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*Putting patients at the centre
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BANS Report 2018

Home Enteral Tube Feeding (HETF) in Adults (2010-2015)

**A report by the British Artificial Nutrition Survey (BANS) -
a committee of BAPEN**

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On behalf of the BANS Committee

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Definition of terms

New registrations:

This is the number of new registrations in the given period of 1 year.

Point prevalence:

This is the number of patients registered with BANS who remained on artificial nutrition support at the specified census point in time (i.e. last day of the calendar year) who had been updated during that year.

Period prevalence:

This is the total number of patients registered with BANS who were receiving artificial nutrition support over the specified period of time (i.e. during the calendar year) who had been updated during that year.

Outcome:

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

Executive Summary

1. Since 2010 new registrations of adults receiving home enteral tube feeding (HETF) decreased by 6% to 3216 in 2015. Point and period prevalence increased by 10% and 9% respectively. The number of reporting centres with new registrations decreased to 88 in 2015 (-38%).
2. In 2015, the majority of new registrations for adult HETF patients were from England (88%). There has been a decrease in the number of reporting centres across all constituent UK countries.
3. The largest diagnostic category for new adult HETF registrations was cancer (43%), 80% of which was head and neck cancer. This patient group were younger, more active and more independent than the overall BANS HETF registrants. Central nervous system and mental health conditions (predominantly cerebrovascular disorders (40%) and neuro-degenerative disorders (33%)) also continued to account for a high proportion (40%) of new HETF registrations in 2015.
4. The majority (65%) of new adult HETF registrations in 2015 were aged over 60 years (increased by 2% since 2010).
5. In 2015, the majority (72%) of newly registered adult patients on HETF were living in their own home (69% in 2010). Overall, although 42% of patients were able to manage independently, most needed some (22%) or total help (37%). 40% of newly registered HETF patients were reported as fully active, with the remainder having limited activity (36%), being housebound (11%) or bedbound (15%).
6. As seen in previous years, the foremost reason for patients registered with BANS starting HETF was 'swallowing disorders' (67%), followed by 'disease-related malnutrition' (20%).
7. Gastrostomy was by far the most common route of feeding (80%), as it has been over the last fifteen years.
8. Home care companies supplied 87% of newly registered adult HETF patients in 2015, consistent with the provision in 2010 (86%). Home care companies reported supporting 20,214 adult patients with HETF at the end of 2015 (point prevalence), more than 3x the number registered with BANS (6720).
9. At the end of 2015, 70% of the patients registered with BANS continued on HETF, 12% returned to oral feeding and 16% of the patients died (predominantly due to the underlying disease).

BANS is looking at the best ways to improve reporting of HETF to make sure there is a more complete national picture of the use of this important way of feeding across the UK. More accurate local and national summaries of the use of HETF can help clinicians review patient demographics and outcome and support clinical and payer decisions on resourcing and service provision.

Thank you to all the BANS reporters across the UK.

Adult home enteral tube feeding (HETF)

1.1 Patients and Reporting Centres

New Registrations, point and period prevalence

From 2010 to 2015 there was a small, 6% decrease in the number of new registrations of adult patients receiving HETF (n=3216 in 2015), (Table 1.1). Point prevalence (the number of adults recorded as still receiving HETF at the end of the year) fluctuated between 2010 (n=3430) and 2015 (n=6270) with an overall increase of 10% since 2010. Period prevalence (the number of adults recorded as receiving HETF during the year) also fluctuated over the years with an overall increase of 9% from 2010 to 2015.

Reporting centres

The number of new reporting centres showed an overall decline of 38% from 2010 to 2015, following the trend of the previous three years. However, the average number of new patients registered per reporting centre continued to increase reaching 37 in 2014 and 2015 (the highest figure in the previous 15 years).

The continued decline in reporting centres coupled with the continued increase in the number of patients per reporting centre may be explained in part by the merger of reporting centres, as hospitals join into larger trusts.

Table 1.1:

Number of new registrations, point and period prevalence, and reporting centres in the UK from 2010-2015

	2010	2011	2012	2013	2014	2015
New Registrations	3430	4107	4457	4060	3514	3216
Reporting Centres	121	120	127	116	96	88
Point Prevalence	5703	6516	7115	7227	6086	6270
Reporting Centres	138	132	134	157	128	117
Period Prevalence	8075	9209	10066	10261	8791	8904
Reporting Centres	148	136	135	160	129	123

Constituent UK countries

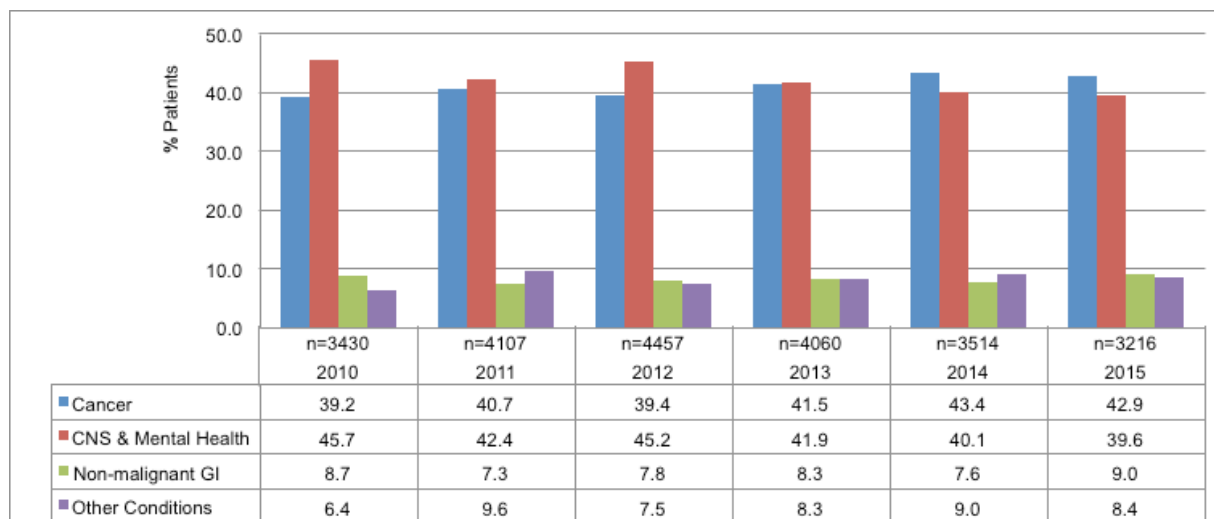
In 2015, most (88%) new registrations for adult HETF patients were from England (compared with 80% in 2010), with 8% from Wales (an increase from 4% in 2010), 3% from N. Ireland (vs. 6% in 2010) and <1% (vs. 9% in 2010) from Scotland. Both point and period prevalence showed similar trends (e.g. point prevalence in 2015, 87% of patients from England, 6% from Wales, 2% from Scotland and 4% from N. Ireland). The number of reporting centres (point prevalence) has mostly decreased across countries (in 2015: 96 in England, 5 in Scotland, 10 in N. Ireland, 6 in Wales) and there were no reporting centres from the Isle of Man.

1.2 Clinical conditions of newly registered adult HETF patients over the past 5 years

Primary patient diagnoses are grouped by BANS into four disease categories: cancer, central nervous system (CNS) and mental health, non-malignant gastrointestinal (GI) disorders and other conditions. Figure 1.2 (A) shows the number of new registrations by disease category from 2010-2015.

Figure 1.2 (A):

Clinical conditions of newly registered HETF adult patients from 2010-2015



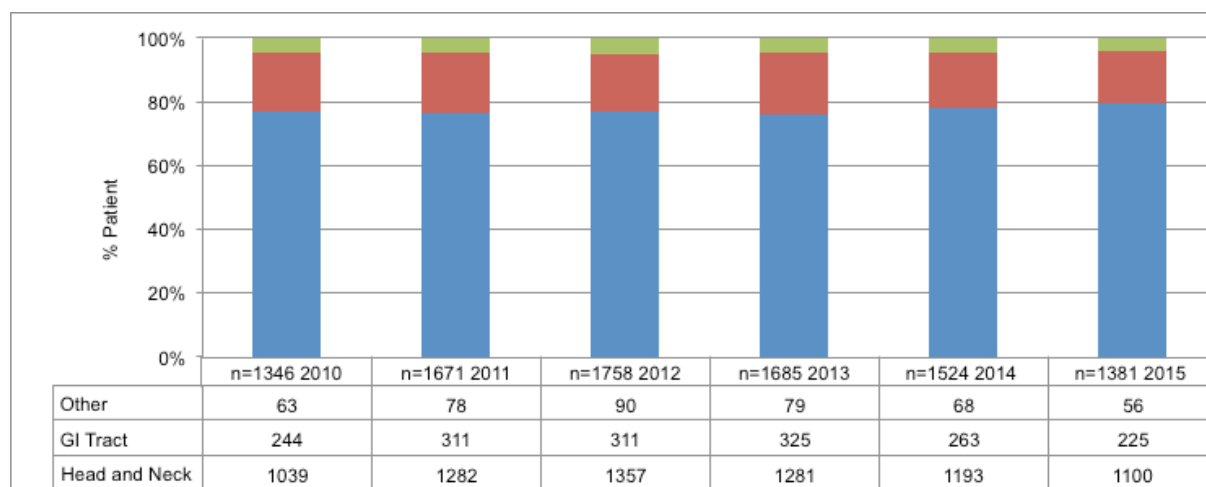
Cancer (n=1381 in 2015)

The proportion of newly registered adult patients receiving HETF and diagnosed with cancer increased from 39% in 2010 to 43% in 2015. The breakdown of the cancer types for newly registered adult patients receiving HETF in 2015 is shown in Figure 1.2(B).

- Head and neck cancer remained the most prevalent cancer in new HETF registrations, accounting for 80% of all cancer diagnoses in 2015; a further increase from 77% in 2010.
- GI cancer, including oesophageal and gastric cancer, made up 16% of new HETF registrations with a cancer diagnosis in 2015, which has fallen slightly from 18% in 2010.
- As in previous years, other types of cancer accounted for a small proportion (4%) of the new registrations with a cancer diagnosis in 2015 (haematology 1%, miscellaneous 3%)

Figure 1.2 (B):

Breakdown of the types of cancer of newly registered HETF adult patients from 2010-2015



Central nervous system (CNS) and mental health conditions (n= 1275 in 2015)

The proportion of newly registered adult patients receiving HETF with CNS and mental health conditions continued to gradually decrease from 46% in 2010 to 40% in 2015.

- Vascular disorders contributed to 40% of all CNS & mental health conditions in 2015 (compared to 43% in 2010) (see section 1.6 for more details).
- 33% of new registrants in this diagnostic category in 2015 had degenerative disorders, with motor neurone disease (46%) remaining the leading diagnosis within the degenerative disorders.
- The remainder of this diagnostic category was made up of a variety of other conditions that affected a smaller proportion of new registrants including: brain injury (11%); miscellaneous conditions (4%); congenital disorders (5%); neurological disorders (4%); tumour (<1%); mental health (3%).

Non-malignant gastro-intestinal tract diseases (n=289 in 2015)

The proportion of new adult registrations with non-malignant gastro-intestinal (GI) tract conditions receiving HETF was 9% in 2015, remaining stable over the past fifteen years. Diagnoses included: head/neck disorders (12%); oesophageal/stomach disorders (51%); gut disorders (19%); hepatobiliary/pancreas disorders (10%); GI surgery (5%) and other GI diseases (4%).

Other conditions (n=271 in 2015)

The proportion of new registrations with other conditions receiving HETF was 8% in 2015, showing a 2% increase over the past five years. Diagnoses included: cardiac disease (6%); dermatological conditions (<1%); inborn errors of metabolism (<1%); metabolic conditions (2%); respiratory disease (19%); renal disease (4%); miscellaneous conditions (68%).

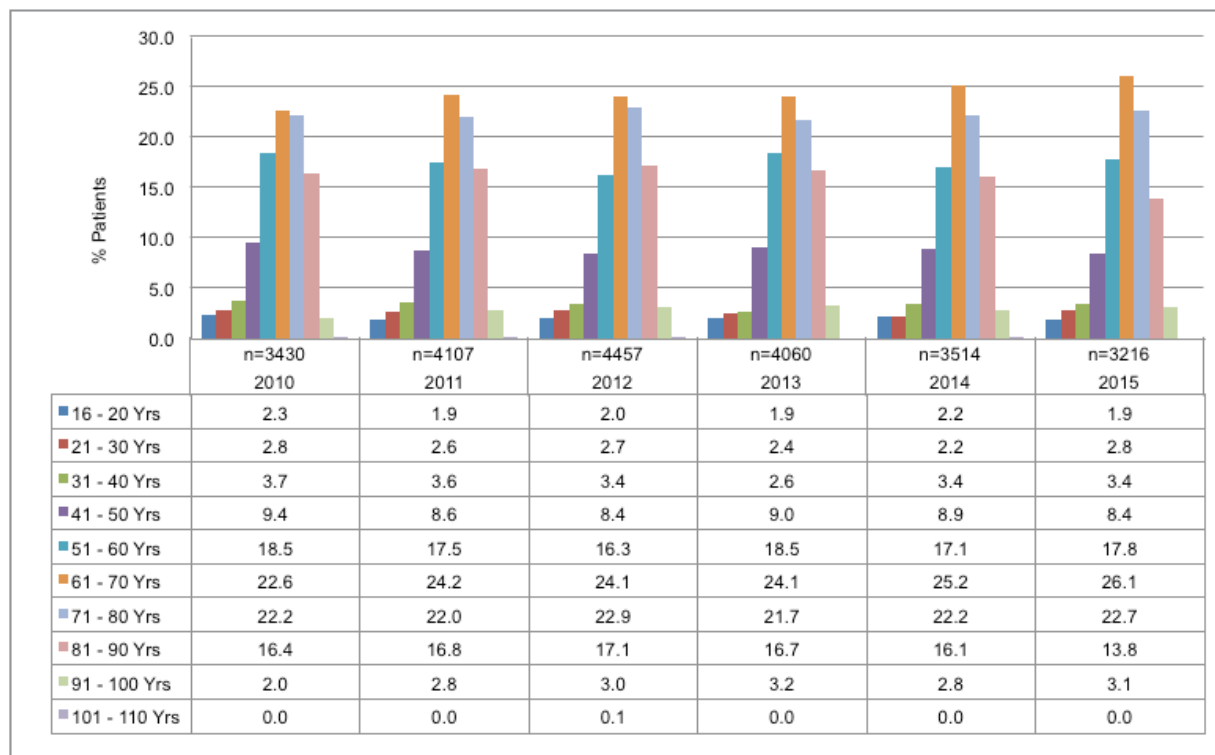
1.3 Age, level of activity, dependency and location of patients

Age

In 2015, 65% of newly registered patients receiving HETF were over 60 years old, an increase of 2% since 2010 (Figure 1.3 (A)). The highest proportion of patients were those aged 61-70 years (26%) and this has remained so for the last five years.

Figure 1.3 (A):

Newly registered adult HETF patients within age bands from 2010-2015

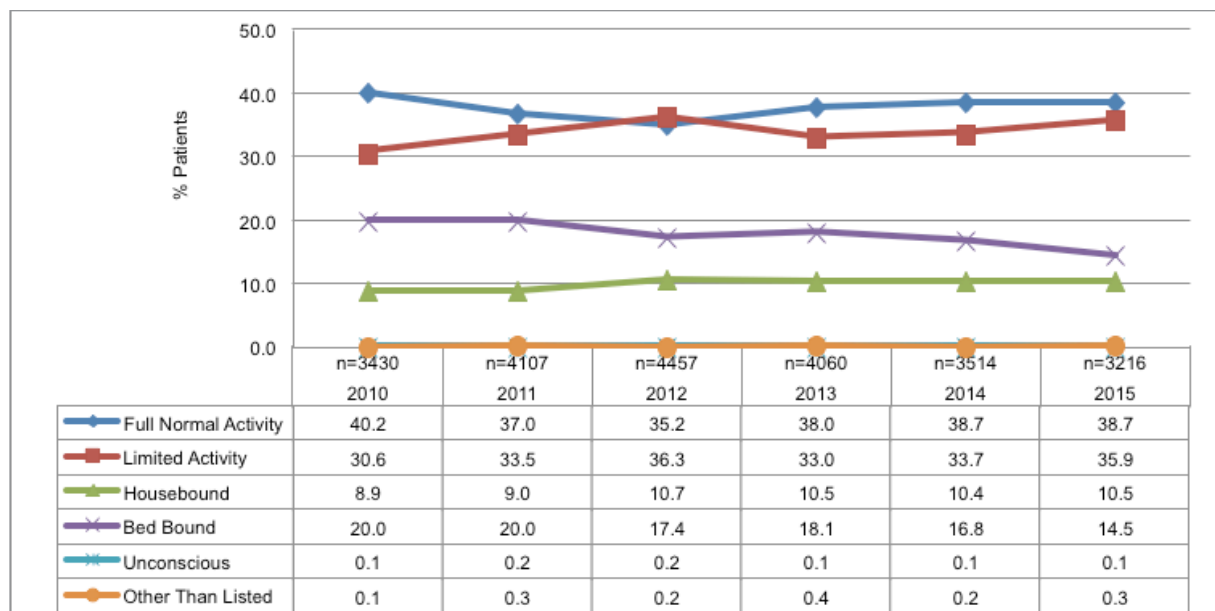


Level of activity

The proportion of patients on HETF and newly registered with BANS who were fully active has remained relatively stable; 40% in 2010 and 39% in 2015. The percentage of newly registered patients with limited activity has increased from 31 to 36%, as has the proportion of patients who were housebound: 9 vs 11%. The proportion of newly registered HETF patients who were bed bound has continued to decrease, falling by 5% from 2010 to 2015 (Figure 1.3 (B)). This drop in the proportion of bedbound patients may be explained in part by changing diagnoses of patients receiving HETF and also by clinicians reconsidering the ethical appropriateness of long term HETF for some patient types.

Figure 1.3 (B):

Activity status of newly registered adult HETF patients 2010-2015

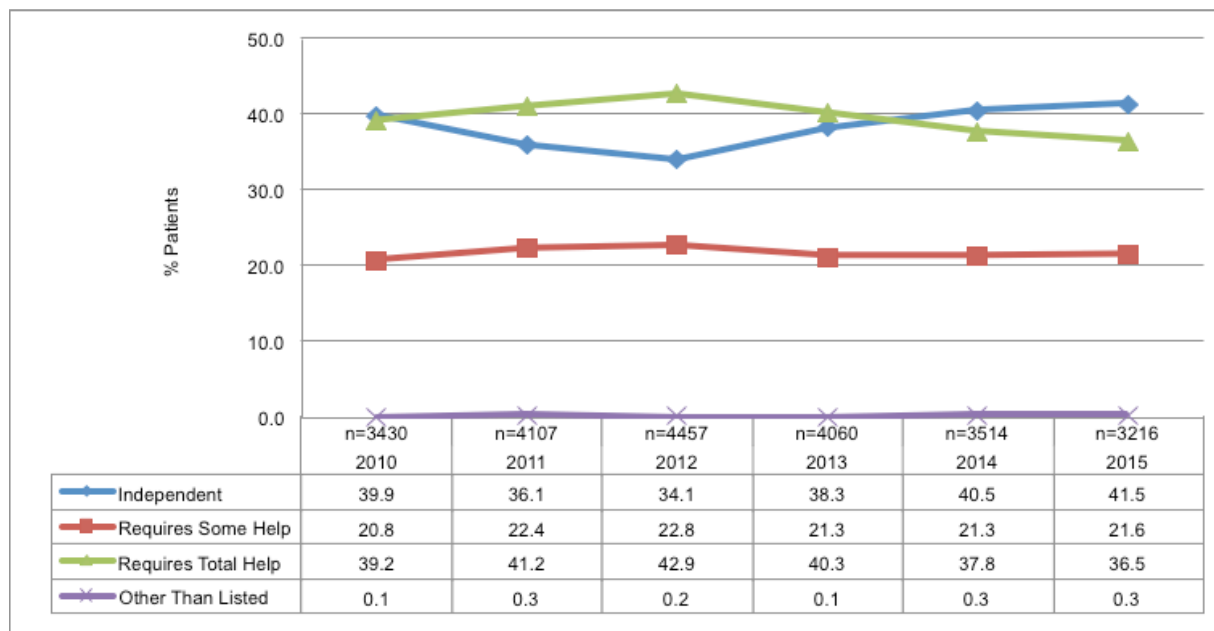


Dependency

The level of dependency in HETF patients newly registered with BANS has fallen slightly over the years. In 2010, 40% of new patients were independent and 39% required total help. Data in 2015 showed a further increase in patients who were independent (42%), again outnumbering the proportion of patients who required total help (37%) (Figure 1.3 (C)).

Figure 1.3 (C):

Dependency levels of newly registered adult HETF patients 2010-2015



Location

The majority of newly registered adult patients on HETF lived in their own home (increase from 69% in 2010 to 72% in 2015). The proportion of patients living in nursing homes or receiving residential care fell further to 25% in 2015. The proportion of newly registered patients living in their own home was 5% higher than the proportion of existing patients living in their own home in 2015, with the reductions seen in those living in nursing homes or receiving residential care.

1.4 Reason for feeding, feeding routes and delivery of supplies for adult HETF patients

Reason for feeding

The two foremost reasons for adult patients starting HETF were: “swallowing disorders” (67%) and “disease related malnutrition” (20%). The remaining indications for feeding were predominantly “GI obstruction” (3%) and “anorexia” (2%) as well as 6% recorded as “other than listed”.

Feeding routes

Gastrostomy was the primary route of feeding for newly registered HETF patients, as it has been over the last 15 years. In 2015, 80% of patients were fed by gastrostomy. Other routes of feeding continued to be less common (jejunostomy 6%; nasogastric tube 10%). Feeding by naso-duodenal or naso-jejunal tube occurred in 3% of patients.

Delivery of Supplies

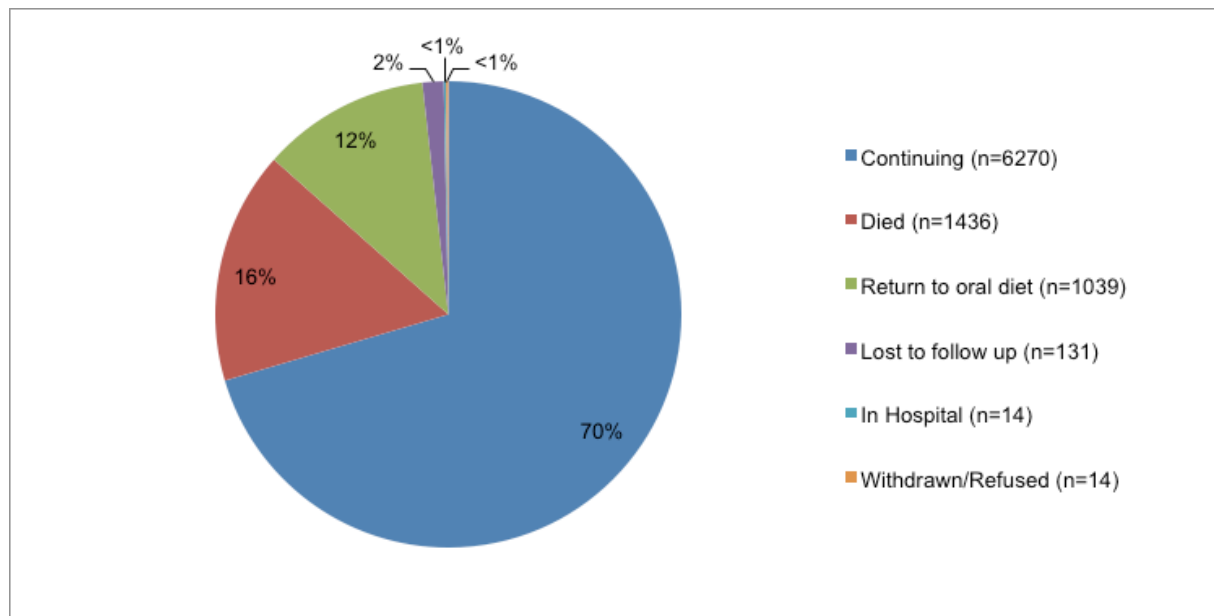
Home care companies supplied 87% of new patients on HETF registered with BANS in 2015. This has remained relatively stable when compared with 2010 (86%). Although for 4% of new patients it was unknown how they obtained their supplies, this was much lower number than earlier years (e.g. 2011), when it was as high as 12%.

1.5 Outcomes for adult HETF patients (Period prevalence, n=8904 in 2015)

The outcomes for adults receiving HETF during 2015 were as follows: 70% of patients continued on HETF, 12% returned to oral feeding, 16% of the patients died, mostly (98%) due to the underlying disease. Very few (<1%) were admitted to hospital, were withdrawn or refused tube feeding and 1.5% were lost to follow up.

Figure 1.4:

Outcomes for adult HETF patients during 2015



1.6 HETF in adults with cerebrovascular disease

Data from the England Health and Social Care Information Centre (2014) shows the prevalence of cerebrovascular disease in the UK has continued to increase from 2004-2014 to 1.7% of the population. With the highest prevalence seen in those aged over 75 years, and an ageing population in the UK, it is likely that this percentage will increase further in years to come. Due to the consequences of cerebrovascular disease, it has always been one of the most common diagnostic categories for adults receiving HETF in the UK and below is a summary of the characteristics of this patient group in 2015:

- In 2015 the number of new registrants to BANS with cerebrovascular disease decreased (514 patients versus 676 in 2010), this is in line with a reduction in the overall number of new patient registrations to BANS.

- Newly registered patients with cerebrovascular disease tended to be significantly older than the HETF population as a whole (66% versus 37% were aged 71-90), with less than a fifth aged 70 years and below (versus 60% for all adult HETF).
- The most common reasons for feeding in this patient group were 'swallowing disorders' and 'disease-related malnutrition' (83% and 12% respectively). The proportion receiving HETF due to swallowing disorders was markedly higher in this diagnostic group than in the overall adult HETF population (67%).
- 40% of patients in this group were bed bound, which is greater than the overall adult HETF population newly registered with BANS (15%).
- 82% of new cerebrovascular patients required total help, which is notably higher than the overall HETF proportion (37%). Just 4% of this patient group were able to manage independently, in contrast to 42% of the overall HETF population.
- 70% of this group required nursing home care compared to 24% of the overall adult HETF population registered with BANS. 28% of the population resided in their own home, compared to 72% of the whole adult HETF population.
- The most frequently chosen route for feeding in this group was gastrostomy (96%) followed by nasogastric feeding (3%).

Outcomes during 2015

The outcomes for patients in 2015 registered with BANS with cerebrovascular disease were based on period prevalence data. Most (69%) patients continued on HETF, with just 5% returning to oral feeding (versus 12% for the overall HETF population). 24% of patients died (98% due to underlying disease) and <1% stopped for other reasons (withdrawn or refused). Only a small number of patients were admitted to hospital (<1%), and lost to follow-up (1%).

Key Points

- Cerebrovascular disease continues to be one of the main diagnoses in adults receiving HETF in the UK in 2015.
- This patient group are generally older, less active and more dependent than the overall BANS registrants due to the nature of the condition, which typically occurs later in life and is often more disabling than some disorders, such as head and neck cancer.

1.7 HETF in adults with head and neck cancer

Incidence rates of head and neck cancer continue to increase, reaching 19.2 per 100,000 population in 2015 (18.5 in 2010), as reported by Cancer Research UK (www.cancerresearchuk.org), with up to 60% of individuals diagnosed with head and neck cancer surviving for 10 or more years. Home enteral tube feeding continues to be commonly used in adults with cancer, especially head and neck cancer. This patient group represents a significant proportion of those adults registered with BANS receiving HETF (Evill et al 2017).

From BANS data, at the end of 2015, the proportion of adult patients receiving HETF with cancer was 26% (1638/6270) and most (83%, n 1353) had head and neck cancer (an increase of 12% since 2010).

Most (70%) patients receiving HETF with head and neck cancer were aged ≤ 70 y and were tube fed primarily because of a swallowing disorder (69%), disease-related malnutrition (19%) or GI obstruction (3%), typically (85%) by gastrostomy.

Most patients lived in their own home (96%) and were independent (75%), with only 4% requiring total help to manage and 20% some help.

The majority of patients had full normal activity (73%), 25% had limited activity, and <2% were housebound or bedbound.

After 1 year, using period prevalence data, 61% continued with HETF, almost a quarter (24%) returned to oral feeding alone, 14% had died, 0% were hospitalised and <1% withdrew or refused HETF.

Key Points

- Around one quarter of adults receiving HETF registered with BANS had a diagnosis of cancer, mostly (>80%) with head and neck cancer.
- Patients with head and neck cancer receiving HETF are a relatively independent and active patient group living at home, compared to other patients receiving this form of nutritional support.

1.8 Home enteral tube feeding patient numbers according to independently acquired data

Adults

At the end of 2015, home care companies reported supporting 20,214 adults with home enteral tube feeding (point prevalence), more than 3x that registered with BANS (6270).

As home care companies supply ~87% of HETF adult patients (see Section 1.4 above), it is estimated that the total point prevalence in the UK at the end of 2015 was at least 23,235 adult patients.

1.9 References

Evill RH, Smith TR, Stratton RJ. Characteristics of home enterally tube fed patients with head and neck cancer in the UK. *Clinical Nutrition* 2017; 35: S217

Organisations/active e-ban reporters

City	Organisation	City	Organisation
Antrim	Antrim Area Hospital	Chester	Countess of Chester Hospital
Basildon	Basildon Hospital	Chesterfield	Chesterfield Royal Hospital
Basingstoke	North Hampshire Hospital	Chichester	St Richards Hospital
Bath	St Martins Hospital	Chigwell	Hainault Health Centre
Belfast	Forster Green Hospital	Co. Antrim	Lagan Valley Hospital
Belfast	Belfast City Hospital	Colchester	Colchester General
Belfast	Forster Green Hospital	Coventry	University Hospital Coventry
Belfast	Royal Belfast Hospital	Cumbria	West Cumberland Hospital
Belfast	Royal Victoria Hospital	Dartford	Darent Valley Hospital
Belfast	Mater Hospital Trust	Derby	Derby City General Hospital
Bournemouth	Royal Bournemouth Hospital	Derby	Derbyshire Royal Infirmary
Bristol	Bristol Royal Infirmary - HMS	Derby	Derby City General Hospital (Childrens)
Bristol	Weston General Hospital	Dorchester	Dorset County Hospital
Burton on Trent	Queens Hospital	Dundee	Strathmartine Centre
Bury St Edmunds	West Suffolk Hospital	Dunstable	Dunstable Health Centre
Camberwell	Home Enteral Nutrition Team	Epping	St Margarets Hospital
Cambridge	Addenbrookes Hospital	Exeter	Royal Devon & Exeter NHS
Cardiff	Velindre NHS Trust	Glasgow	Pollock Health Centre
Cardiff	University Hospital of Wales	Gloucester	Gloucestershire Royal Hospital
Carlisle	Cumberland Infirmary	Grimsby	N E Lincs NHS Trust
Chelmsford	Broomfield Hospital	Harrogate	Harrogate District Hospital

City	Organisation	City	Organisation
Harrow	Northwick Park Hospital HEN Team	Middlesex	Uxbridge Dietitians
Hereford	Hereford County Hospital	Middlesex	Hillingdon Hospital
High Wycombe	Wycombe General Hospital	Milton Keynes	Milton Keynes Hospital
Hull	Victoria House Dietitians	Motherwell	Strathclyde Hospital
Ipswich	Ipswich Hospital	Newcastle on Tyne	Newcastle General
Isle of Wight	St Marys Hospital	Newcastle upon Tyne	Freeman Hospital
Kent	Tonbridge Cottage Hospital	Newport	St Cadocs Hospital
Kent	Kent Community Dietetic Service	Newry	Daisy Hill Hospital
Kent	HEN - Tonbridge Cottage Hospital	North Shields	North Tyneside G.H.
Kingston Upon Thames	Kingston Hospital NHS Trust	Northern Ireland	Whiteabbey Hospital
Leeds	Leeds General Infirmary	Norwich	Norfolk & Norwich University Hospital
Leicester	Leicestershire Nutrition & Dietetic	Nottingham	Queens Medical Centre
Leicester	Leicester Royal Infirmary	Nottingham	Nottingham City Hospital
Lincoln	United Lincolnshire HEN Team	Nuneaton	George Eliot Hospital
London	Royal London Hospital	Orkney	Balfour Hospital
London	Queen Elizabeth Hospital	Oxford	Churchill Hospital
Lowestoft	Lowestoft Hospital	Plymouth	Plymouth Hospitals NHS Trust
Luton	Luton & Dunstable Hospital	Poole	Poole Hospital
Manchester	Wythenshawe Hospital	Port Talbot	Neath Port Talbot Hospital
March Cambridgeshire	Doddington Hospital	Portadown	Craigavon Area Hospital Group
Middlesborough	James Cook University Hospital	Portsmouth	Queen Alexandra Hospital

City	Organisation	City	Organisation
Prescot	Prescot Primary Care Resource Centre	Torquay	Torbay Hospital
Preston	Whiston Hospital	Truro	Royal Cornwall Hospital
Romford	Harley Street Queens Hospital - Sky B Ward	Walsall	Manor Hospital
Rotherham	Oakwood Hall	Warwick	Warwick General Hospital
Runcorn	Halton General Hospital	Watford	Watford General Hospital
Salford	Salford Royal Hospital	Wembley	Wembley Centre for Health & Care
Salisbury	Salisbury District Hospital	West Bromwich	Sandwell District General Hospital
Scunthorpe	Scunthorpe General Hospital	West Midlands	Good Hope Hospital
Sheffield	Royal Hallamshire Hospital	West Sussex	Princess Royal Hospital
Sheffield	Sheffield Teaching Hospitals (NHS Foundation Trust)	Whitstable	Whitstable & Tankerton Hospital
Somerset	Somerset Community Dietitians	Winchester	Royal Hampshire County Hospital
Southampton	Southampton General Hospital	Worksop	Doncaster & Bassetlaw NHS Foundation Trust
St Albans	St Albans City Hospital	Worthing	Worthing Hospital
Stourbridge	Stourbridge Health & Social Care Centre	Wrexham	North East Wales Trust
Sunderland	Sunderland Royal Hospital	York	York Teaching Hospital NHS Foundation Trust
Surrey	St Peters Hospital		
Surrey	Primary Care Dietetics Service		
Swansea	Singleton Hospital		
Swindon	The Great Western Hospital		
Tamworth	Sir Robert Peel Hospital		
Tayside	Ninewells Hospital		



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