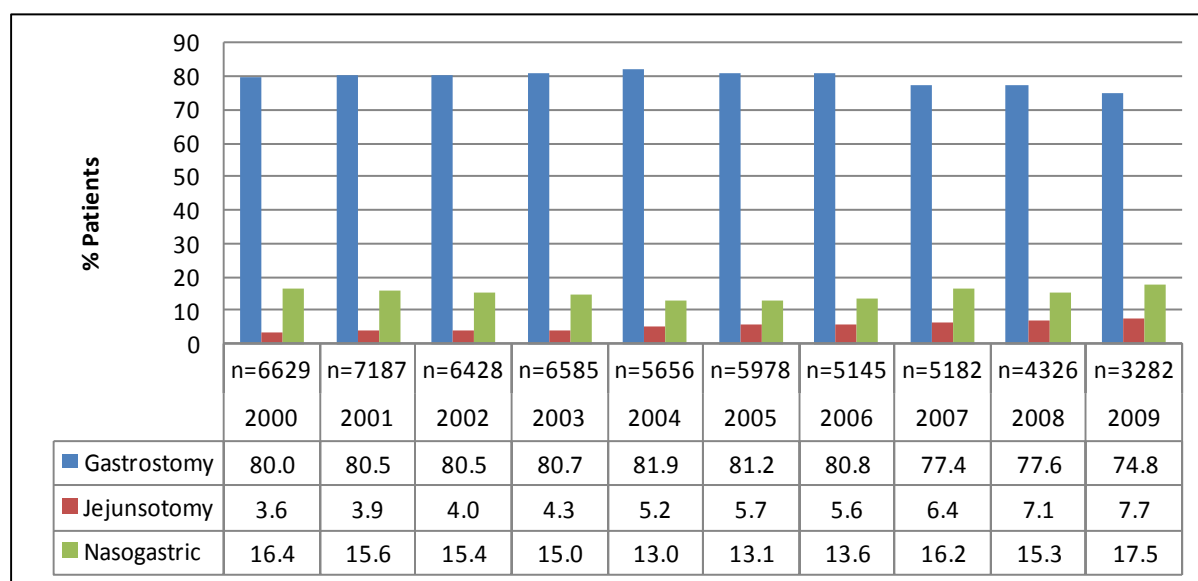
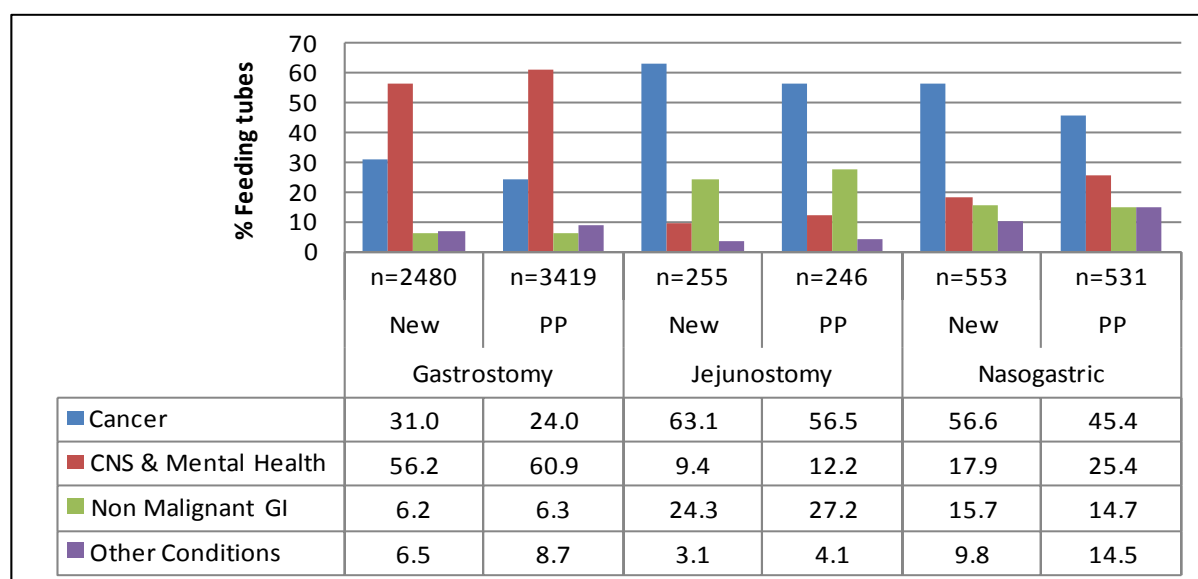


Figure 4.5 (B): Feeding tubes used in 2009 for new and existing (point prevalence) patients by clinical condition



Delivery of Supplies: Home Care companies supplied 89% of new and 87% of existing patients in 2009, an increase of 15% since 2000. It was not known how 3% patients obtained their supplies.

Key points

- The two main reasons for feeding remain as 'swallowing disorders' and 'to maintain nutritional status'. Given the reduction in neurological patients and the increase in cancer indications it is not unexpected that over the last three years swallowing disorders as a reason for feeding has reduced by 9% with a similar increase in the need to maintain nutritional status.
- Since 2000 the use of gastrostomy tubes has remained fairly stable (>80%). However, from 2006 there has been a downward trend to 75% in 2009, resulting in an increase in the use of nasogastric tubes (4%) and jejunostomy tubes (2%). This may be associated with a greater awareness of the contraindications for PEG placement, improved techniques for securing nasogastric tubes such as nasal bridles and/or the changing clinical profile of the HETF population.

4.6 Outcomes in 2009

Period prevalence data have been analysed to identify the outcomes of patients receiving HETF in 2009. Only patients who had been registered and/or updated in 2009 were included. Of these, 4174 (62%) continued on HETF and less than 1% refused or stopped feeding (see Figure 4.6).

736 (11%) patients were 'lost to contact' 3% were transferred to other hospitals and 1% were re-admitted to hospital.

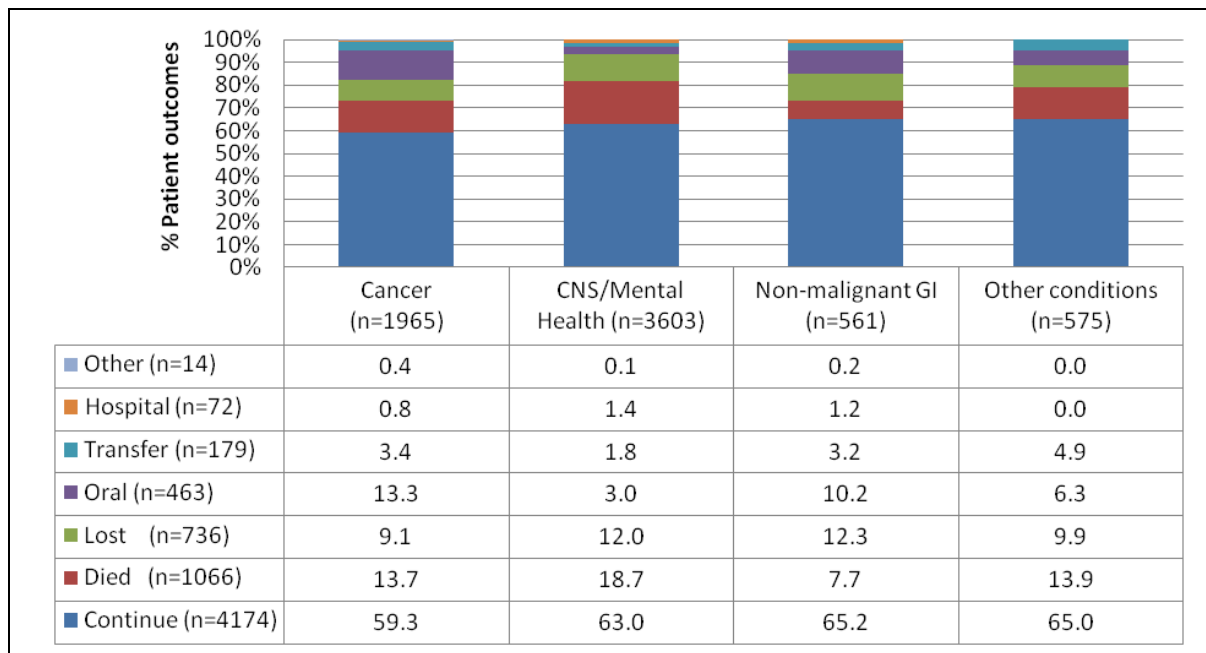
1064 (16%) patients died, of whom 995 (93%) died from underlying disease; 67 (6%) from unspecified causes and <0.5% from complications unrelated to feeding.

Key points

The mortality rates are most definitely underestimated as there is no way of knowing what happened to the patients who were lost to contact, re-admitted or transferred to other hospitals.

The BANS outcomes as such say little about the HETF patient journey. It would be useful to track a cohort of patients in more detail to find out more.

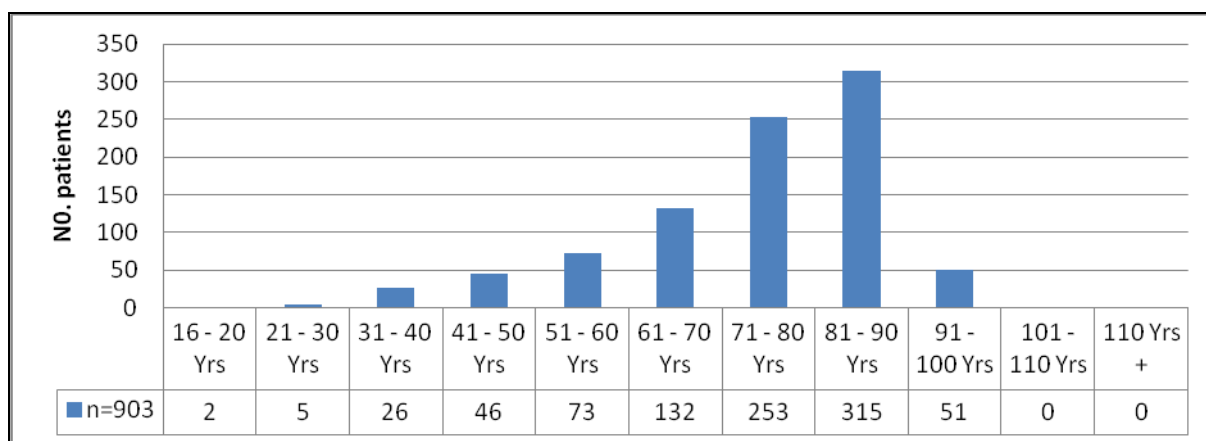
Figure 4.6: Outcomes (%) of 6704 adult patients receiving HETF in 2009



4.7 Patients in Nursing Homes (NH) in 2009

Figure 4.7 (A) shows the age distribution of 903 new patients who were resident in nursing homes in 2009; 83% of them were over 61 years of age.

Figure 4.7 (A): Age of new HETF nursing home (NH) patients in 2009



4.7.1 Associated clinical conditions (new patients)

The main diagnoses within each main category are shown in italics as a percentage of whole HETF nursing home population:

- Central nervous system and mental health problems (86%): *vascular disease - mainly CVA (48%); degenerative disease (20%); other CNS disorders (9%); brain injury (6%); congenital disorders (<2%)*.
- Cancer (6%): *oesophageal (1.2%); head & neck (4%); other cancers (0.8%)*.
- Non malignant GI disorders (<3%): *mainly dysphagia & oesophageal conditions*.
- Other conditions (6%): *respiratory disease (2.5%), cardiac (0.5%) other not listed (3%)*.

4.7.2 Reasons for feeding, feeding routes and supplies

HETF was instigated for patients with swallowing difficulties (75%) and a further 23.5% required nutritional support (included in this number are 7 patients classed as failure to thrive). No reason was given for the remainder. New patients started feeding by gastrostomy (85%), jejunostomy (2%) or naso-gastric tube (12%). Gastrostomy feeding increased to 90% for existing patients (point prevalence) whilst naso-gastric feeding dropped to 8%. 90% of supplies were delivered by a Home Care company.

4.7.3 Activity level and ability to manage

Table 4.7 shows the activity levels of both new and existing patients across three age bands. Overall 57% new and 52% existing patients was described as bed-bound however there was a difference in bedbound and housebound status between new and existing patients in groups 1 and 3. Established patients registered as bed-bound dropped by 4% in both groups when compared to new registrations, and the proportion registered as housebound increased by 8% in group 1 and 3% in group 3. This may suggest an improvement in function, particularly in the younger group and/or a higher mortality rate in the older bedbound group.

Overall 35 new (4%) and 44 existing (4%) nursing home patients were considered fully independent, whilst almost 90% required total help in both new and existing groups.

Table 4.7: Activity and dependency status of new and existing (point prevalence (PP)) nursing home patients

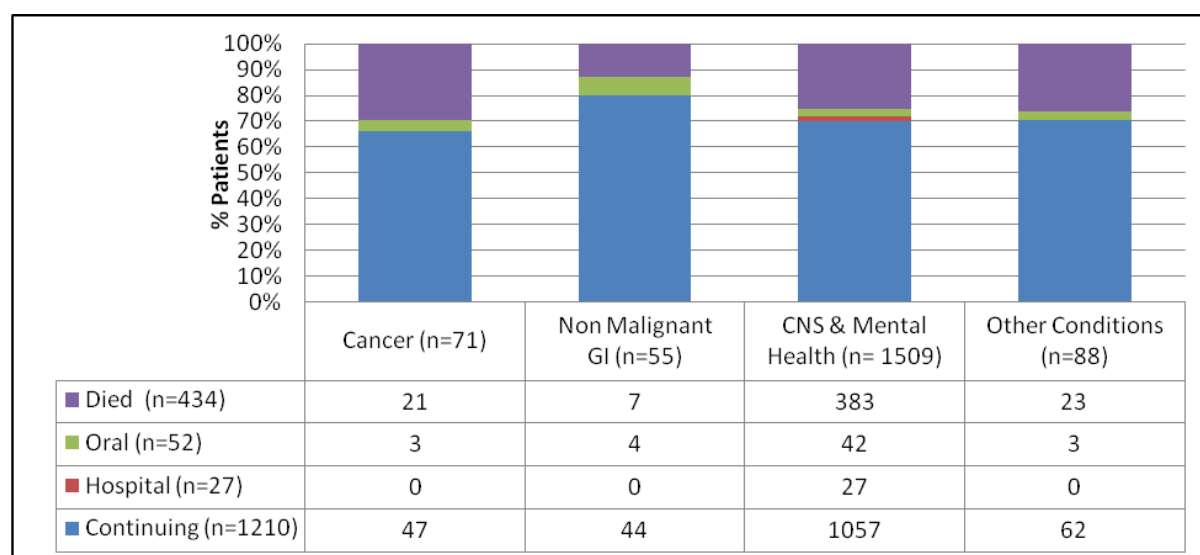
	Group 1 16-64yrs.		Group 2 65-75yrs.		Group 3 >75yrs.	
	New	PP	New	PP	New	PP
Activity level	n=200	n= 371	n=181	n=220	n=522	n=626
	%	%	%	%	%	%
Full Normal Activity	7	5	2	2	2	2
Limited Activity	32	32	27	27	21	22
Housebound	9	17	14	14	15	18
Bed Bound	49	45	56	54	60	56
Unconscious	3	1	1	2	1	1
Ability to Manage						
Independent	6	5	3	3	3	3
Requires Some Help	11	8	9	10	7	7
Requires Total Help	83	88	88	87	91	90

4.7.4 Outcomes

Figure 4.7 (B) shows the outcomes of 1723 nursing home patients who received HETF in 2009 (period prevalence) by diagnostic category. Two patients not included withdrew from feeding.

- One quarter (434) of all patients died, in the majority of cases from underlying disease (2 died from unspecified causes and 35 from complications unrelated to feeding). The highest mortality rate was seen amongst cancer patients (29%), the lowest in those with a non malignant GI condition (13%).
- 1210 patients (70%) continued with HETF.
- <2% (all CNS patients) went back to hospital.
- No patient refused feeding

Figure 4.7 (B): Outcomes of 1723 nursing home patients who received HETF in 2009 by diagnostic category



Key Points

- 88% of all patients had a CNS or mental health disorder.
- More than 50% of all patients were bedbound and almost 90% required total help. There appeared to be some improvement in function, particularly in the younger age group over time.
- Mortality rate (25%) primarily from underlying disease was high, particularly for the cancer patients. There were no deaths related to complications of feeding.
- Overall 70% patients were continuing feeding whilst 52 (3%) had returned to oral feeding and only 27 (<2%) were re-admitted to hospital.

This section demonstrates the success of HETF in supporting these vulnerable patients in the community who without enteral nutritional support would be at high risk of increased morbidity and mortality from malnutrition.

Section 5

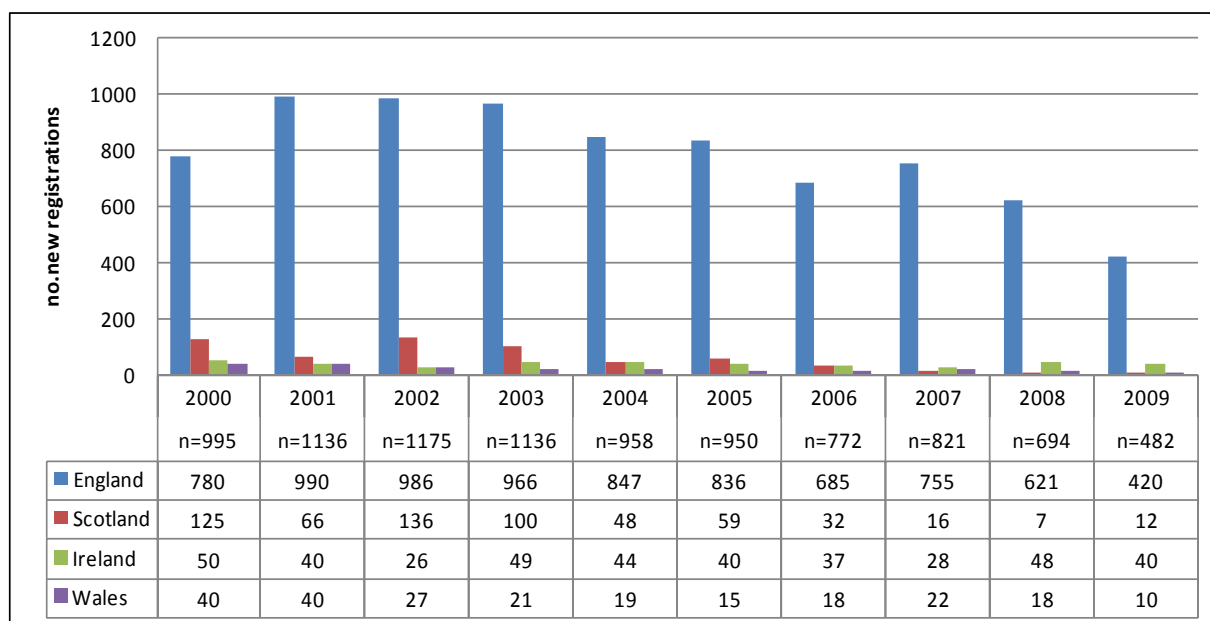
Home enteral tube feeding (HETF) in children

Amanda Hirst

5.1 New registrations, point and period prevalence

In 2009, 482 new patients were registered. Figure 5.1 (A) shows new registrations by UK constituent countries. A continued downward trend is seen in all countries since 2008 when overall, new registrations fell by 30% from 694 to 482 new children.

Figure 5.1 (A): New registrations for children receiving HETF in UK constituent countries from 2000-2009



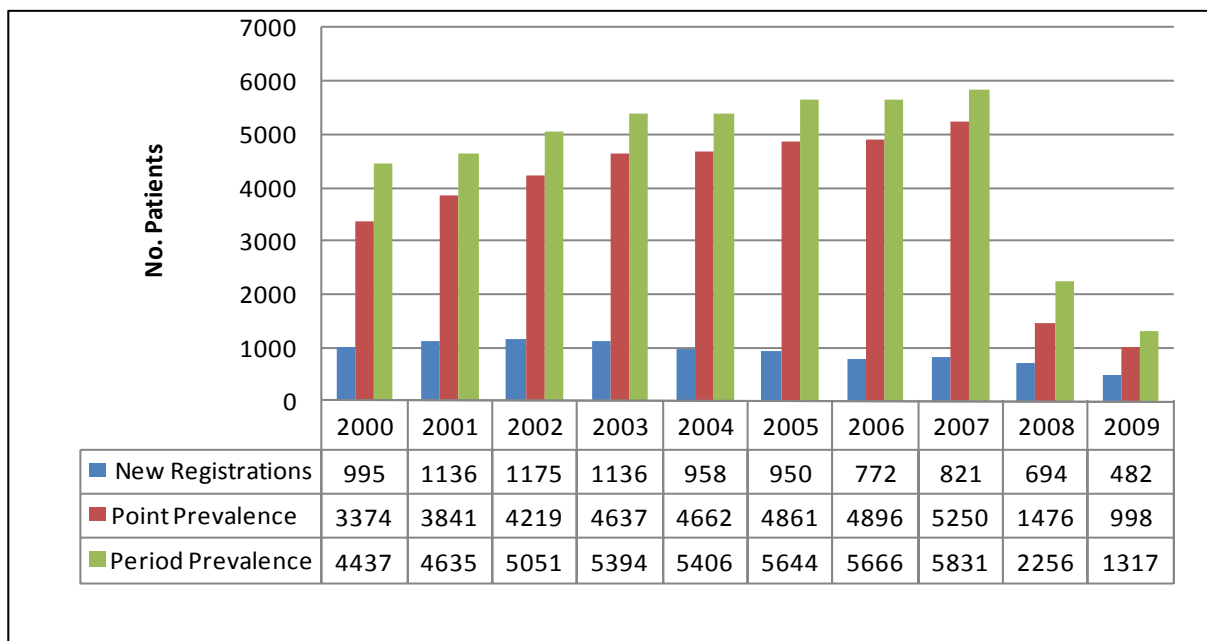
Point and Period prevalence are difficult to estimate as only patients who were updated in year have been recorded since 2008. (Figure 5.1 (B))

Despite anecdotal reports of sustained growth in children's home enteral feeding there was a reduction in all categories of data nationally collated via BANS. The reasons for this reduction were explained in detail in last year's report where it was concluded that the issue of reporters being required to obtain informed consent before submitting data to BANS had a major effect resulting in:

- Nutrition companies who previously undertook many of the new registrations ceased reporting because of confidentiality and consent issues.
- Time factors – dietitians and nurses have very large case loads and are unprepared 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.

- The BANS Committee accept that the Children’s HETF data is less complete than the adult HETF 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.

Figure 5.1 (B): New registrations, point and period prevalence of children receiving HETF in UK, 2000 – 2009



*Point & period prevalence figures for 2008 and 2009 show only the numbers of patients who were updated in year

Key Points

- Changes to the BANS patient data set have been approved by NIGB (National Information Governance Board) who have given their permission for NON CONSENTED DATA TO BE COLLECTED.
- Electronic reporting (e-BANS) was introduced in July 2010 which speeds up data entry, allowing reporting centres to enter new patients and update in real time. In terms of existing patients, only patients updated in the previous year will be included in the prevalence data. Further details about these changes are given in section 9.

5.2 Reporting Centres

The number of centres reporting new children decreased by 49%, dropping from 137 to 70 centres between 2007 to 2009 as the need for consent was introduced (figure 5.2 (A)). A similar pattern was seen across the UK constituent countries 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%) (see table 5.2).

Overall, the number of centres updating existing patients fell more dramatically by 67% (point prevalence) and 61% (period prevalence) over the same period. (Figure 5.2 (A)).

Figure 5.2 (A): Number of centres reporting new and prevalence data from 2000-2009

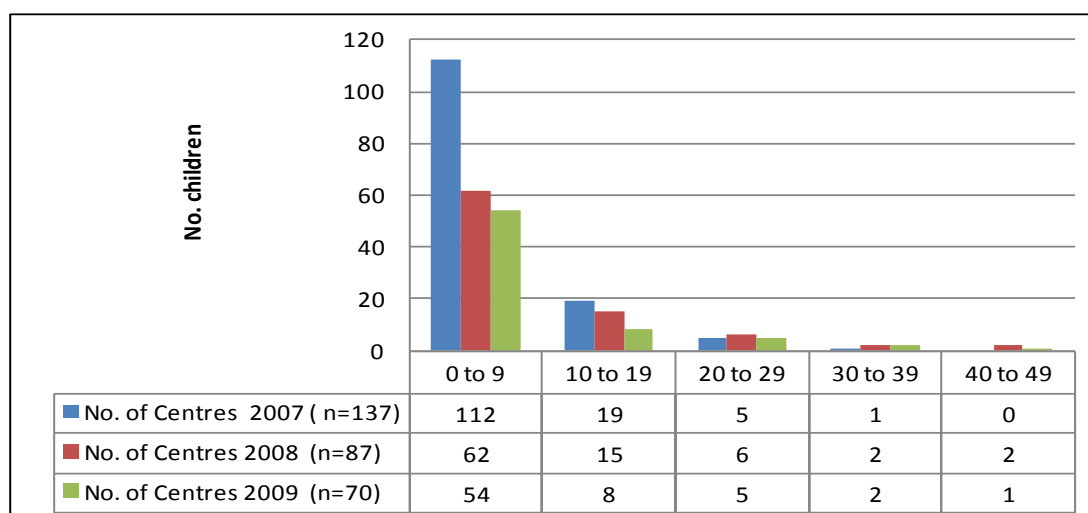


Table 5.2: Changes in number of centres reporting new children in UK constituent countries since 2007/08

	2007-08	2008-09	2007-2009
	n=137	n=87	n=70
England	-41	-16	-57
Scotland	-6	0	-6
N. Ireland	3	-2	1
Wales	-6	1	-5
UK	-50	-17	-67
Overall % reduction			
UK	-37%	-12.5%	-49%

Number children per centre: nine or fewer new children were registered by 77% (n, 54) of centres, of which 34% (n 24) registered only one child each. Despite the decline in reporting there was a similar distribution to 2007. (Figure 5.2 (B))

Figure 5.2 (B): Centres grouped by number of new children registered (2007-2009)



Key Points

- Given the reduction in number of centres failing to update existing data it is difficult to draw any meaningful conclusions from point and prevalence data. The remainder of this chapter will concentrate on new patient data only.
- BANS is making a concerted effort to reconnect with existing reporters who have stopped reporting and to recruit new reporters to join E-BANS.

5.3 Clinical Conditions

Figure 5.3 shows the percentage of new registrations grouped into 4 categories: *Cancer, CNS & Mental Health, Non-Malignant Gastrointestinal (GI) and other conditions*. Diagnoses within each of these categories are listed in table 5.3

Over the period 2000 to 2009, from the new registration data reported the proportion of new children with Cancer increased from 6.2% to 10.4% whilst. CNS & Mental Health dropped from 34.1% to 30.5%. There was little change in the proportion of the non-malignant GI ($\approx 14.5\%$) and other conditions ($\approx 45\%$) Cardiac and respiratory are now within this group rather than shown as separate categories as previously reported.

Key points

- Despite extensive work to include the majority of likely diagnoses there are still 141(29%) children’s diagnoses classed as ‘other’. A list of all diagnoses is given in chapter 9.
- There are many rare disorders that do not warrant their own category, however ‘other conditions’ listed are reviewed and the diagnosis categories

updated to fit demand. Where a child can fit into several categories the condition affecting their nutrition should be chosen and where possible fitted into the closest category to avoid large numbers being added to 'other than listed. More work is required to extend this to encompass all diagnoses.

Figure 5.3: Main HETF diagnostic categories for new registrations in 2000-2009

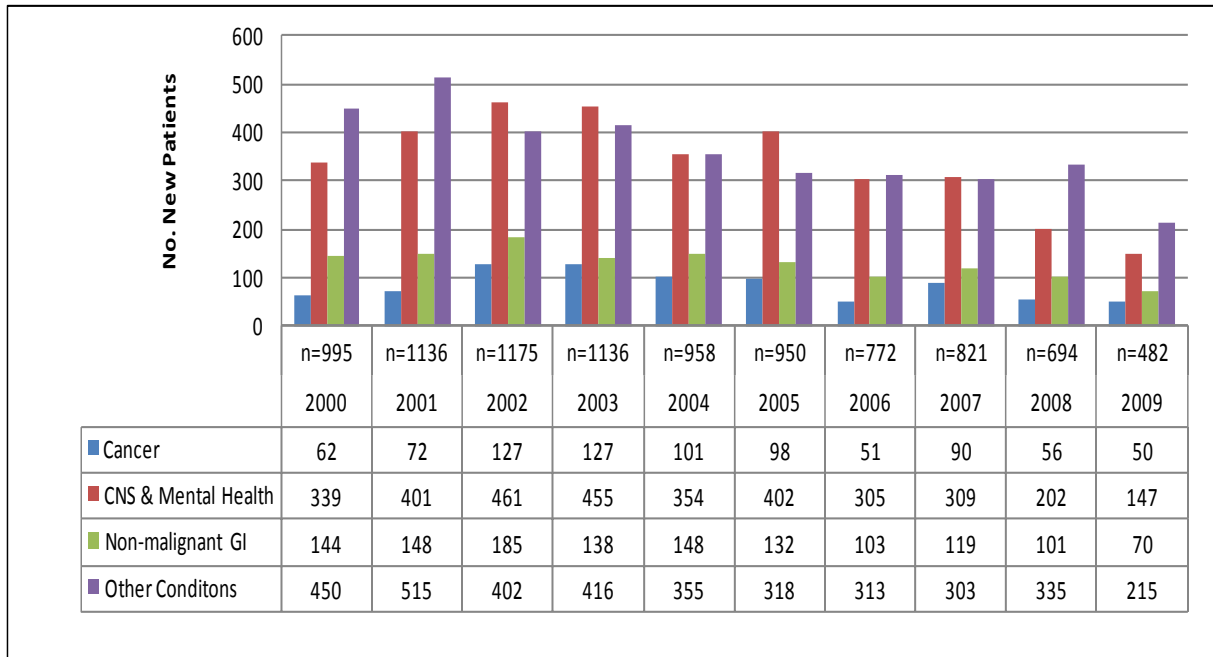


Table 5.3: Diagnoses of 482 children registered in 2009

CANCER- number of cases	50
GI Cancer - total	2
Cancer: Oesophageal	2
Haematology - total	17
Leukaemia	17
Head and Neck - total	9
Cancer: Head & Neck	8
Cancer: Oropharyngeal (incl orolaryngeal)	1
Other Cancers - total	22
elsewhere than stated	22

GI - NON MALIGNANT	70
Gut - total	21
Autoimmune enteropathy	1
Benign intestinal strictures	1
Crohn's Disease	8
Gastroschisis	1
Idiopathic intractable diarrhoea (infancy)	2
Post-necrotising enterocolitis	1
Pseudo-obstruction/motility disorders	4
Volvulus	3
Head & Neck - total	5
Cleft Lip/Palate	4
Pharyngeal	1
Hepatobiliary/Pancreas - total	3
Liver Disease	2
Pancreatitis - chronic	1
Totals	3
Oesophageal/Stomach - total	30
Dysphagia of unknown cause	5
Gastro-oesophageal reflux	18
Oesophageal Strictures (benign)	3
Other Oesophageal Disease (achalasia, fistula)	4
Surgery - total	1
Short gut/bowel syndrome	1
Other GI disease - total	10

CNS & MENTAL HEALTH - no. new cases	147
Brain Injury - total	7
Cerebral trauma	7
Congenital - total	84
Cerebral Palsy	39
Congenital malformation	26
Congenital Handicap	18
Down's Syndrome	1
Degenerative - total	6
Motor Neurone Disease	2
Muscular Dystrophy	4
Mental Health - total	2
Anorexia Nervosa	1
Learning Difficulties	1
Tumour - total	3
Cerebral tumour	3
Vascular - total	5
Cerebrovascular disease	5
Other CNS	40

OTHER CONDITIONS	215
Cardiac - total	32
Cardiac Failure	1
Congenital Heart Disease	24
Other Cardiac Disease	7
Inborn Errors of Metabolism - total	17
Renal Disease - total	4
Respiratory - total	25
Cystic Fibrosis	6
Other respiratory disease	16
Premature/Chronic Lung Disease	3
Miscellaneous - total	134
Auto Immune Diseases	1
Faltering Growth	8
Failure to thrive	56
Other un-named	69

5.4 Age distribution

The proportion of under 1 year olds gradually increased from 22% in 2000 to almost 53% in 2009. The greatest fall was in the age group 1-2 yrs falling by 20% from 34.5% to 14.5% over the same period. There were only small changes in all other groups. The increase in infants could reflect earlier and proactive nutritional support in this group but also a greater survival rate of neonates with demanding medical and nutritional needs (see figure 5.4 (A)).

Figure 5.4 (A): Age distribution (%) of new children from 2000 to 2009

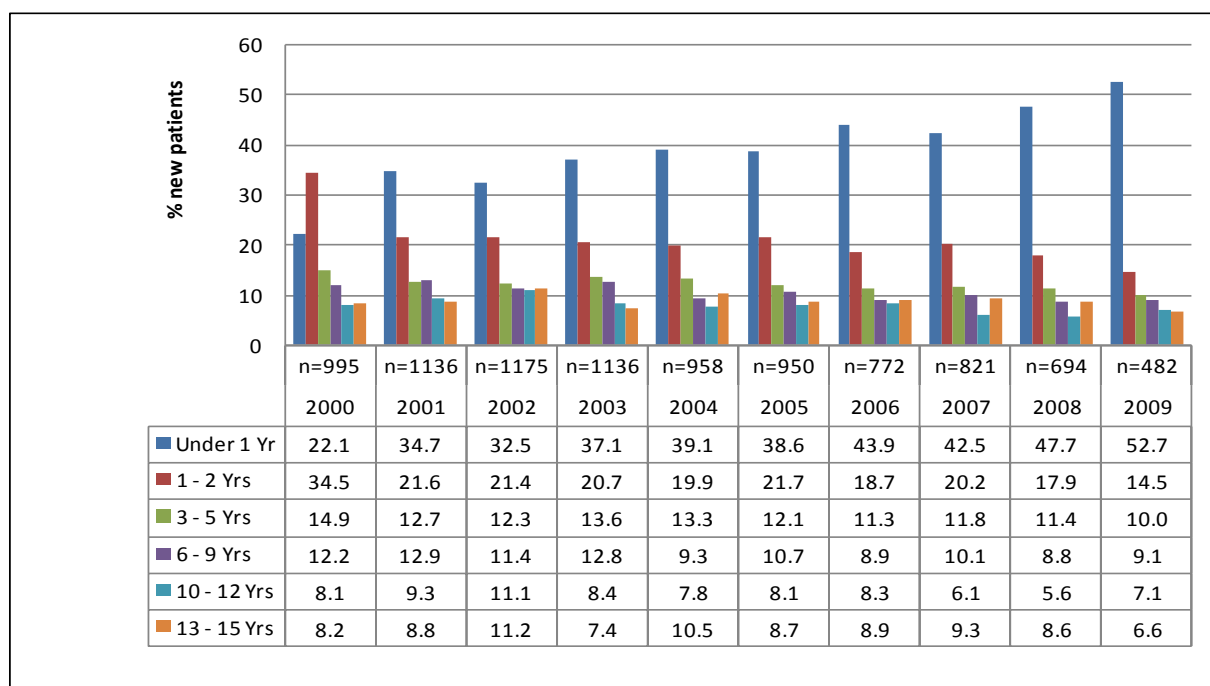
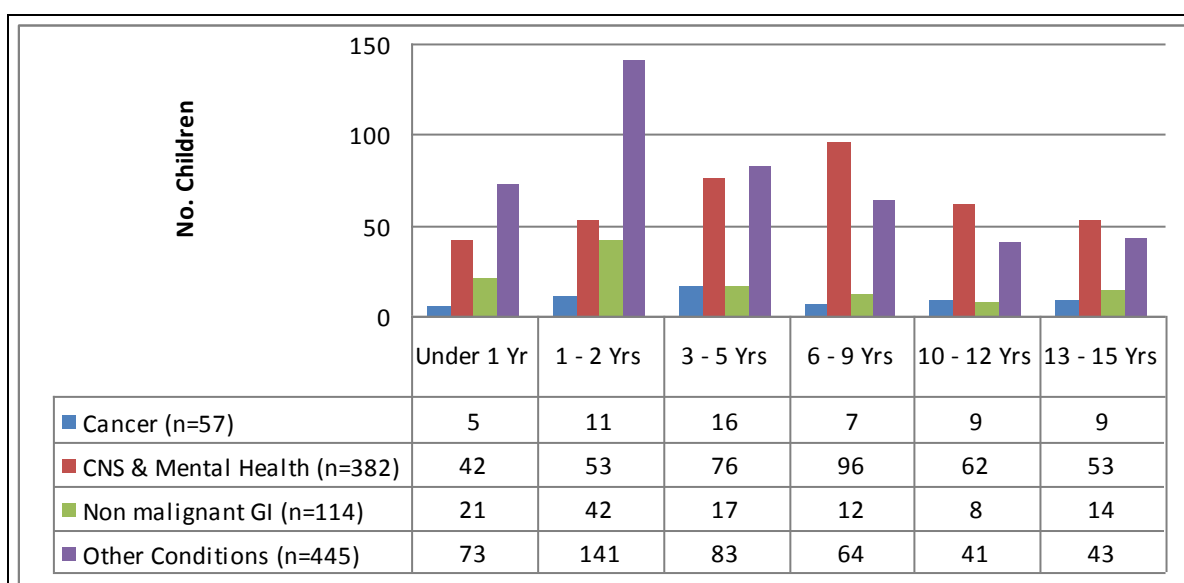


Figure 5.4 (B) illustrates the use of HETF specifically in children under 2 years with 'other diagnoses', capturing conditions often requiring short term feeding. Short term nutrition support can be valuable in slightly older children during periods of treatment of leukaemia or Crohn's disease. It is also noticeable that 'other than listed' is beginning to increase as a reason for feeding. This may be related to metabolic conditions where overnight feeds are required to maintain adequate blood glucose concentrations or avoid fasting.

Figure 5.4 (B): Diagnoses by age of new registrations in 2009



Key point

In 2009 over 50% of new children registered with BANS were infants <1 year old. This has risen year on year from 22% in 2000.

5.5 Reason for feeding & feeding routes

Reason for feeding: The main reasons for feeding for new children in 2009 were: to improve nutritional status (46%); faltering growth (23%); swallowing difficulties (21%); gastrointestinal disorders (4%) including: *fistula* (0.4%), *short bowel* (1.5%), *malabsorption* (1.7%) and *obstruction* (0.4%); anorexia (0.4%) and 'other' (5.8%). See table 5.4

Table 5.5: Reason for feeding (%) for new registrations in 2009

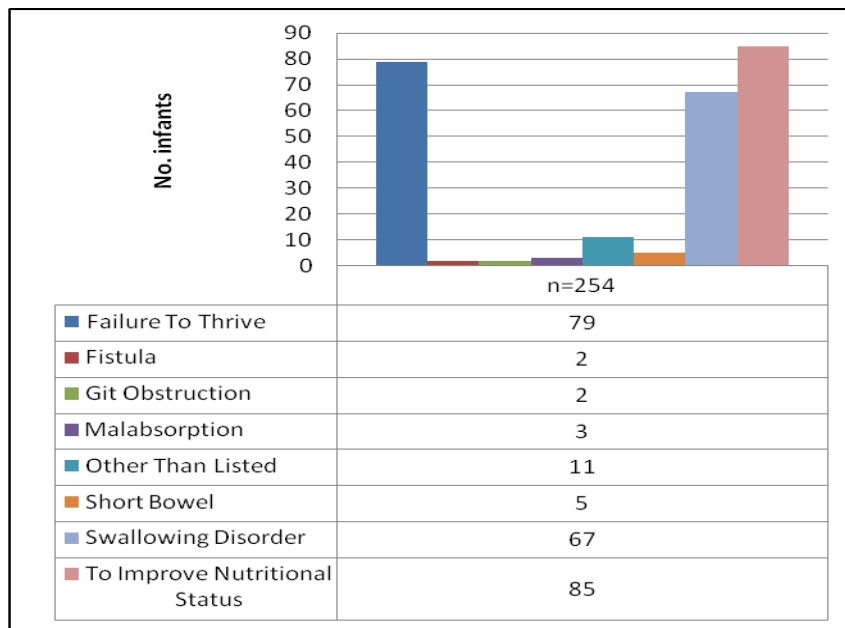
Reason for Feeding	2000 n=995	2001 n=1136	2002 n=1175	2003 n=1136	2004 n=958	2005 n=950	2006 n=772	2007 n=821	2008 n=694	2009 n=482
To Improve Nutritional Status	26.1	34.3	40.1	40.8	40.1	42.7	45.1	40.8	39.9	45.9
Faltering growth	35.4	33.2	28.6	31.3	24.6	24.0	23.1	29.6	27.1	23.2
Swallowing Disorder	23.3	20.4	22.3	17.7	24.0	21.8	22.4	20.6	23.2	20.7
Anorexia	1.7	1.3	1.1	2.1	1.7	0.8	0.1	0.9	0.4	0.4
Fistula	0.1	0.4	0.1	0.2	0.3	0.3	0.5	0.0	0.4	0.4
GI tract Obstruction	1.0	0.6	0.4	0.6	0.7	0.5	0.6	0.6	0.1	0.4
Malabsorption	3.1	2.7	2.2	1.4	1.8	2.2	1.0	2.1	1.9	1.7
Short Bowel	1.0	1.4	0.7	1.1	2.4	2.0	1.2	1.2	1.9	1.5
Unpalatability Specialised Feeds	1.7	1.6	2.0	1.3	2.1	2.9	1.2	1.8	1.6	0.0
Not Recorded	6.5	3.6	0.9	0.4	0.2	0.3	0.9	0.7	0.0	0.0
Other Than Listed	0.0	0.4	1.6	3.2	2.1	2.3	3.9	1.7	3.5	5.8

As infants (< 1 year) is the largest group of new registrations over the last year the reason for feeding in this group is shown in Figure 5.4 (A).

Since 2000 the proportion new children requiring nutrition support has risen by nearly 20%. This may in part be due to drop (12%) in those classed as 'faltering growth', supporting aggressive nutritional support rather than allowing growth to be compromised.

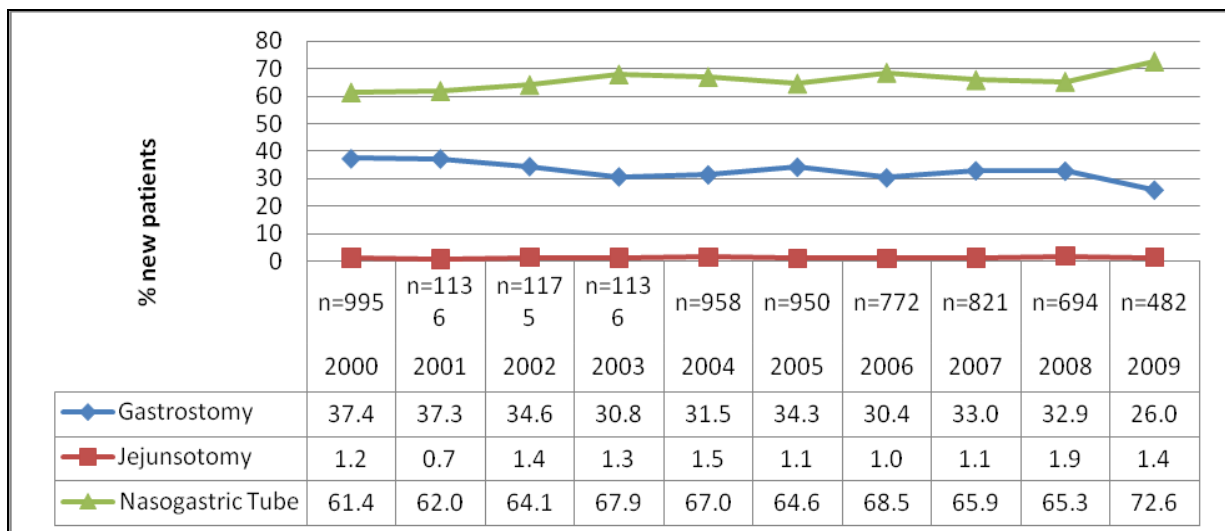
Swallowing disorder has remained fairly consistent at 20% which is likely to encompass many of the children with cerebral palsy within a CNS diagnosis category, but also conditions such as tracheomalacia, tracheo-oesophageal fistula, oesophageal atresia or various types of palsy listed under other diagnosis.

Figure 5.5 (A): Reason for feeding new registration infants in 2009



Feeding routes: Since 2000 to 2009 the ratio of naso-gastric to gastrostomy has increased from: 1.6:1 (2000), 2.3:1 (2006) reaching 2.8:1 (2009).

Figure 5.5 (B): Feeding routes for new children 2000-2009



In contrast to adult HETF (where 85% new and 90% existing patients receive gastrostomy feeding), the use of naso-gastric tube feeding is more prevalent in children; 72.6% of new registrations use a naso-gastric tube. 77% of new registrations are under 5 years of age demonstrating the frequent use of naso-gastric feeding in young children.

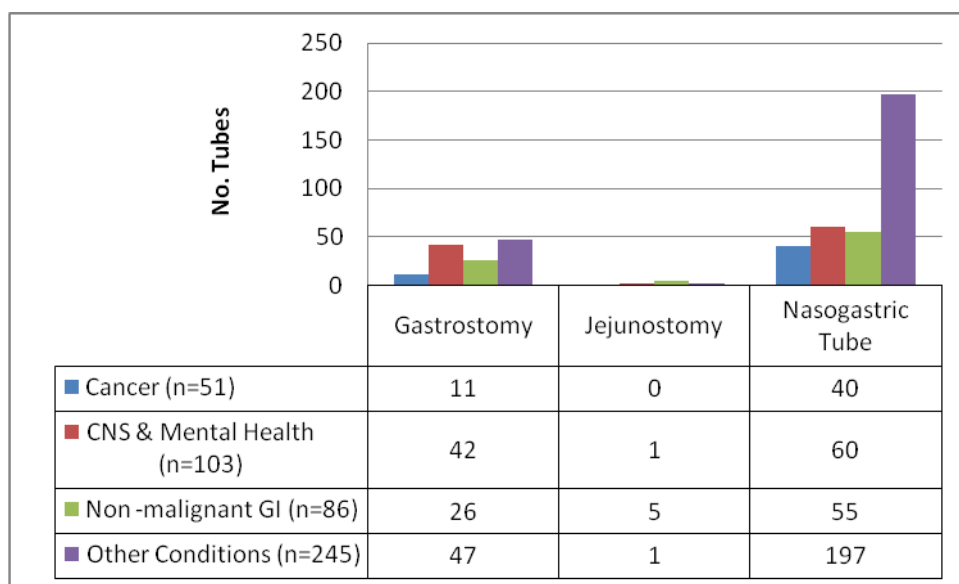
Naso-gastric feeding is accepted more readily in infants and children to ensure optimal nutrition and hydration. It allows time for medical diagnosis to be made,

surgical interventions to take place, for example in the case of many cardiac conditions, cleft lip and palate. Alternatively, it simply gives the child time to grow and develop normal oral skills and weaning to take place allowing better management of respiratory illness or gastro-oesophageal reflux.

Figure 5.4 (B) and 5.5 (C) gives an overall picture of feeding routes used to provide HETF to children and the medical diagnoses that have the greatest need throughout different age groups.

Children under 2 years within 'other diagnoses' capture conditions requiring short term feeding via a naso-gastric tube (see table 5.3). CNS and mental health show a gradual rise to 9 years of age when it is likely to also to see a transition from naso-gastric to gastrostomy feeding; that is reflected by a fairly even split in type of feeding route. Cancer and non malignant GI diagnostic categories include children who are fed across all ages, but a greater preference towards naso-gastric feeding reflecting short term nutritional support. There is a peak in the cancer category around 3-5 years supporting the short term nutrition support for leukaemia which accounts for 35% within the cancer category.

Figure 5.5 (C): Feeding routes by clinical condition for new children in 2009



There are 13 children registered with both gastrostomy and jejunostomy feeding. Associated clinical conditions are: *gastro-oesophageal reflux* (1), *cardiac disease* (2), *faltering growth* (2) *cerebral palsy* (1), *congenital malformation* (1) and 'other conditions' (6). Age range of this cohort is <1-15yrs. Jejunostomy is likely to be the main feeding route due to the presence of severe reflux and/or poor intestinal motility.

Key point

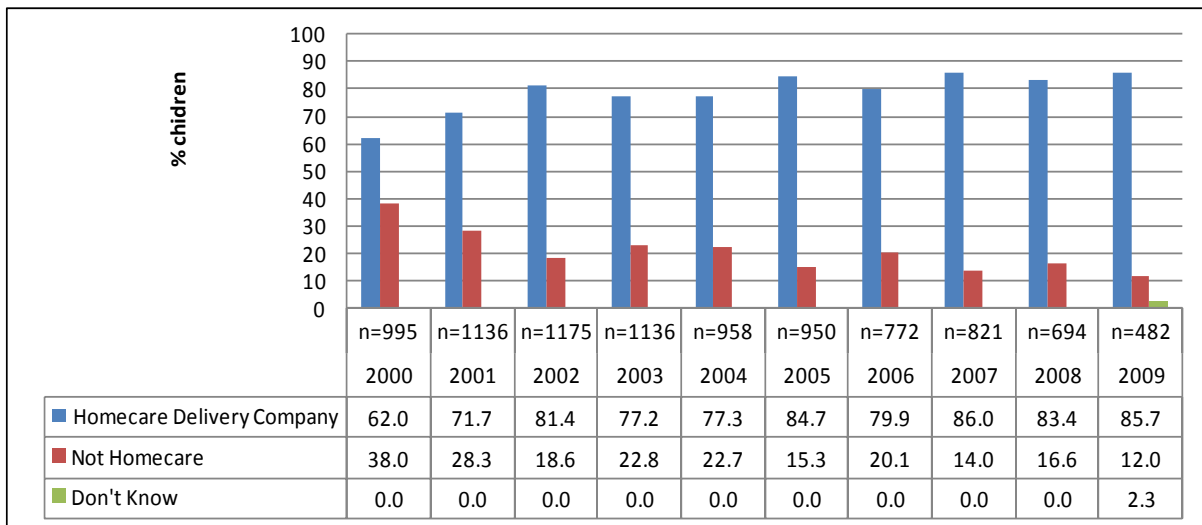
Anecdotal reports indicate that there is a rise in enteral feeding in paediatric specialist areas such as renal, gastroenterology and oncology; it would be interesting to capture this national data by raising the profile and benefits of e-BANS within such specialist paediatric groups.

5.6 Location and delivery of supplies

In 2009 two new children were documented to live in nursing homes and 2 in residential care, whilst 476 (98.8%) children lived in their own home, a slight rise of 2% since 2000. This is in stark contrast to the adult HETF population of whom 28% live in nursing homes and only 68% live in their own homes.

In 2009 Homecare companies were involved with families in 86% 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 (see figure 5.6).

Figure 5.6: Use of Homecare companies by new registrations 2000-2009



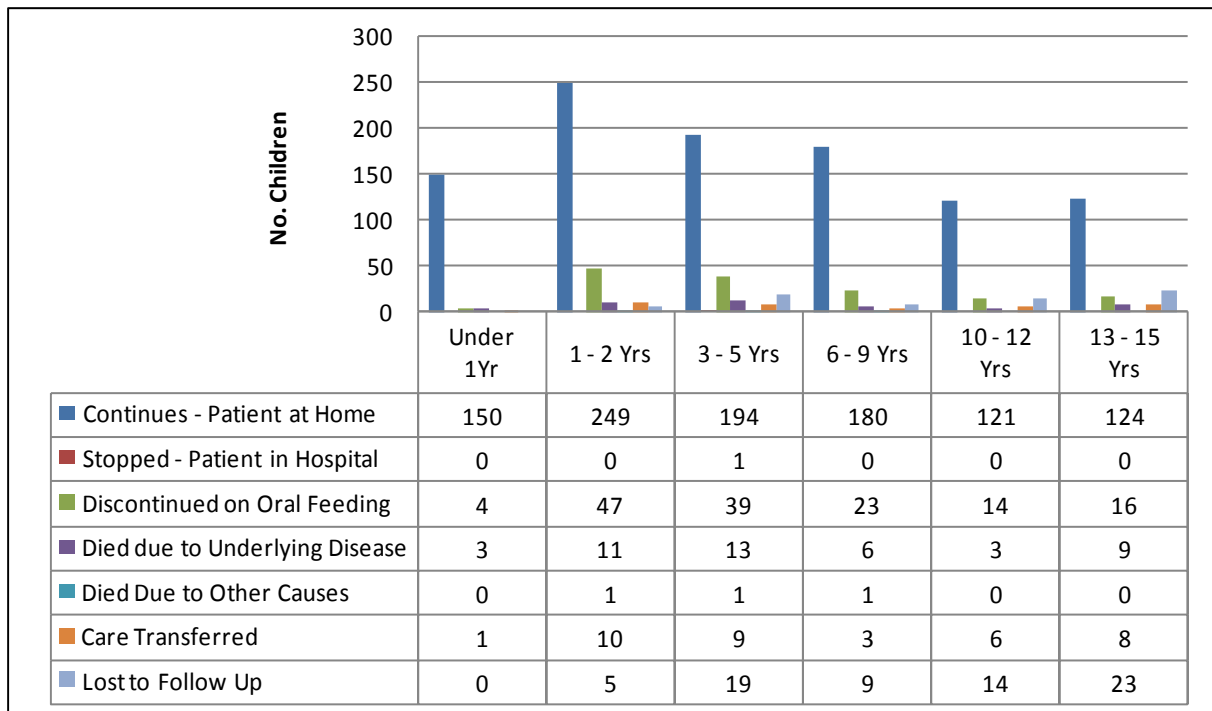
Key point

As with adults 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.

5.7 Outcomes

This snapshot of data for outcomes of children receiving enteral tube feeding during 2009 shows a positive picture of ongoing feeding, with 82% of registered children continuing to receive HETF, 11% returning to oral feeding and 4% dying from underlying or other causes. 63% of the children returning to oral feeding do so by the age of 5 years, confirmed by other data showing a peak of short term naso-gastric feeding in under 5 age group (see figure 5.7).

Figure 5.7: Outcome of new registrations by age in 2009



Key point

Overall HETF is a successful method of maintaining a child's nutrition predominantly in the home environment.

Section 6

Adult Home Parenteral Nutrition (HPN)

Dr Trevor Smith

6.1 New registrations, point and period prevalence

148 new adult HPN patients were registered with BANS during 2009, compared with 157 in 2008 and 138 in 2007; prior to this there had been a long period of stability at around one hundred new cases per year (see figure 6.1 A). Increasing numbers of registrations in England account for most of the growth in HPN cases. New registrations in Scotland have been stable for many years, which probably reflects the structure of HPN services in Scotland with an established managed clinical network. However, Scottish registrations fell to 6 patients during 2009, which is the lowest since 2000. New cases in Wales and Northern Ireland remained unchanged at 13 and 4 patients respectively (see figure 6.1 B). There were large reductions in reporting rates during 2008, which were described in the 2009 BANS report. During 2009 point and period prevalence have fallen again to 345 and 435 cases respectively; this represents a 50% reduction compared to 2007 and demonstrates the negative impact of the requirement for reporters to obtain consent from patients during 2008 and 2009 (see figure 6.1 A and C).

Figure 6.1(A): Number of new registrations, point prevalence and period prevalence of HPN in UK, 2000 -2009

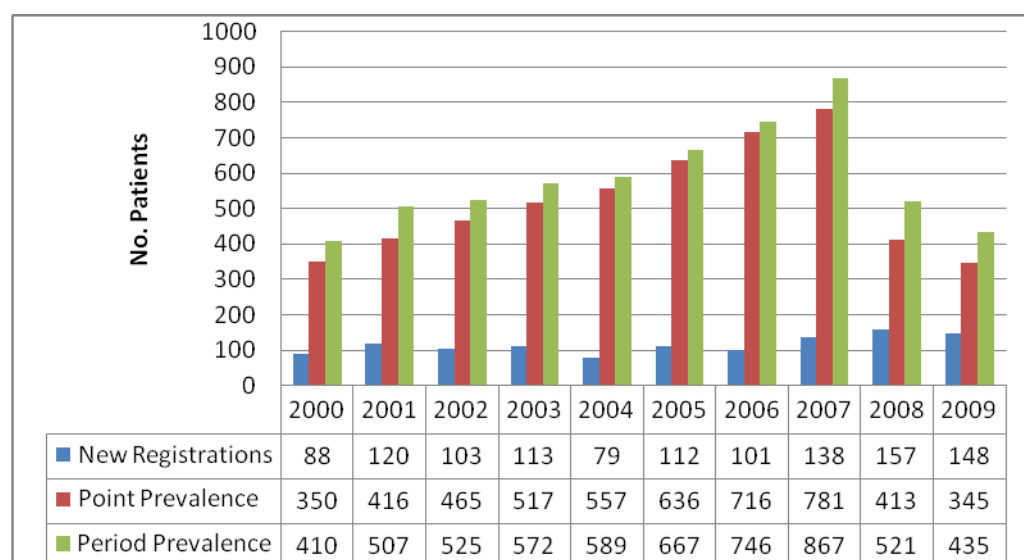


Figure 6.1 (B): New registrations in constituent countries of UK, 2000 – 2009

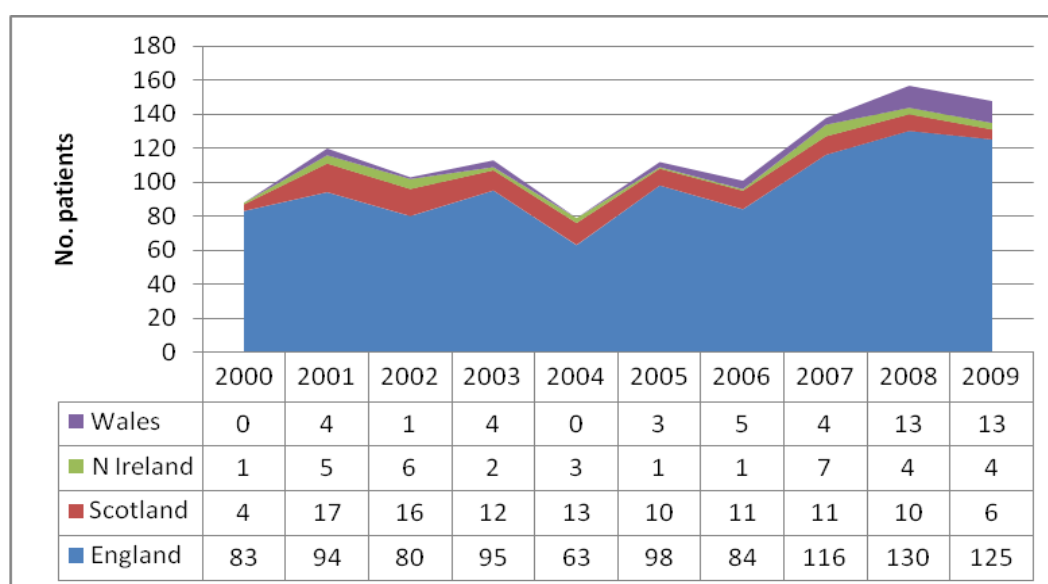
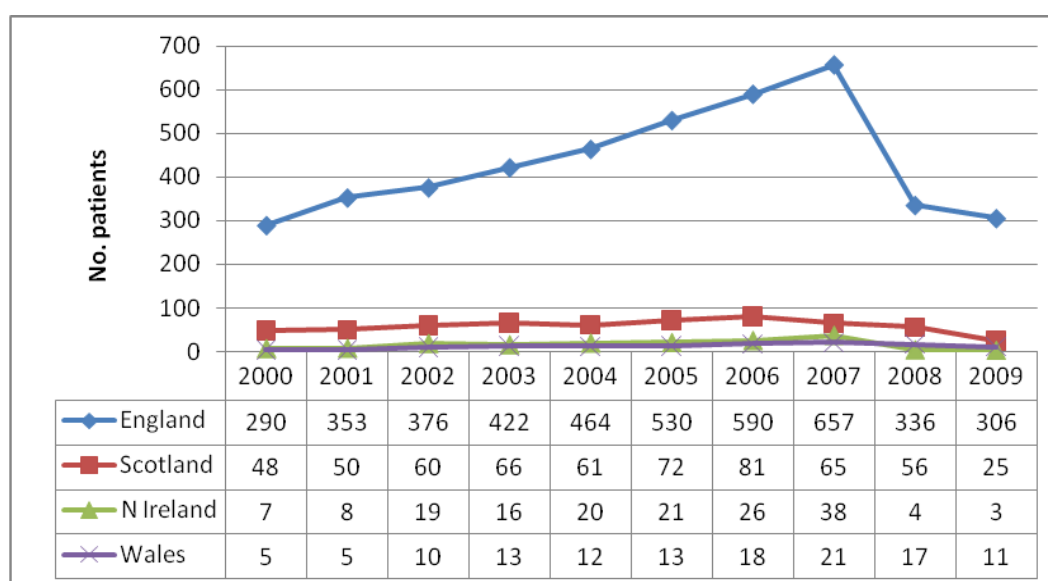


Figure 6.1 (C): Point prevalence in constituent countries of UK, 2000 – 2009



Expressed in terms of population size, the prevalence of new HPN cases was 2.4 per million of the UK population, with a period prevalence of 7 cases per million. The BANS committee recognise that these data represent considerable under-reporting, particularly of prevalence data, and therefore no further useful conclusions can be drawn (see table 6.1). 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.ncg.nhs.uk/index.php/key-documents/intestinal-failure-and-home-parenteral-nutrition/>. BANS is currently working with the Intestinal Failure Strategy Clinical Reference Group to formalise the reporting structure.

Table 6.1: Prevalence per million population* in UK and home countries in 2009 (2007 in brackets)

	New	Point prevalence	Period prevalence
UK**	2.4 (2.3)	5.6 (13.1)	7.0 (14.5)
England	2.4 (2.3)	5.9 (13.1)	7.1 (14.5)
Scotland	1.2 (2.0)	4.8 (15.1)	9.8 (16.1)
Wales	4.3 (1.4)	3.7 (7.1)	4.7 (7.5)
N. Ireland	2.2 (4.1)	1.7 (22.2)	2.2 (22.8)

*Sources: Population estimates, 2009: Office for National Statistics, www.statistics.gov.uk

(Population UK 61,792,000; England 51,810,000; Scotland 5,194,000; Wales 2,999,000; N Ireland 1,789,000).

Trends for new registrations and both point and prevalence are illustrated for UK constituent countries below, although under-reporting compromises the validity of the data (see figures 6.1 D-G).

- New registrations in England during 2009 (125 patients) were similar to 2008 (130 patients); new patient registrations grew by 8% compared to 2007 and 48% compared to 2006. Point and period prevalence fell to 306 and 366 patients respectively, a reduction of over 50% compared to 2007 (see figure 6.1 D).
- Scottish data are reported via the Scottish Managed Clinical Network and have shown a prolonged period of stability. However there was a fall in new registrations during 2009; given the relatively small number of patients this may indicate normal variation, although the reductions in prevalence data suggest under-reporting is also likely (see figure 6.1 E).
- Previous acknowledged under-reporting in Wales has been addressed through the Welsh HPN network and reporting of new patients is likely to be complete. However reporting of established patients has fallen which is likely to be secondary to under-reporting, as described in other UK constituent countries (see figure 6.1 F).
- In N. Ireland, the number of new cases has remained stable but the reporting of established patients remains very low, as described in last year's report (see figure 6.1 G). However personal communication from the NI service (Sarah-Jane Hughes) has confirmed that 25 patients received HPN during 2009.

Figure 6.1 (D): Trends in HPN in England, 2000 – 2009

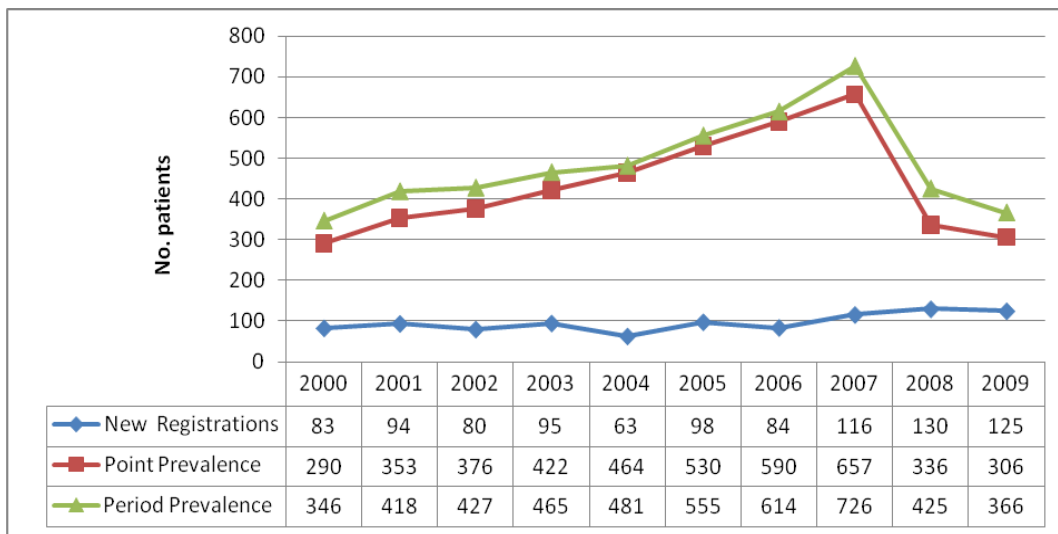


Figure 6.1 (E): Trends in HPN in Scotland, 2000 – 2009

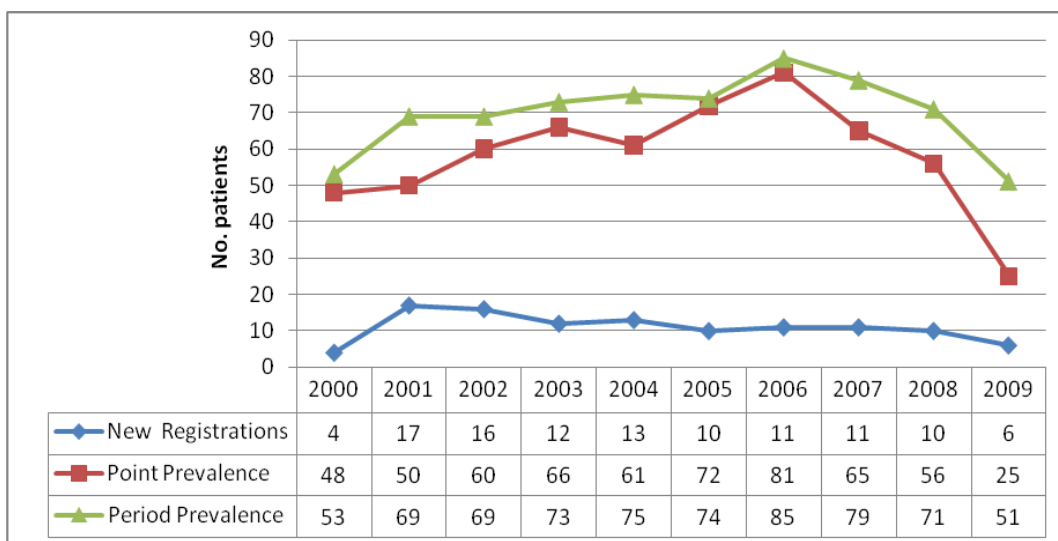


Figure 6.1 (F): Trends in HPN in Wales, 2000 – 2009

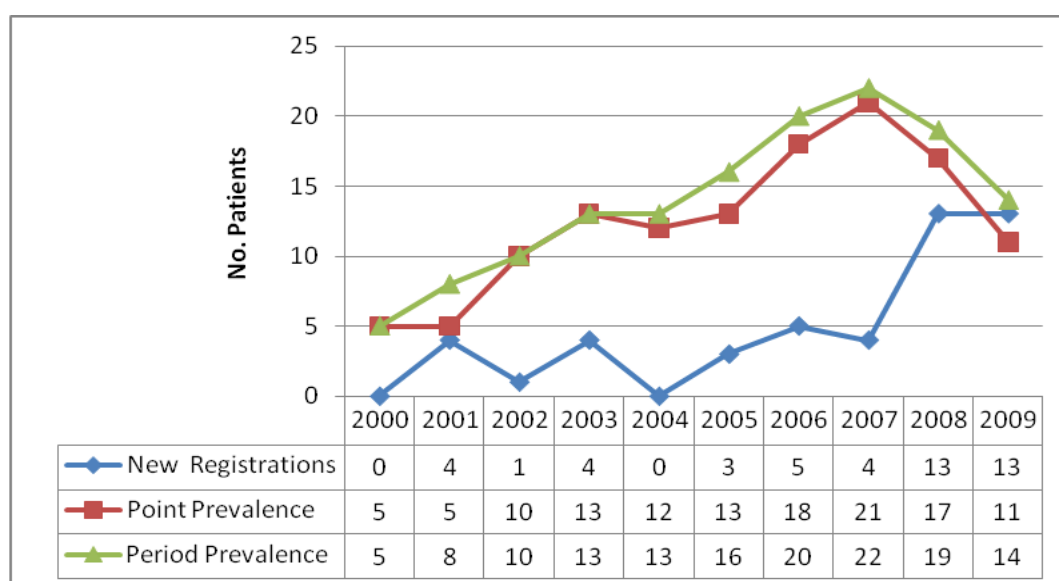
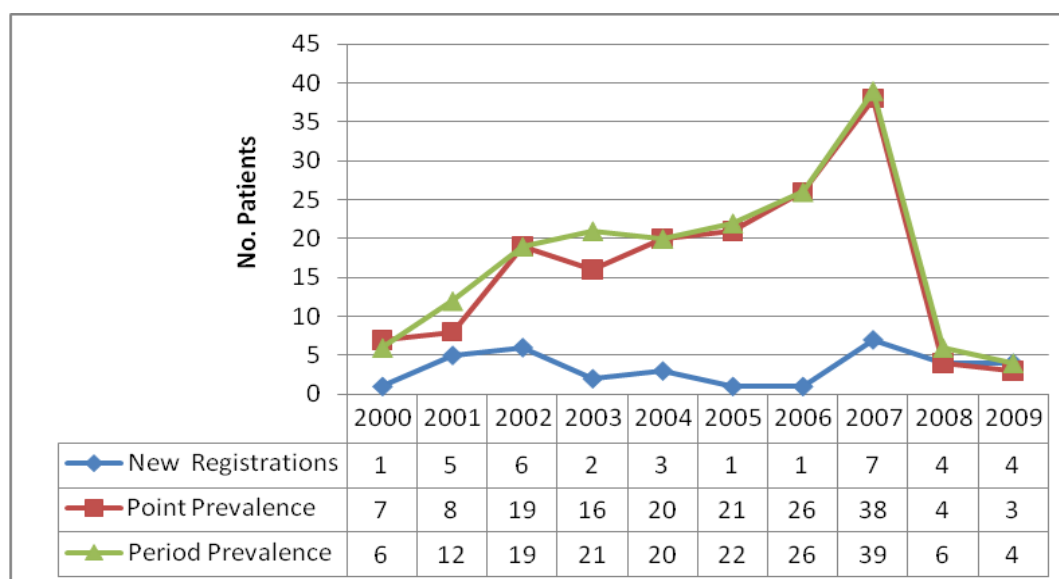


Figure 6.1(G): Trends in HPN in N Ireland, 2000 – 2009



6.2 Reporting Centres

27 centres registered new patients to BANS in 2009, an increase of 3 centres compared to 2008. The majority of these centres are located in England, although the committee recognises that several centres have not reported to BANS over the last two years (See figures 6.2 A and B). Point and period prevalence data were reported by 29 and 35 centres respectively, representing a reduction compared to previous years. This mirrors the reduction in reporting rates and is likely to be an indication of difficulties reporters have faced with patient consent. Despite these problems, the data accord with previous reports (see BANS report 2005) suggesting that there are still many centres managing very small numbers of HPN patients.

Figure 6.2 (A): Numbers of adult HPN reporting centres in UK for new registrations, point prevalence and period prevalence, 2000 – 2009

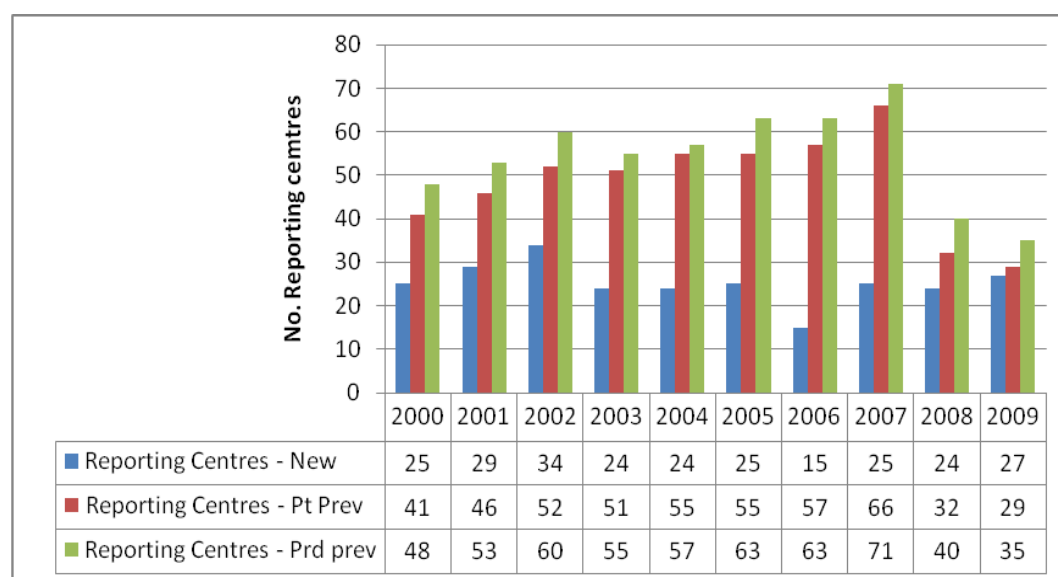
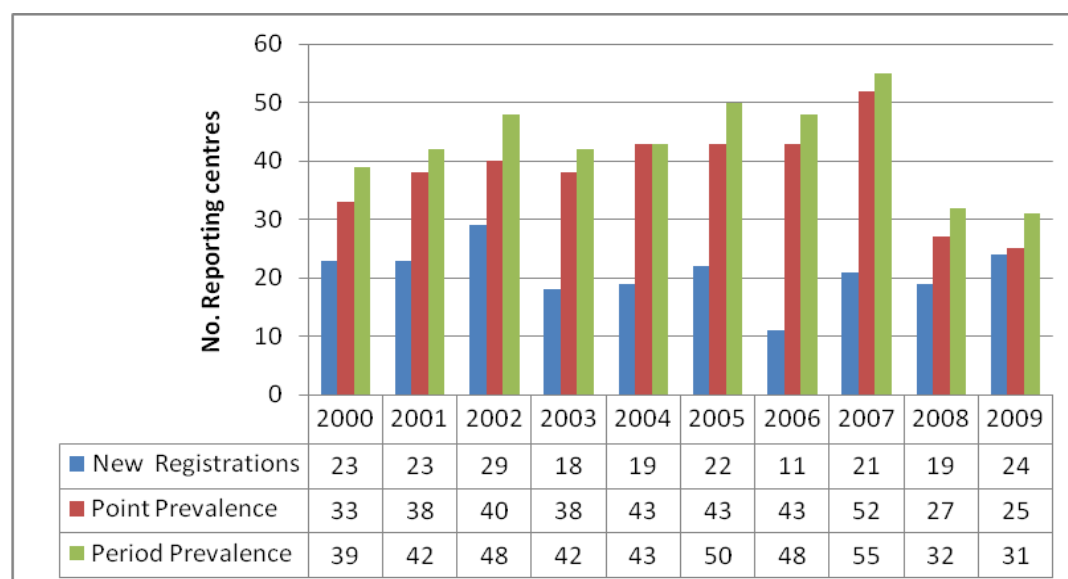


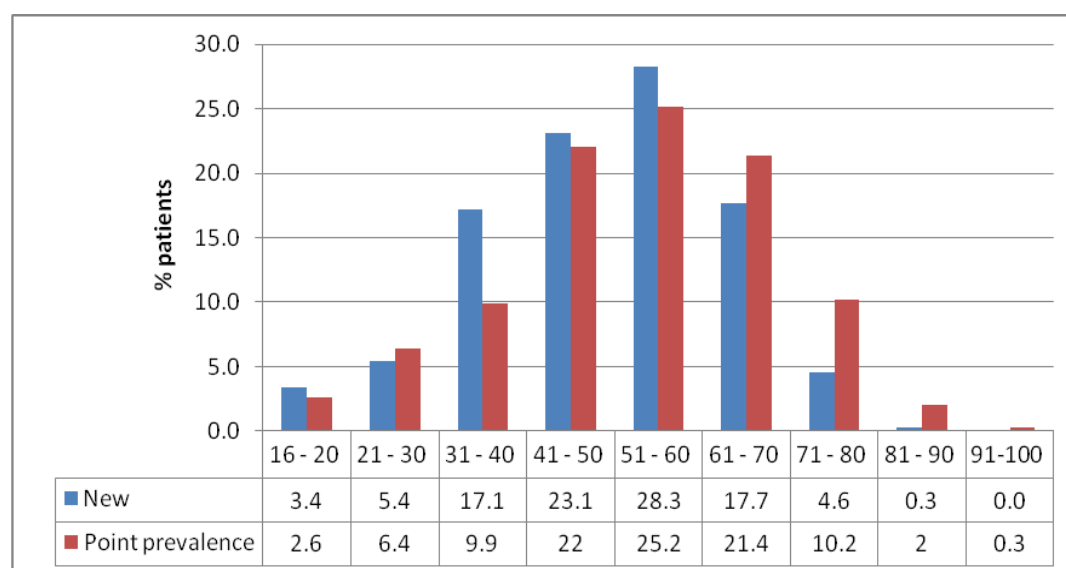
Figure 6.2 (B): Numbers of adult HPN reporting centres in England for new registrations, point prevalence and period prevalence, 2000 – 2009



6.3 Age distribution

The majority of HPN patients are aged between 31 and 70 years of age (86.2% of new registrations and 78.5% of established patients). The age distribution peaked at 51-60 years and less than 13% of patients established on HPN are over 70 years old (see figure 6.3)

Figure 6.3: Age distribution of Adult HPN in UK for new registrations and point prevalence, 2009



6.4 Reasons for HPN

Short bowel syndrome remains the commonest indication for new HPN patients (41.2%). Fistula is cited as the main reason in 18.2%, malabsorption in 14.2%, “to improve nutrition” in 7.4%, gastrointestinal obstruction in 7.4% and swallowing difficulties in 4.1%. Short bowel syndrome is also the main reason for HPN in established patients (55.4%). (See table 6.4)

Table 6.4: Reasons for Adult HPN, 2000 and 2009

	% New		% Point prevalence	
	2000	2009	2000	2009
Short bowel	40.9	41.2	61.4	55.4
Fistula	17.0	18.2	6.0	10.1
Malabsorption	12.5	14.2	14.6	14.8
Obstruction	9.1	7.4	6.3	7.5
To improve nutrition	11.4	7.4	4.8	4.6
Swallowing disorder	5.7	4.1	2.3	2.3
Other	3.4	7.5	4.6	5.3

6.5 Diagnoses and HPN

Crohns disease remains the leading diagnosis for adults established on HPN (point prevalence 30.4%); whilst this figure had been slowly falling the point prevalence of HPN due to Crohns disease increased in 2009 compared to 2004 - 2008. New registrations for Crohns disease increased during 2009 to 21.6%, having previously fallen to 17.2% in 2008, compared to 25% in 2000. Vascular disease is the other

major diagnostic category leading to HPN dependence, accounting for 18.9% of new registrations in 2009. Cancer, of all types, including leukaemias, accounted for 9.5% of new registrations and only 5.2% of point prevalence which, in contrast to Home Enteral Tube Feeding, represents a fall in comparison to the year 2000. Gastrointestinal cancers accounted for 4.7% 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 12.8% between 2000 and 2009). The proportion of newly registered patients with 'other gastrointestinal' diagnoses, which includes surgical complications, is increasing (6.8% in 2000 to 20.1% in 2009). However, the point prevalence has only increased by 3.1%, suggesting that many of these patients receive short term HPN. (See Tables 6.5 A & B).

Table 6.5 (A): Diagnostic categories of Adult HPN, 2000 and 2009

	% New registrations		% Point prevalence	
	2000	2009	2000	2009
Crohns	25.0	21.6	34.3	30.4
Ulcerative colitis	3.4	2.0	2.9	1.7
Ischaemia*	14.8	18.9	17.7	18.8
Radiation enteritis	5.7	3.4	5.1	4.3
Pseudo-obstruction	4.5	9.5	9.1	12.8
Systemic Sclerosis	3.4	0.7	2.9	2.9
Other...including Surgical complications	6.8	20.1	11.1	14.2
Cancer**	17.0	9.5	5.7	5.2
Total	81.8	87.8	90.9	91.3
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	2009
Numbers	120	131	147	156	160	175	196	213	117	105
%	34.3	31.5	31.6	30.2	28.7	27.5	27.4	27.3	28.3	30.4

6.6 Location, Ability to Manage and Activity level

The percentage of new registrations placed initially in a nursing home has remained very small (1.1% in 2000 and 3.4% in 2009) despite a rise to 10.1% in 2007. 93.2% of patients were discharged to their own home, with 3.4% discharged to unspecified locations. Amongst established patients (point prevalence), the number in nursing homes was slightly higher at 2.3% in 2009, compared to 0.7% in 2008; 96.2% of patients lived in their own homes. Newly discharged patients described as independent essentially remained unchanged at 52% in 2009, compared to 53.5% in 2008. Independence levels improve following discharge in established patients with 65% described as independent. Approximately 48% of new registrations require “some help” or “total help” but only 35% of established cases require such help. These figures are mirrored by activity data. Thus, 60.8% of new cases and 66.1% of established cases are described as fully active. Limited activity (new 35.1%; point prevalence 31%) and house or bed bound (3.4% and 2.6%) account for the remainder.

6.7 Access route and Administration of Adult HPN, 2008

Venous access was via an external catheter in 93.9% and subcutaneous ports in 6.1% of newly registered patients.

Commercial homecare companies provided for all new patients in 2009; their contribution to point prevalence has been steadily rising from 70.6% in 2000 to 91.3% in 2009. This suggests that the greater contribution to new patients is being carried through to established patients.

6.8 Outcomes for patients receiving HPN during 2009

435 patients received HPN and were registered with BANS during 2009 (period prevalence); 83.4% were still on HPN at the end of the year but only 6.9% had reverted to oral nutrition. 2.1% were in hospital, 3% were transferred to other centres (and no further outcome data were available) and the mortality rate was 4.4%. HPN was withdrawn in one patient.

Section 7

Paediatric Home Parenteral Nutrition (HPN)

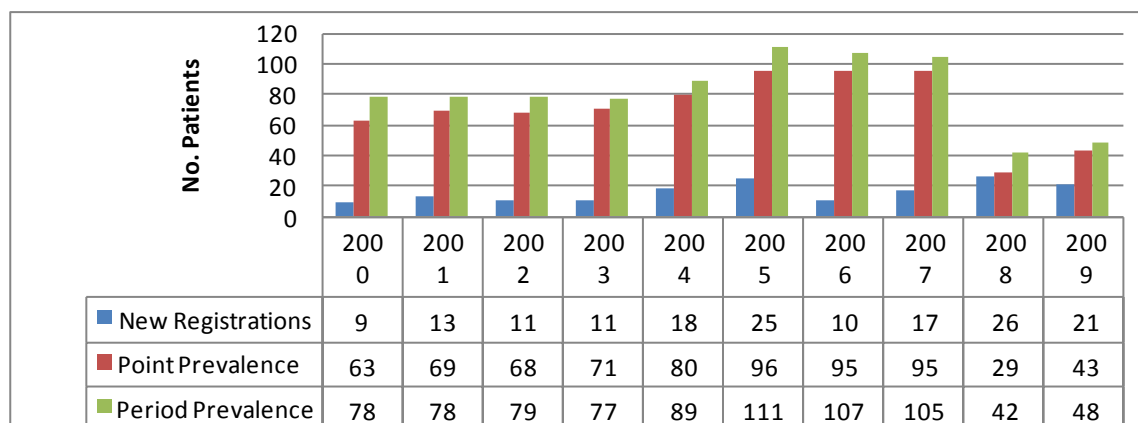
Dr Janet Baxter

7.1 New registrations, point and period prevalence

21 new children were registered with BANS during 2009, a 20% reduction on the previous year. During 2009 point and period prevalence have fallen to 43 and 48 cases respectively; this represents a more than 50% reduction compared to 2007 showing a similar trend to that of adult HPN.

Data from Section 8 of this report demonstrates that we are describing a fraction of the likely number of patients actually receiving treatment. Extrapolation of data supplied by the home care companies suggests that only a third of children discharged with HPN are reported to BANS. It is hoped that the relaxation of the need for consent will see reporting patterns back to the numbers seen in 2005-7.

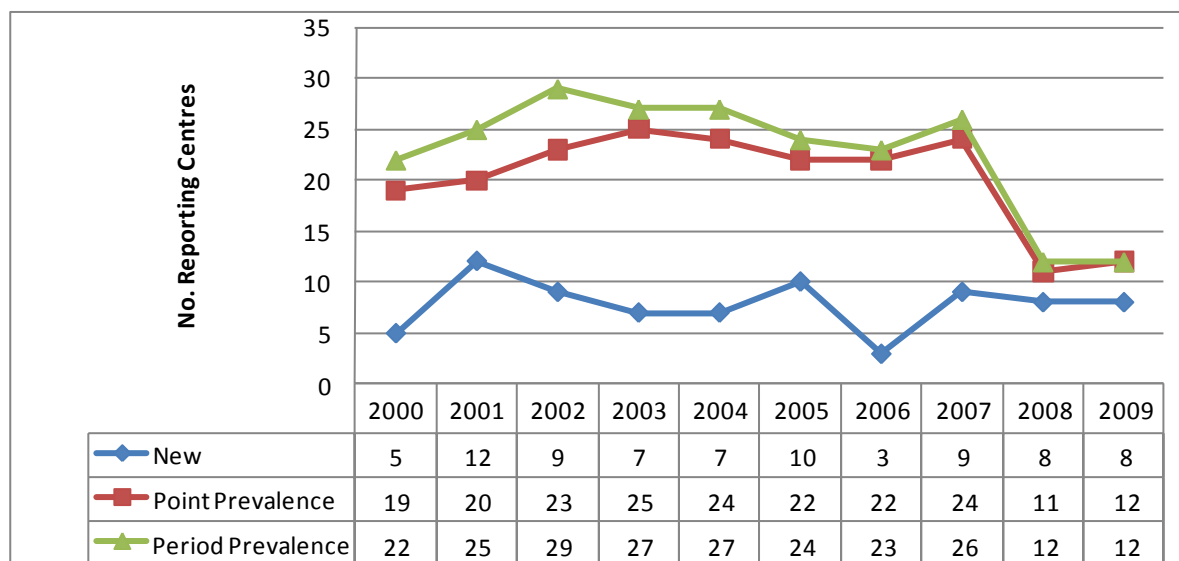
Figure 7.1: Number of new registrations, point prevalence and period prevalence of HPN in UK, 2000 -2009



7.2 Reporting Centres

Eight centres registered new paediatric HPN patients to BANS in 2009, similar to the previous year (see figure 7.2). Point and period prevalence data were both reported by 12 centres again similar to previous years.

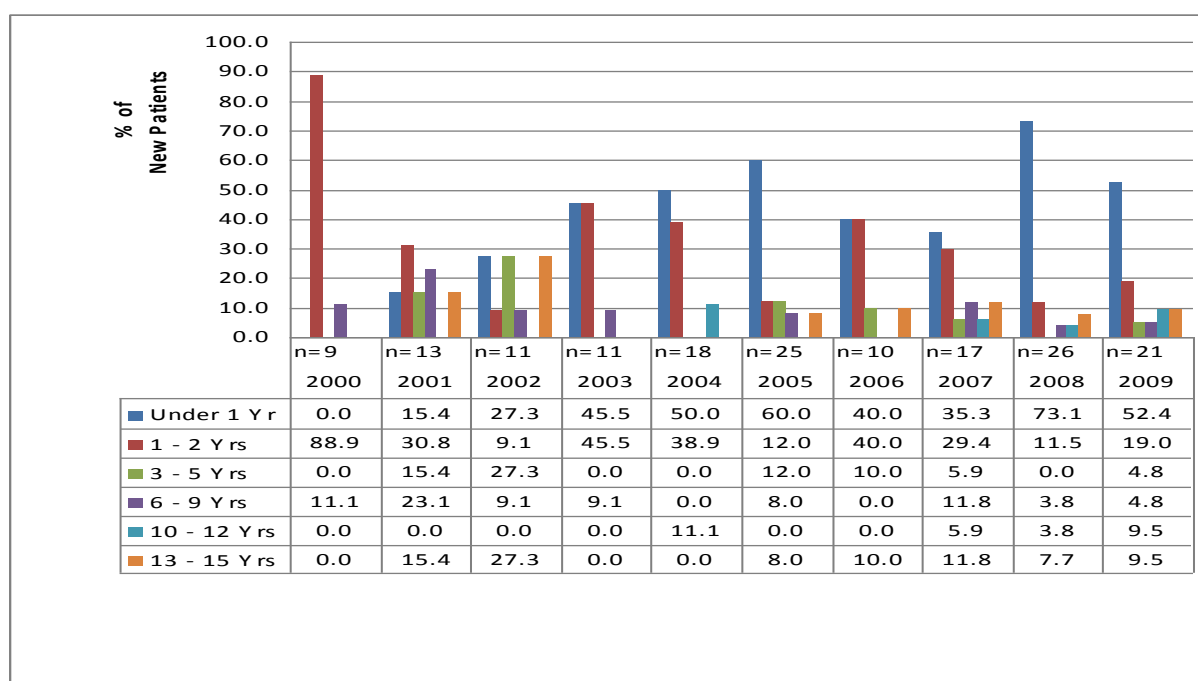
Figure 7.2: Numbers of paediatric HPN reporting centres in UK for new registrations, point prevalence and period prevalence, 2000 – 2009



7.3 Age distribution

Just over 70% of children on HPN are less than 2 years old.

Figure 7.3: Age distribution of paediatric HPN in UK for new registrations, 2009



7.4 Indication for HPN

The table below shows that the reasons for feeding children with HPN have changed over the past 9 years from short bowel and malabsorption to a range of other reasons including 'to improve nutritional status' (50% in 2008 and 25% in 2009).

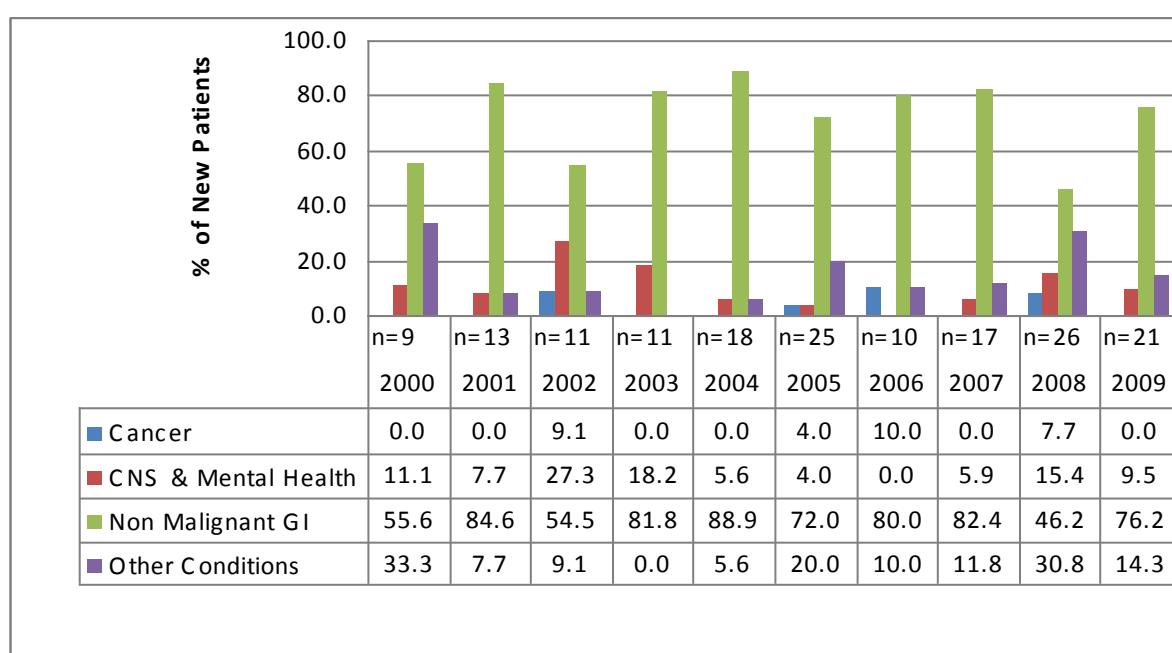
Table 7.4: Reasons for Paediatric HPN in new registrations 2000-2009

Reason for Feeding	2000 n=9	2001 n=13	2002 n=11	2003 n=11	2004 n=18	2005 n=25	2006 n=10	2007 n=17	2008 n=26	2009 n=21
Failure To Thrive	0	0	1	2	1	3	0	0	0	1
Fistula	0	1	0	0	0	1	0	1	0	0
GI tract Obstruction	0	2	1	1	0	0	0	2	1	1
Malabsorption	3	4	2	2	5	7	3	5	3	5
Other Than Listed	0	0	1	2	2	0	0	0	1	3
Short Bowel	6	5	2	4	9	10	7	8	8	6
Swallowing Disorder	0	1	3	0	1	0	0	0	0	0
To Improve Nutritional Status	0	0	1	0	0	4	0	1	13	5
Totals	9	13	11	11	18	25	10	17	26	21

7.5 Diagnoses and HPN

The predominant diagnostic category in children is non-malignant gastrointestinal diseases. This pattern has not changed much over the years contributing up to 85% of the diagnostic categories in 2004 and still as high as 77% in 2009. There were no reported cases of children with cancer on HPN reported in 2009.

Figure 7.5: Diagnostic categories of children on HPN, 2000-2009



7.6 Location of patients HPN patients

Since 2000, most of the newly reported children on HPN are discharged to their own home – this year one patient was recorded as at an ‘other’ location.

Table 7.6: Description of location of patients

% New										
Location	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009
	n=9	n=13	n=11	n=11	n=18	n=25	n=10	n=17	n=26	n=21
Other	0.0	0.0	9.1	0.0	0.0	4.0	0.0	5.9	3.8	4.8
Own Home	100.0	100.0	90.9	100.0	100.0	96.0	100.0	94.1	92.3	95.2
Residential Care	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	3.8	0.0
Totals	100	100	100	100	100	100	100	100	100	100

7.7 Access route and Administration of paediatric HPN, 2009

Venous access was via an external catheter in 85.7% and subcutaneous ports in 14.3% of newly registered children on HPN.

Commercial homecare companies provided for all but one of the 21 new patients in 2009. However the paediatric HPN patient data supplied by the homecare companies demonstrates (see Section 8) that this area of BANS data is significantly under reported. It is likely that the majority of paediatric HPN patients are supported by a home care company.

Section 8

Independently acquired data on home artificial nutrition in adults and children

Dr Janet Baxter

As with previous BANS reports we have obtained data from the home care companies (HCCs) who supply HETF and HPN to patients in the UK. The companies are each asked to provide point prevalence data, and once aggregated the data are compared with that provided by BANS reporters. This means that we can estimate the shortfall of patients reported to BANS and provide a more accurate reflection of patients receiving artificial nutrition support at home.

The table below shows the point prevalence at December 2009 of UK patients compared with the 2009 point prevalence reported to BANS as well as the estimated shortfall.

Table 8.1: The point prevalence of HAN – HCC acquired, from 2009 BANS data and the estimated shortfall.

2009 data	HETF		HPN	
	ADULT	PAED	ADULT	PAED
Total number supplied by HCCs	22 364	10 126	859	125
Point prevalence (BANS)	4 192	998	345	43
% use for HCCs from BANS	86.8	82.8	91.3	93
HCC number known to BANS	3 637	826	315	40
Estimated point prevalence	25 777	12 234	941	134
Estimated % shortfall	83.7	91.8	63.4	68

When registering a patient with BANS, the reporter documents whether a home care company delivers the artificial nutrition. Table 8.2 details the percentage of patients supported by HCCs.

Table 8.2: Use of home care companies – BANS data 2009.

	New (%)	Point prevalence (%)
Adult HETF	88.7	86.8
Paediatric HETF	85.7	82.8
Adult HPN	98.6	91.3
Paediatric	95.2	93

Section 9

e-BANS: An Update

Dr Trevor Smith

As outlined in Section 2, the BANS committee have worked closely with PIAG/NIGB to develop an 'exit strategy' that will not require reporters to obtain consent from patients. There have been some relatively small, but important changes to the patient code and reporters are now requested to submit:

- First part of the post code
- Year of birth
- Last 4 digits of the NHS/CHI number.

These data produce a pseudonymised code and NIGB have provided written confirmation that reporters are not required to obtain consent (this letter is available for all reporters to view at www.e-bans.com).

The submissions to PIAG/NIGB have run in parallel with the development and introduction of electronic reporting through e-BANS. We have received very positive feedback from reporters using the website and have updated the reporting tool following several meetings with reporters at BAPEN conference and elsewhere. Recognising the problems encountered by reporters with consent over recent years, BANS has now re-launched a new and updated website: www.e-bans.com. This allows reporters to:

- Register and update patients in real time i.e. as changes occur
- Update patients who have been registered or updated since January 2009 (patients registered prior to 2009 who have not been updated will be removed from the database)
- Re-register patients whose updates have lapsed over the last few year – this is optional although re-registering them will make a significant contribution to BANS

e-BANS reporters are able to download an 'individual patient report' to keep on file; this will also support reporters to identify patients from the pseudonymised code and match them to local records. Importantly, reporters are also able to generate local reports directly from the e-bans website. Registration and log-in details can be obtained from bans@streets-heaven.com and a detailed user guide is also available to download from the website.

Section 10

Provision of Home Enteral Tube Feeding (HETF): a national survey

Ann Micklewright

10.1 Introduction

In 2003 BANS completed a national survey about the provision of services for Home Enteral Feeding in the UK. The survey showed a number of shortcomings, in particular, around insufficient staff to manage the patients, inconsistent standards of care and difficulties in financing ancillary equipment. (Jones et al. 2005).

It was decided to repeat elements of this survey with the aim of reviewing the infrastructure of HETF in 2010 from an organisational, clinical and financial perspective and identifying any changes that had taken place since 2003. At the same time the committee wished to evaluate an electronic survey package which would help design, distribute and then analyse and summarise the data which could be used for any future BANS projects.

10.2 Method

The survey was designed using the on-line package 'SurveyMonkey' (www.surveymonkey.com). Given that dietitians play a major role in the organisation and management of HETF, the survey was circulated via an electronic link through the British Dietetic Association (BDA) Dietetic Managers Network and the PEN Group (Parenteral & Enteral Nutrition Group of the BDA). A total of 500 electronic questionnaires were distributed throughout the UK.

The summarised data from SurveyMonkey was extremely well laid out and the tables and comments were easy to follow. The number of respondents who either answered or skipped the question was recorded. Where respondents were asked to expand on their answers these were listed and later 'themed' by the author. However, there were a number of duplicate entries which had to be removed from the full data set resulting in the need for the summarised data to be re-adjusted.

10.3 Results

Question 1: I am completing the survey for:

76 dietitians logged on to the questionnaire (15% response rate). There were 65 organisations named, some of whom completed the survey two or more times providing the same answers. Six did not give their organisations' names (these data were checked and none appeared to be duplicated). As a result 36 centre's entries were removed due to: duplication (20) or lack of responses to any questions (16). Therefore 60 dietitians from 40 centres submitted data for inclusion in the analysis.

Centres were classed as reporting: *children only (4)*; *reporting children and adults (18)*; *reporting adult only (18)*.

Questions 2- 5: How many adults and children are on HETF today and were fed during 2009?

Four separate questions attempted to determine the point (day of answering survey) and period prevalence (during 2009) of both adult and children’s HETF in 2009. Only 46 respondents answered each of the 4 questions.

Point and period prevalence data for both adults and children are shown in table 10.1. Numbers were either actual or estimated. The number of adult patients per organisation ranged from 6-386 and children 1-249. For both adults and children 11% and 5% of organisations respectively did not know the point prevalence, and the proportion of ‘*don’t knows*’ was higher for period prevalence at 39% and 27%.

Table 10.1: point and period prevalence of adult HETF

	ADULT HETF						CHILDREN'S HETF					
	Point Prevalence			Period Prevalence			Point Prevalence			Period Prevalence		
	Actual	Estimate	Total	Actual	Estimate	Total	Actual	Estimate	Total	Actual	Estimate	Total
No. Patients	2636	1540	4176	1379	2120	3499	1140	226	1366	741	303	1044
Range			6-386			1-252			0-219			1-249
Responses n.	20	12	4*	9	13	14*	17	4	1*	9	7	6*
%	56	33	11	25	36	39	77	18	5	41	32	27
* respondent answered 'don't know'												

Question 6: What training is given prior to discharge and who is mainly responsible?

Table 10.2 shows ten tasks and identifies the HCP (Health Care Professional) responsible for training the patient to undertake them. (The number of responses to each task is shown in the last column). Ward and company nurses tended to focus on feed administration, access routes, personal care and hygiene, whilst ward dietitians concentrated on feed and fluid requirements, ordering supplies of feed and equipment and problem solving. Nutrition nurses and HETF dietitians also featured and were responsible for similar elements of training as their professional colleagues.

Eight respondents identified a range of other tasks, for example: ward or company nurses taught patients how to administer medicines via their tubes; dietetic assistants were listed as undertaking training regarding administration of feed and how to order supplies.

Table 10.2: HCPs responsible for training HETF patients prior to discharge

Answer Options	Ward Nurse	Company Nurse	Nutrition Nurse	Ward Dietitian	HETF Dietitian	Response n.
Feeding regimen & fluid requirements	1	1	0	30	2	34
Administration feed & fluids	10	10	1	11	1	33
Use of feeding pump	6	20	1	4	2	33
Flushing tubes	13	13	4	2	2	34
Care of enteral tubes	8	15	4	2	2	31
Care of stoma site	9	15	4	2	2	32
Hand washing/hygiene techniques	14	11	3	0	2	30
Passing NG tubes	9	3	5	0	1	18
Mouth care	21	6	2	0	0	29
Ordering supplies	3	6	1	16	6	32
Problem solving	5	7	1	15	7	35

Question 7: Is written information given to back up training?

36 respondents said they gave written information to back up training; only two did not. All 36 described the information given:

- Complete Nutrition Company information packs which covered the whole spectrum of feeding issues.
- Information prepared locally by HETF services (or in conjunction with Nutrition Companies) which included daily feeding and fluid regimens, hygiene, feed storage, use/cleaning of syringes, use of giving sets, taking medication via feeding tube; other written information as appropriate e.g. how to bolus feed using a syringe, gastrostomy aftercare checklist.
- Some services used booklets with inserts to enable them to tailor information to meet patient's needs.
- Most gave trouble shooting instructions and contact details.

Question 8: Which health care professionals (HCPs) are involved in the care of the patients once they are discharged from hospital and how much input do they have?

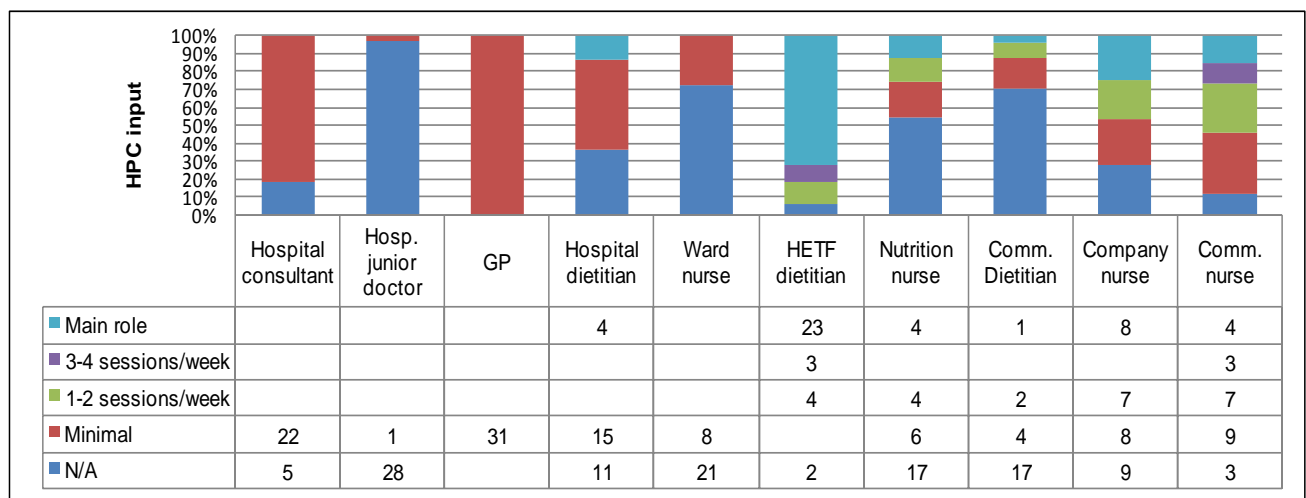
Figure 10.1 identifies the amount of time given by each group of HCPs. This was the main (full time) role for specialist HETF dietitians (23) and some hospital dietitians (4) and company (8) community (4) and nutrition nurse specialists (4). The input from medical staff and ward nurses was minimal or not applicable.

A number of respondents said that they found this question difficult to answer as it depended on individual patient need. For example some clients might need a community nurse to visit every day to give medicines, set up feed etc. whilst others would not. For patients with learning difficulties all of the above were involved but the frequency depends on individual factors.

Not all HETF patients were under the care of a consultant as this depended on the individual's diagnosis. For instance there was involvement of hospital consultants with head and neck cancer patients which was more than minimal but less than once a week. Children were also seen by physicians once, twice or three times a year, but definitely not weekly.

Other staff involved, included health visitors, speech and language therapists, physiotherapists, specialist nurses/dietitians (paediatric, renal, cystic fibrosis etc.) and dietetic assistants.

Figure 10.1: HPCs involved in HETF once patient is discharged home



Question 9: Do you consider the level of staffing appropriate? If NO, describe briefly what you need

14 out of 33 responding dietitians (42.5%) felt they had sufficient staff, 3 (9%) did not know and 16 (48.5%) answered 'No'.

Shortfalls were around:

- Increased turnover from 45-75% in 5 yrs without extra support.
- Patient numbers more than doubled over the past 4 years with no increase in funding, and as a result 3 monthly patient review targets were not being met.
- Only funded for a few hrs/month for HETF but need at least 1.0 WTE to really effectively manage the caseload as the consultant only sees children every 3-4 months.
- Only part time posts for nurses and dietitians with no out of hours cover.
- Poor access to company nurses in remote areas; lack of community nutrition nurses to give advice e.g. stoma site problems.
- Lack of nutrition nurses in some organisations

HETF services require:

- HETF co-ordinator to liaise between hospital and community staff.
- More dietetic assistant time at higher grade to help with case load management, routine checks and visits where appropriate, to enable the dietitians to concentrate on clinical care.
- Beneficial to have a small team of appropriate health professionals looking after HETF clients in the community which might comprise a community nutrition nurse and specialist HETF team.
- More dietitians, nutrition nurses, district nurses and training nurses.

Question 10: Do you have written standards/guidelines for HETF?

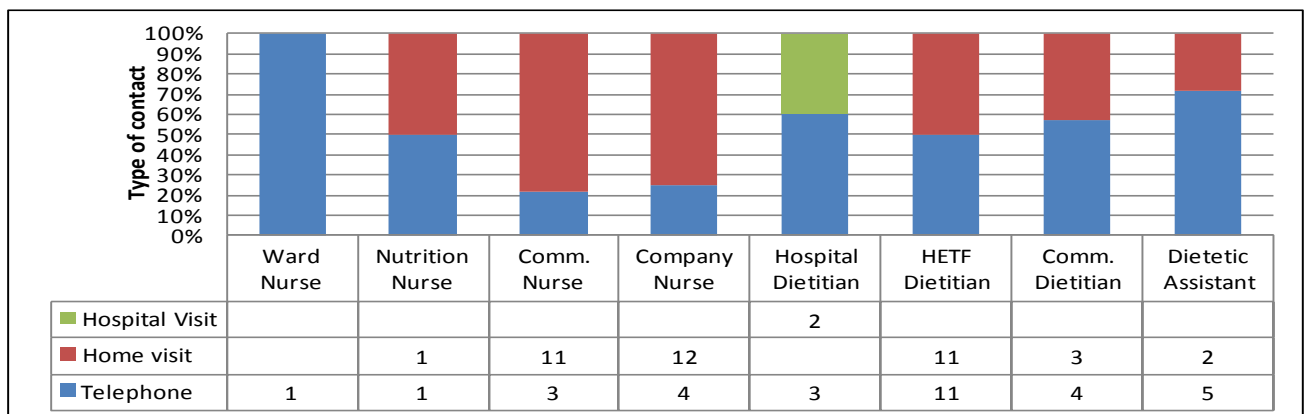
28 organisations (88%; 32 responses) had written standards of care whilst three (9%) did not and one (3%) did not know. Three organisations stated they had developed guidelines based on *Nice CG32* or *Crest guidance*. Regional guidelines had been developed for the Scottish Highlands but these were not always applicable to each area. The remainder were local organisational guidelines or joint guidelines developed across primary and secondary care.

Guidelines covered the whole spectrum of enteral feeding including patient and staff training, management, monitoring, problem solving and prevention of complications. There does not appear to be a UK wide standard approach.

Question 11: Please state who GENERALLY contacts the patient within the first week after discharge and how is this USUALLY undertaken?

Figure 10.2 shows contacts made within the first week and the HCP who contacts the patient. However, some respondents said that the person who visits depends on patient need or clinical condition e.g. speech and language therapist or specialist learning disabilities (LD) dietitian.

Figure 10.2: Type of contact within first week of discharge



Question 12: What is your ROUTINE STANDARD for follow up care?

32 organisations responded of which 13 (41%) contacted their patients on a monthly basis by home visits (7) and telephone (6), five (16%) others made contact every 3 months (4 home and 1 telephone) whilst the remaining 14 (44%) either visited (10) or telephoned at 3-6 months intervals. Troubleshooting was generally done by telephone though occasionally home or hospital visits were required. Most dietitians said that it depended on clinical need, clinical stability of the patient and complexity of the case. Examples given were: may vary between weekly for premature babies to 3 months for older stable children; may be more frequent for patients being supported by clinical areas such as oncology where treatment is ongoing or changing.

For some, inadequate staffing is an issue. *'I try and follow up as frequently as possible but usually end up responding to problems rather than being proactive'. 'Generally, we telephone for routine adult follow up at 3 monthly intervals otherwise we are contacted by telephone if and when problems occur. Children's follow up is as and when needed due to limited funding'*

Question 13: Which of the following parameters are monitored and how frequently?

There appears to be little standard monitoring (Figure 10.3) other than for weight and BMI. Other anthropometrics, TSF (triceps skinfold thickness) and MUAC (mid upper arm circumference) are performed only when weight cannot be measured or when there is a clinical need, as is the case for most biochemical markers. One dietitian commented *'Some GPs do not let me order the blood tests which I would like annually for all the enterally fed patients in the community'*. Compliance with feeding regimen is monitored at each follow-up visit and swallowing assessments are undertaken either at each follow-up appointment or where a clinical need is identified.

Table 10.3: Monitoring frequency for HETF

	6-12 months	Clinical Need	Each F/U visit	Never	Response n.
Weight	1	2	27		30
Ht./length in children	1	4	12	1	18
BMI	3	5	22		30
TSF		15	1	10	26
MUAC		18	1	6	25
U&E	4	23	2		29
LFT	4	21	2	1	28
FBC	4	22	1	1	28
Glucose (non DM)	2	20	2	3	27
HBA ¹ c(Diabetic)	10	14	2	1	27
Trace elements		20	1	5	26
Vitamins		20	1	5	26
Compliance with feeding regimen			30		30
Swallowing assess. If appropriate	1	6	23		29

Question 14: Do you use Patients/Carers input into developing your HETF service?

AND Question 15: Have you undertaken a patient questionnaire or survey?

32 respondents answered both questions. Almost half (15 organisations) involved patients in the development of services, whilst 14 did not and 3 did not know. This was mainly done through patient questionnaires and surveys, which were used to measure such things as patient satisfaction with the provider service, compliance with NPSA 19 (National Patient Safety Agency) and to establish what information patients would like before discharge. Some organisations used the Home Care Companies' surveys with local adaptations.

Patient input was also used to evaluate new equipment such as feeding pumps and syringes and in developing patient information leaflets. One area was attempting to set up a local branch of PINNT (Patients on intravenous and Nasogastric Nutrition Therapy) www.pinnt.com

Question 16: Who manages the ancillaries budget for HETF?

There were 30 respondents; the budget for HETF was managed by various departments: Dietetic Departments (DD) in acute Trusts (8), HEFT Dietetic teams (2), Community HETF Dietetic teams (2), Community DD (7), PCTs (3) and 8 'Other'. Within the 'Other' category there were two examples of joint funding arrangements: Acute Trust DD funded ancillaries, GP funded the feeds, community nurses funded syringes; Acute DD funded giving sets and syringes, community DD funded replacement tubes, extension sets, y-connectors.

Question 17: Is your budget for consumables adequate? If No, please explain the effect on patient services.

The consumable budget was adequate for 16 (52%) whereas 11 (35%) did not know. 4 (13%) gave reasons why they felt the budget was inadequate:

- Requests for syringes have to be made to district nurses who are sometimes reluctant and don't provide sufficient supply.
- No service is claiming the budget for giving sets.
- No one has taken into account the need for EF tube extension sets etc. and that we could get a better price as part of a contract.
- Costs are increasing and ancillary costs are currently supported by funding from other areas of the department's budget so no major effect at present but this will become a problem in future.

Question 18: If you require additional funding, please describe how you acquire this?

Only 7 respondents answered this question. 3 said they were unsure; 1 said it was not an issue; 2 said through discussions with the PCTs and 1 said she was new to post though funding was not secured for her specific post.

Question 19: How are feeding solutions financed?

21 organisations (68% of 31 responding organisations) obtained feeding solutions via a GP prescription whilst 5 (16%) were 'off script' (an agreement is made for local HETF services to contract for feed as well as ancillaries so that an individual monthly prescription is not required). 5 (16%) 'did not know'.

Question 20: Please explain how cross boundary referrals are financed.

In general funding for HETF patients depends on where an individual lives. If the patient's GP was outside the discharging organisations PCTs area, the individual was likely to be transferred to a HETF service within their own location. Where a different supplier to the discharging hospital was used, the patient was likely to be changed onto the feeds and equipment of the new organisation's home care company. However, if the patient is still receiving clinical treatment at the discharging hospital he/she may continue to be managed there and the costs would be re-charged to the appropriate PCT.

Question 21: How does your organisation interact with BANS?

10 Reporters had used paper forms to report to BANS. Only 7 were currently E-BANS reporters. 16 had stopped reporting.

10.4 Discussion

There was a poor response which may have been due to lack of interest or complexity of the survey. The response may have improved if the BANS reporters had been targeted BANS rather than the dietetic managers. Some respondents seemed to encounter difficulties in entering data, either exiting the survey after question one or completing the survey two or more times leading to duplicate/triplicate entries which had to be removed.

Patients & Staff

A high proportion of respondents estimated both point and period prevalence data or did not know the extent of their case load (Table 10.1). This has implications for commissioning services and acquiring appropriate funding and staffing. Reporting to e-BANS could help departments to monitor their work load and obtain useful benchmarking information for commissioners.

Wide ranging training, backed up by written information was given to patients prior to discharge thus encouraging safe practice, preventing hospital re-admissions and

death from complications of enteral feeding (see 'outcomes' in sections 4 & 5 of this report). For some healthcare professionals (HETF dietitians, Company nurses, Nutrition nurses) caring for tube feeding patients is a full time role. However, there appears to be good communication amongst other HCPs (community nurses, speech & language therapists etc.) who become involved on a clinical need basis. Where dietetic assistants are employed, administrative duties and monitoring tasks are undertaken freeing up clinical time for dietitians. The Home Care Company Nurse is very prominent in some areas and provides a valuable nursing service.

Almost 50% stated they had insufficient staff and quoted increased turnover without additional funding. A shortfall of a whole range of HCPs was highlighted including: dietitians, community nutrition nurses, dietetic assistants and in remote areas lack of access to company nurses.

Clinical Care

There appears to be no standardised care pathway across the country in relation to the first review following discharge and ongoing follow up care. Basic anthropometrics measurements, compliance with feeding and swallowing assessments are done on a regular basis though biochemical monitoring on the whole is done in an *ad hoc* manner. Vitamin & minerals are rarely measured. Whilst patients receiving 1500kcal/day or more will be receiving the full recommended daily allowance of micro-nutrients, those with reduced mobility and very low energy requirements (<1000kcal/day) will not and might benefit from appropriate biochemical monitoring.

Almost half of the organisations involved patients in their service through the use of patient satisfaction surveys and in developing patient information and evaluating new products.

Budgetary Arrangements

Budgets for HETF ancillaries (tubes, giving sets, syringes etc.) were managed by a variety of departments both in the acute sector and/or in the community. In some cases different departments paid for different pieces of equipment, for example: giving sets by dietetics in acute trust and syringes by community nursing. In some cases there was no explicit budget, and funding came out of a general department budget which raised concerns as patient numbers continue to rise. Over 50% said that the budget for these items was inadequate but there was uncertainty in some areas of where to obtain additional funding.

68% organisations obtained feeding solutions via a GP prescription whilst 16% were 'off script'. Procurement for the 'off script' option is an interesting concept which brings most elements, including tube feeds and ancillaries together under one contractual agreement, making the overall costs of HETF easier to identify.

Interaction with BANS

Only 7 respondents were currently e-BANS reporters and 16 had stopped reporting altogether. Section 5 & 6 of this annual report discuss the loss of reporters and Section 9 reviews the actions the BANS committee is taking to address this situation.

10.5 Overall conclusion and recommendations

Many of the same problems identified in 2003 still existed in 2010. These were around inadequate staffing and a non standardised clinical, financial and management infrastructure.

Since 2003 the numbers of patients on HETF had increased by >30% for adults and 45% for children by 2009, when >25,000 adults and > 11,000 children (point prevalence) were on tube feeding at home (Section 8 of this report). As numbers increase and NHS funding becomes more challenging, it is important that a robust infrastructure is in place to ensure a high quality, equitable service with good outcomes. To facilitate this, a BANS HETF working party which will produce guidelines for all aspects of HETF is proposed.

Acknowledgement: the BANS Committee would like to thank all those who completed this survey.

Section 11

The British Intestinal Failure Survey (in children)

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11.1 Introduction

Intestinal failure (IF) refers to a functionally impaired gastrointestinal tract that is unable to maintain biochemical homeostasis and support normal growth. Until the advent of parenteral nutrition (PN), failure of the gut almost invariably resulted in the patients' death. With developments in PN, not only are more of these patients surviving, but they are also surviving for longer. Despite this, there is a paucity of national data on the incidence and outcomes of paediatric IF. This prompted the British Association of Paediatric Surgeons, the British Society of Paediatric Gastroenterology, Hepatology and Nutrition, and the Department of Health through the National Commissioning Group to institute the British Intestinal Failure Survey (BIFS). The chief aims of BIFS are:

- To determine the incidence and outcome of paediatric IF in the UK (including Scotland, Wales and Northern Ireland)
- To quantify the number of children who may require intestinal transplantation

11.2 Methods

Ethics

BIFS has been granted multi-centre research ethics committee approval, and as it is a registry rather than a trial there is no local investigator – only a local collaborator - so a Site Specific Assessment is not required. Each local hospital or trust R&D department has to grant approval for the trust to register patients. Registration of each individual patient is conditional on obtaining informed consent, almost always from the parent or guardian. To help the parents make a decision on this, a series of patient information leaflets have been produced.

Eligibility

Patients up to 18 years of age who start PN are eligible for inclusion if they remain on this treatment for 28 days or more. Premature newborns given PN solely because they have immature gut function are excluded as they would normally be expected to establish enteral autonomy and have an excellent prognosis.

Dataset

Data collected includes basic demographics (date of birth, initials, part postcode, ethnic background, and sex), their diagnosis, any major events such as episodes of jaundice, sepsis or operations, changes in their PN (for example if they are sent home on PN) and their current status or outcome.

Follow-up

The method of follow up of registered patients depends on whether or not the centre is using an electronic PN recording system (see discussion later). Centres relying on a paper *pro forma* to submit data to BIFS are sent details of their patients that are held on the BIFS central database every six months and are asked to confirm if the current information is correct. Whilst gathering data on patients using an essentially paper based system remains popular with contributors, it does have a number of drawbacks:

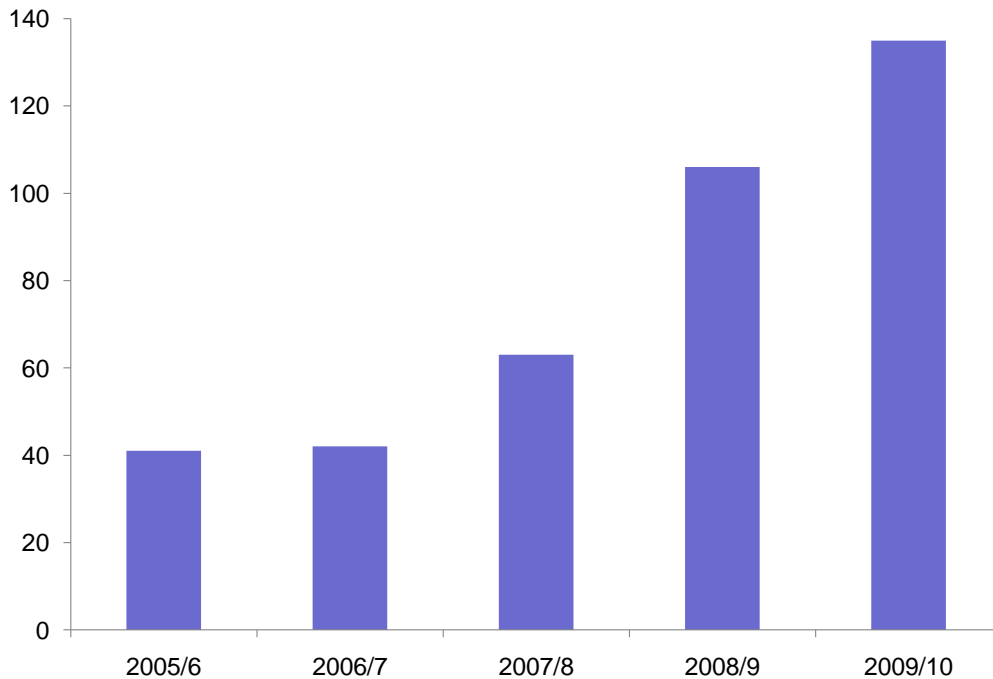
1. Data still has to be typed into the central BIFS database.
2. Follow up involves checking over notes to ensure that details, such as date PN was stopped, are correctly reported to BIFS

11.3 Results

Patient recruitment

Recruitment has been increasing annually for the 5 years BIFS has been operating (Graph 1). This is due to a combination of more centres submitting data, and better data capture within individual centres. It has to be stressed that while recruitment is increasing, this does not mean that there are more patients staying on PN for 28 days or more each year but rather that BIFS is recruiting a larger proportion of the eligible patients. National estimates using an extrapolation from a comprehensive survey carried out in the West Yorkshire region containing 414,000 children, suggest that the number of paediatric patients (excluding premature infants with immature gastrointestinal motor function) remaining on PN for 28 days or more is approximately 800 per year (Köglmeier et al, 2008). Thus BIFS may be recruiting around 20% of the total number of eligible patients exposed to PN for 28 days or more.

Fig 1. BIFS recruitment by year



Results to date (to the end of July 2010) are given in Table 1.

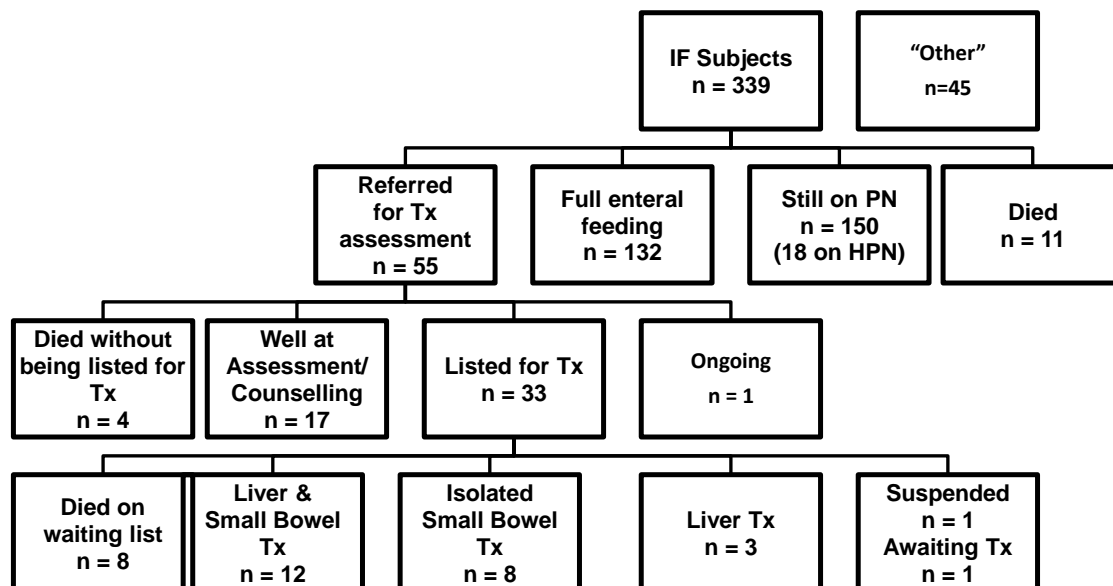
Table 1. BIFS Primary Diagnosis (n=384)

Primary diagnosis	n (%)	Median age at start of PN (range)	Referred for Tx assessment (Tx)
Short bowel syndrome	238 (62.0%)	4 days (0 – 17 yr)	39 (18)
Disorder of motility	54 (14.1%)	~ 1 year (0 – 16 yr)	8 (4)
Enteropathy	47 (12.2%)	~ 2 years (0 – 18 yr)	8 (1)
Other	45 (11.7%)	~ 3 years (0 – 17 yr)	0

About 2/3rd of the patients have been registered with conditions classified as short bowel syndrome, with the remaining 1/3rd being divided up fairly evenly between motility disorders, enteropathies and “other”. The “other” diagnoses include neoplasms, heart defects and so on. These patients remained on PN for 28 days or more, so were eligible for inclusion in the BIFS registry.

Examining the data further (fig. 2) we can see that of the 339 patients with the more conventional intestinal failure diagnoses (i.e. removing the “other” diagnoses from the investigation) we can see how many patients came off PN without transplant, how many remain on PN and so on.

Fig 2. Results July 2005 – June 2010
IF subjects n=339



Centre recruitment

Recruitment of centres began initially with 6 large units with established home PN programmes. After this pilot phase other centres were recruited via professional contacts within the British Society of Paediatric Gastroenterology, Hepatology and Nutrition and this has been increasing year on year over the past 5 years (see Fig 1). Some centres have yet to be granted local Rand D approval, although a total of 33 centres are now participating in other audit projects relating to the provision of PN (Flynn and Gowen 2010, Beath et al 2010). The number of patients treated at different centres is variable (Fig 3) and the rate of reporting within individual centres also varies (Fig 4).

Fig 3. Paediatric point prevalence of HPN

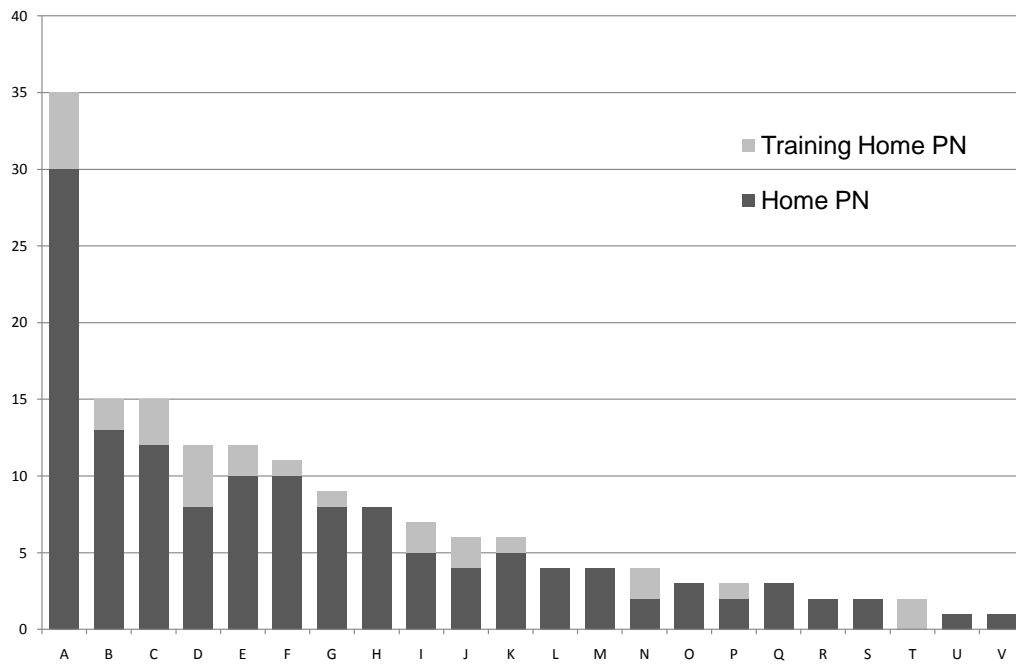
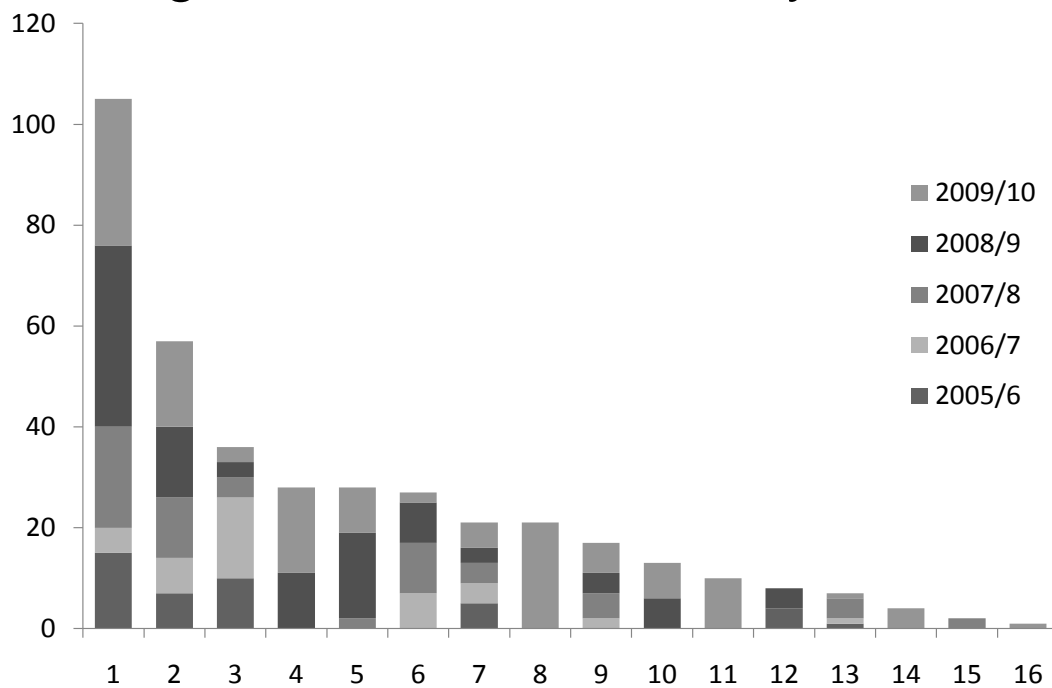


Fig 4. BIFS recruitment by trust



11.4 Discussion

It is important to remember that BIFS is a registry, rather than a study. The success of any registry will depend in its completeness of data capture, the uniformity of data being contributed by each centre, and the timeliness of reporting and follow up. Data submitted by the majority of centres initially used extraction of data from paper records, and so submitting this data to BIFS involved repetition of work. Initially it was hoped that an on-line *pro forma* would help, but very few centres used this facility and it was abandoned.

In order to reduce the amount of replication of work, a PN database has been created and is currently being trialled / developed in a number of centres that contribute data to BIFS. It is a Microsoft ACCESS database, which is a programme that is universally used throughout the NHS.

The database has been designed to:

1. Collate data on ALL patients that receive PN within a hospital or trust
2. Be easy to adapt to the requirements of different trusts.
3. Notify the operator when a patient is eligible to be approached to give consent to register with BIFS, and
4. Facilitate the reporting and follow-up process via a secure NHS.NET e-mail account.

It is hoped that re-designing the database as above will improve recruitment and reporting of patients to BIFS. However it must be acknowledged that the requirement to obtain informed consent has greatly restricted recruitment. The problem is not that parents and carers object to their child's medical condition being recorded on a national database, but that by the time they becomes eligible for inclusion at 28 days, most have settled into a pattern of visiting which is outside office hours and the local investigator or consent taker are unable to see them. By the time an appointment is agreed the child may have been weaned off PN and recruitment to BIFS becomes a low priority for busy clinicians. BIFS is working with the NIGB to develop a registry which does not require informed consent and this may involve removing some patient identifiable data.

The other factor noted is that local re-structuring and staff absence through maternity leave, re-deployment, unfilled vacancies etc has disrupted reporting and, because of this, some centres show variable patterns of recruitment (see Fig 5).

The establishment of the BIFS database demonstrates that important demographic and outcome data can be collected. Further improvements in case ascertainment particularly of medium term PN dependency cases (4-12 weeks of PN) are needed. The recent NCEPOD enquiry into parenteral nutrition has called for more nutrition support teams and better accountability through audit.

Perhaps the major achievement for BIFS has been to establish a network of paediatric gastroenterologist in 33 hospitals across the UK which has provided the basis for two simple audits so far with others planned in the future.

Future directions for BIFS

- Improved organisation of IF services and a greater commitment from NHS Trusts will lead to better networking and sharing of information. BIFS will contribute to this process as well as being a beneficiary of it.
- The use of the same Microsoft ACCESS programme by all pharmacies administering PN will facilitate audit for local purposes as well as providing a convenient means of linking confidentially with the national database. BIFS will continue to work with local investigators and pharmacists to establish this mechanism nationally.
- Surveys of vascular access teams and also arrangements for shared care in provision of home PN are planned for 2011.

Acknowledgements

Dr Sue Beath and Dr John Puntis for reviewing the manuscript.

Section 12

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Section 13

The BANS Committee, 2010

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)
- Winnie Magambo, CNS, (Wales)

Others:

Janet Baxter, Dietitian and Manager, Scottish Managed Clinical HPN Network, Scottish Representative on BAPEN (ESPEN HANS group representative)

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