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*Putting patients at the centre  
of good nutritional care*

# **BANS Report 2016**

**Artificial Nutrition Support in  
the UK 2005-2015**

**Adult Home Parenteral Nutrition  
& Home Intravenous Fluids**

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

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On behalf of the BANS Committee

**Published on BAPEN (British Association of Parenteral and Enteral Nutrition) website  
[www.bapen.org.uk](http://www.bapen.org.uk)**

**ISBN: 978-1-899467-08-4**

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This report was produced on behalf of BAPEN by the BANS Committee: Trevor Smith (Chair), Mani Naghibi, Rebecca Stratton, Sean White, Sarah Zeraschi, Sarah-Jane Hughes, Mia Small, Phil Scot-Townsend.

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# Contents

	Page
Section 1: Definition of terms	4
Section 2: Executive summary	5
Section 3: Adult Home Parenteral Nutrition (HPN)	6
Section 4: Adult Home Intravenous Fluids (HIVF)	18

## **Section 1: 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.

## Section 2: Executive Summary

1. 420 new adult Home Parenteral Nutrition (HPN) patients were registered to BANS during 2015; this compares to 262, 351, 472 and 400 newly registered patients in 2011, 2012, 2013 and 2014 respectively.
2. 75 new adult Home Intravenous Fluids (HIVF) patients were registered to BANS during 2015; this compares to 31, 51, 74 and 69 newly registered patients in 2011, 2012, 2013 and 2014 respectively. Therefore a total of 495 new patients, receiving HPN and HIVF, were registered with BANS during 2015.
3. The reported point and period prevalence for HPN was 1144 and 1360 patients, and for HIVF was 207 and 243 patients, during 2015; this compares to 611 & 743 patients for HPN, and 46 & 49 patients for HIVF, in 2011.
4. Expressed in terms of the population size, the prevalence of HPN plus HIVF was 7.7 new cases per million of the UK population during 2015; this has increased from 4.5 new cases per million of the population in 2011. The combined HPN/HIVF point prevalence was 21 cases per million, with a period prevalence of 25 cases per million during 2015.
5. Prevalence data were voluntarily supplied to BANS from five of the six home care companies in operation in 2015. These data demonstrated that 2353 adult patients were registered with home care companies for parenteral support. The data do not allow for distinction between HPN and IVF. Hence, the true UK period prevalence for HPN/HIVF during 2015 was approximately 40 cases per million of the population.
6. 34 centres registered new HPN patients to BANS during 2015; 41 centres reported and updated patients established on HPN (period prevalence data). 18 centres registered new HIVF patients, whilst 27 centres reported HIVF prevalence data during 2015.
7. Short bowel is the most common indication for establishing HPN (34% of new cases in 2015) and HIVF (48% of new cases).
8. Cancer is now a major diagnostic indication for HPN and HIVF – cancer accounts for one in four new HPN/HIVF registrations. Crohn's disease remains a leading diagnosis for adults receiving HPN, accounting for 14% of newly registered HPN patients (17% of new HIVF patients), with a point prevalence of 21% (32% for HIVF patients) during 2015.
9. The vast majority of HPN and HIVF patients were under 71 years of age during 2015; two thirds of patients were between 41 and 70 years of age.
10. The percentage of new HPN/HIVF registrations initially placed in a nursing home has remained very small at 1.6%; the vast majority are discharged to their own home.
11. Venous access was via an external catheter in 98% of new registered HPN/HIVF patients.
12. 84% of established patients remained on HPN/HIVF at the end of 2015; 6.5% had reverted to oral nutrition and the mortality rate was 7% (the remaining patients were in hospital or had been transferred to other centres, and therefore no further outcome data was available).

### Section 3: Adult Home Parenteral Nutrition (HPN)

#### 3.1 New HPN registrations, point and period prevalence

There has been a steady increase in the number of new adult HPN registrations between the period 2008 and 2013, with the peak in 2013 of 472 new registrations. This increase is in part due to increased reporting after 2008, but also represents an increase in activity.

In 2014, 400 new patients were registered (-15% compared to 2013), followed by an increase to 420 patients in 2015 (+5%). The point and period prevalence in 2015 were the highest in BANS history at 1140 and 1360 patients reported respectively (Figure 3.1). All point prevalence data are captured on 31<sup>st</sup> December.

The largest proportion of new patient registrations were in England (95%), followed by Wales and Northern Ireland (3.5% and 1.5% respectively), with no new patient registrations in Scotland since 2011 (figure 3.2). Although there has been no formal reporting from Scotland in recent years, the BANS committee have been informed that there were approximately 160 patients on HPN in 2015 (personal communication from Dr Ruth McKee). Details of the point and period prevalence data in each of the constituent countries of the UK are presented in Table 3.1.

Expressed in terms of population size, the prevalence of new HPN cases in 2015 was 6.5 per million of the UK population, with a point and period prevalence of 17.7 and 21.1 cases per million respectively during 2015 (Table 3.2). In light of the under reporting across all countries, the overall UK HPN prevalence is higher than reported.

Prevalence data were voluntarily supplied to BANS from five of the six home care companies in operation in 2015. These data demonstrated that 2353 adult patients were registered with home care companies for parenteral support. The data do not allow for distinction between HPN and IVF. This reveals the reporting rate to BANS to be approximately 60% in this time period (or approximately 70% when combining HPN and Home Intravenous Fluid prevalence data (section 4.1)). Hence, the true UK period prevalence for HPN/HIVF during 2015 was approximately 40 cases per million of the population.

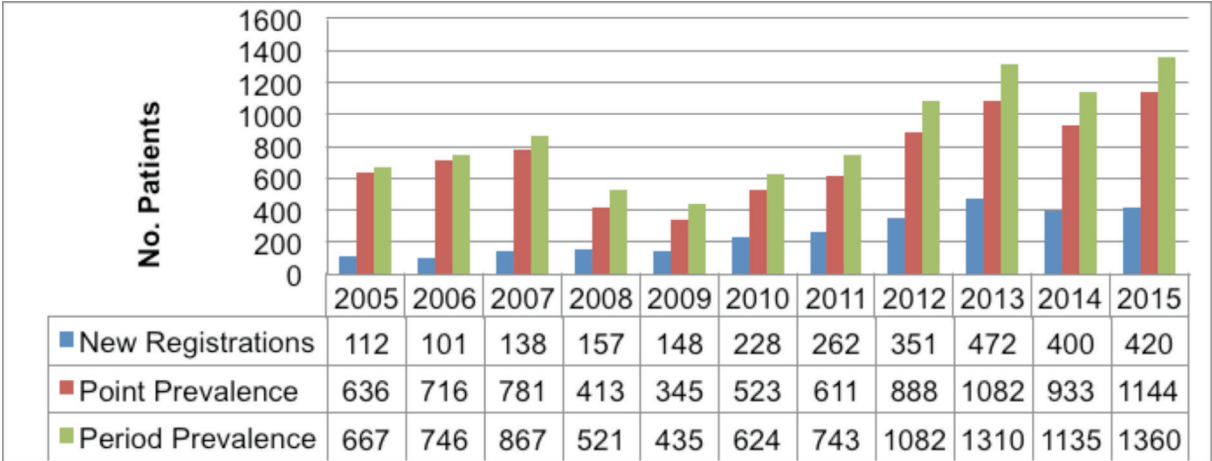


Figure 3.1 - Number of new registrations, point prevalence and period prevalence of HPN in the UK, 2005 -2015

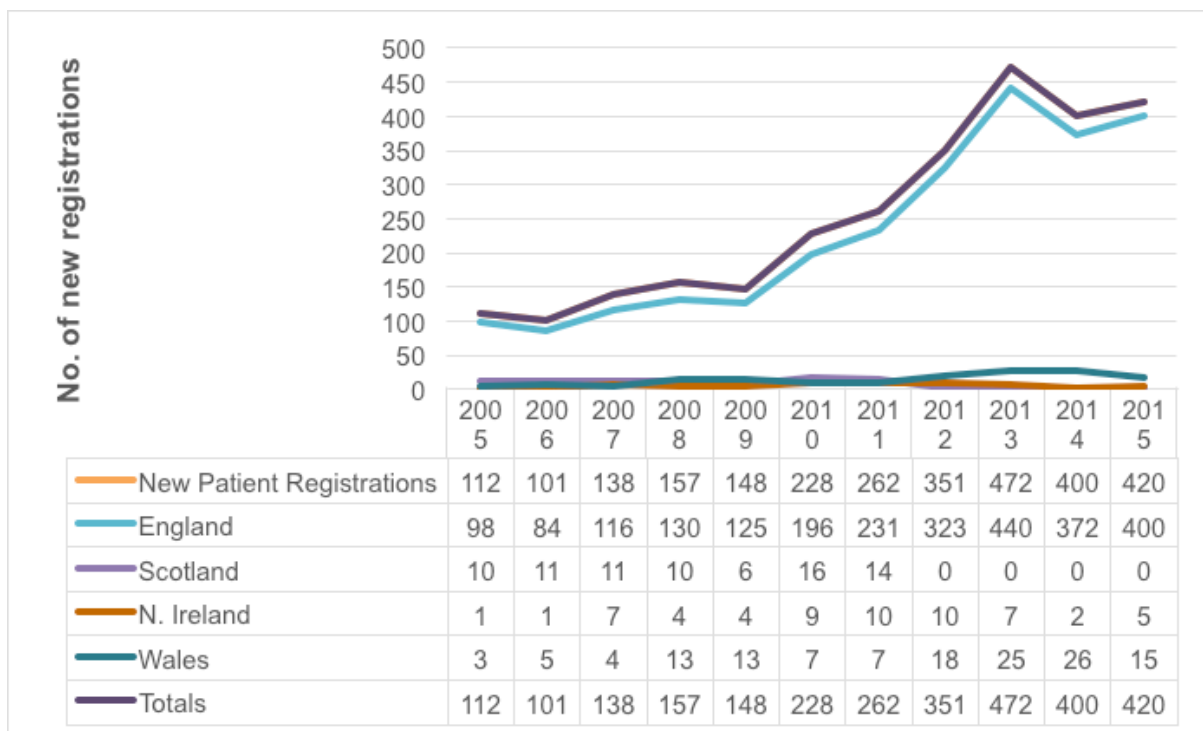


Figure 3.2 - New HPN registrations in constituent countries of the UK, 2005 – 2015

Table 3.1 - Adult HPN point and period prevalence in constituent countries of the UK, 2005 – 2015

	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
<b>Patient Point Prevalence</b>	<b>636</b>	<b>716</b>	<b>781</b>	<b>413</b>	<b>345</b>	<b>523</b>	<b>611</b>	<b>888</b>	<b>1082</b>	<b>933</b>	<b>1144</b>
England	530	590	657	336	306	413	512	775	989	905	1117
Scotland	72	81	65	56	25	59	68	68	0	0	0
N. Ireland	21	26	38	4	3	28	24	20	26	4	6
Wales	13	18	21	17	11	23	7	25	67	24	21
Totals	636	716	781	413	345	523	611	888	1082	933	1144
<b>Patient Period Prevalence</b>	<b>667</b>	<b>746</b>	<b>867</b>	<b>521</b>	<b>435</b>	<b>624</b>	<b>743</b>	<b>1082</b>	<b>1310</b>	<b>1135</b>	<b>1360</b>
England	555	614	726	425	366	506	631	959	1202	1096	1323
Scotland	74	85	79	71	51	67	71	68	0	0	0
N. Ireland	22	26	39	6	4	28	34	30	26	4	6
Wales	16	20	22	19	14	23	7	25	82	35	31
Totals	667	746	867	521	435	624	743	1082	1310	1135	1360

Table 3.2 - HPN prevalence per million of the population in UK and home countries (2015)\*‡

	New	Point prevalence	Period prevalence
<b>UK</b>	<b>6.5</b>	<b>17.7</b>	<b>21.1</b>
<i>England</i>	<i>7.4</i>	<i>20.1</i>	<i>24.4</i>
<i>Scotland</i>	-	-	-
<i>Wales</i>	<i>4.8</i>	<i>6.8</i>	<i>10.0</i>
<i>N. Ireland</i>	<i>2.8</i>	<i>3.3</i>	<i>3.3</i>

\*Sources: Population estimates, 2015: Office for National Statistics, www.statistics.gov.uk (Population UK 64.6 million; England 54.3 million; Scotland 5.3 million; Wales 3.1 million; N. Ireland 1.8 million)

‡ See text for revised higher prevalence data based on HPN company data

### 3.2 Reporting Centres

34 centres registered new patients to BANS during 2015, which has not changed since 2013, though is an increase of 13 centres compared to 2010. The majority of these centres were located in England (one centre in Northern Ireland and one centre in Wales) (Figure 3.3).

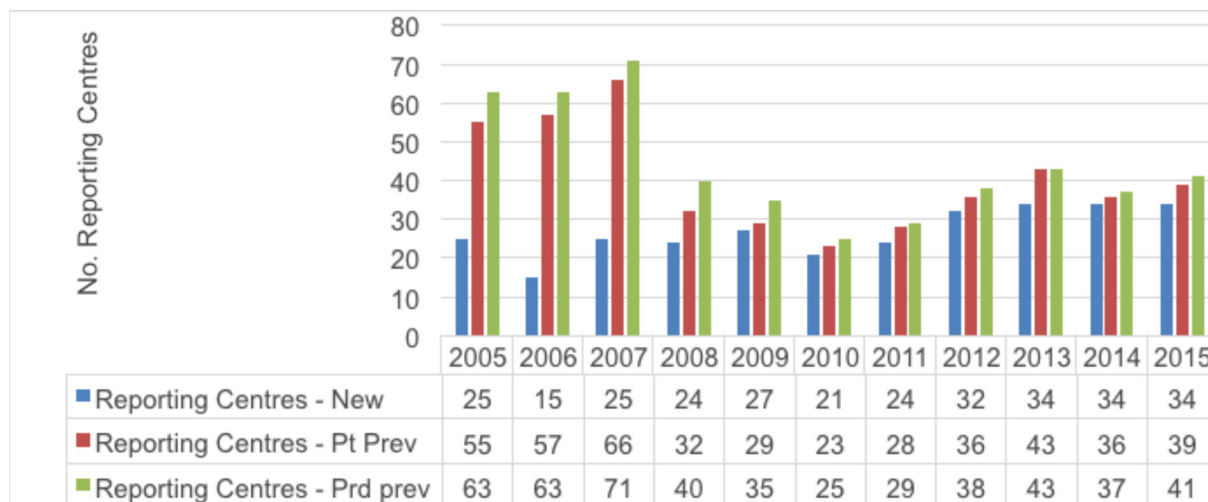


Figure 3.3 - Numbers of adult HPN reporting centres in the UK for new registrations, point prevalence and period prevalence, 2005 – 2015

### 3.3 Indications for HPN

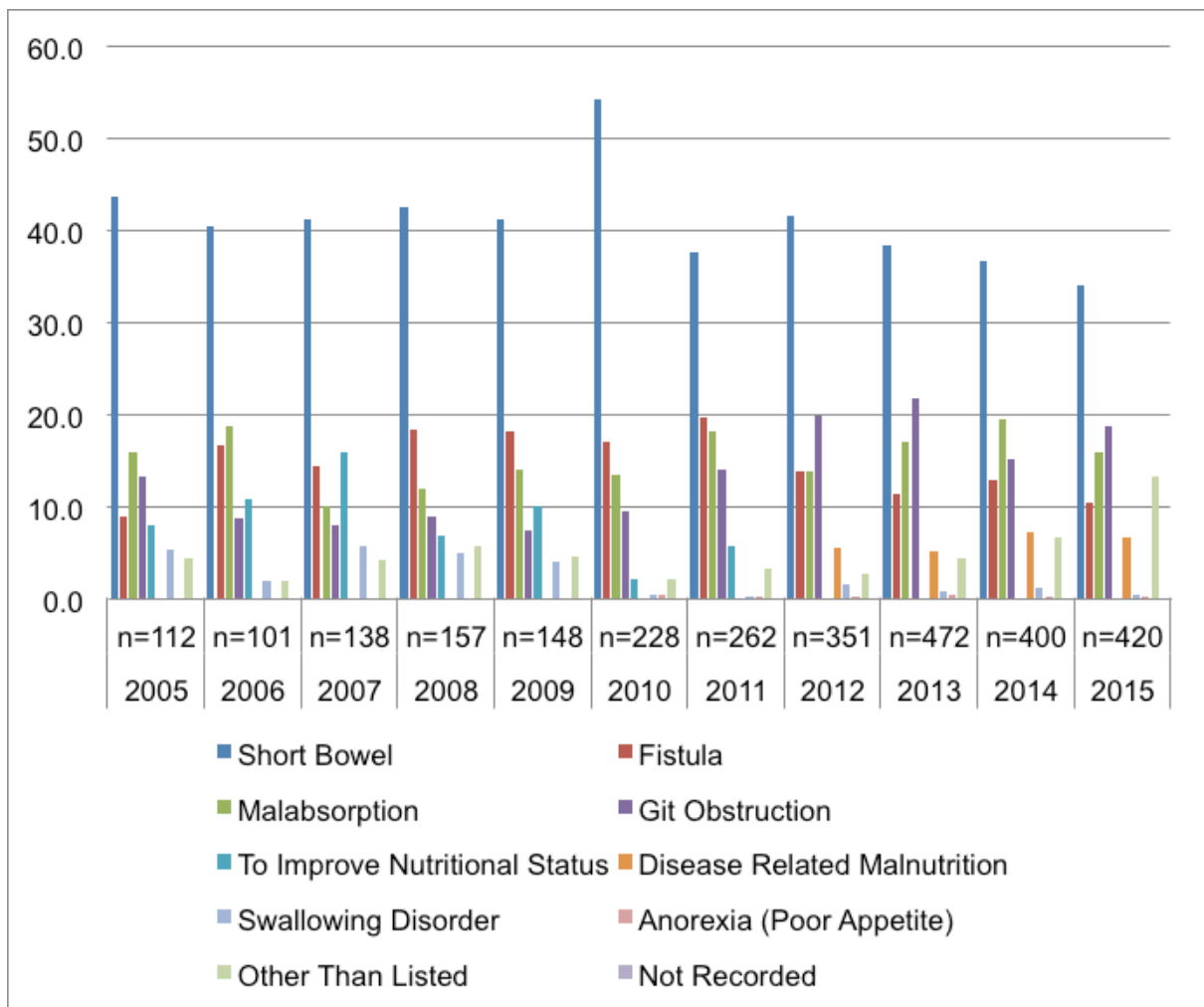
Short bowel syndrome (SBS) remains the commonest indication for HPN for newly registered patients (34% in 2015). Although the overall numbers of new patients with SBS treated with HPN are increasing, over the last 10 years, the proportion of all HPN patients with SBS is reducing. The notable indication that has increased in prevalence for new registrations is 'gastrointestinal obstruction' (table 3.3 and figure 3.4). In 2015, the major underlying diagnosis for new patients with 'gastrointestinal obstruction' treated with HPN was malignancy (69%); further details are discussed in section 3.4. Table 3.3 demonstrates the indications for HPN for established patients.

The category 'to improve nutritional status' has not been used as indication for a new registration since 2011, while 'anorexia (poor appetite)' and 'swallowing disorder' have generally been used in less than one per cent of all new registrations since 2010. The launch of the eBANS intestinal failure registry will provide an updated indication list to reflect the current reporting trends.



**Table 3.3 - Indications for new adult HPN registrations (in percentages), 2005-2015**

Reason for Feeding	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
Patient No.	n=112	n=101	n=138	n=157	n=148	n=228	n=262	n=351	n=472	n=400	n=420
Short Bowel	43.8	40.6	41.3	42.7	41.2	54.4	37.8	41.6	38.6	36.8	34.0
Fistula	8.9	16.8	14.5	18.5	18.2	17.1	19.8	14.0	11.4	13.0	10.5
Malabsorption	16.1	18.8	10.1	12.1	14.2	13.6	18.3	14.0	17.2	19.5	16.0
Gastro-intestinal Obstruction	13.4	8.9	8.0	8.9	7.4	9.6	14.1	19.9	21.8	15.3	18.8
To Improve Nutritional Status	8.0	10.9	15.9	7.0	10.1	2.2	5.7	0.0	0.0	0.0	0.0
Disease Related Malnutrition	0.0	0.0	0.0	0.0	0.0	0.0	0.0	5.7	5.3	7.3	6.7
Swallowing Disorder	5.4	2.0	5.8	5.1	4.1	0.4	0.4	1.7	0.8	1.3	0.5
Anorexia (Poor Appetite)	0.0	0.0	0.0	0.0	0.0	0.4	0.4	0.3	0.4	0.3	0.2
Other Than Listed	4.5	2.0	4.3	5.7	4.7	2.2	3.4	2.8	4.4	6.8	13.3
Totals	100	100	100	100	100	100	100	100	100	100	100



**Figure 3.4 - New HPN registrations by indication (in percentages), 2005-2015**

**Table 3.4 - Indications for established adult HPN registrations (point prevalence): 2005-2015**

Reason for Feeding	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
Short Bowel	333	369	419	230	191	308	316	457	563	457	531
Fistula	52	66	73	41	35	50	75	85	91	84	93
Malabsorption	113	126	121	60	51	72	116	156	187	189	232
Gastro-intestinal Obstruction	41	46	48	32	26	47	50	87	129	90	115
To Improve Nutritional Status	44	52	63	21	20	19	28	0	0	0	0
Disease Related Malnutrition	0	0	0	0	0	0	0	59	57	59	68
Swallowing Disorder	29	32	29	9	8	6	3	6	9	7	7
Anorexia (Poor Appetite)	2	2	1	1	1	1	1	2	3	1	2
Other Than Listed	18	19	23	19	13	20	22	36	43	46	96
<b>Totals</b>	<b>636</b>	<b>716</b>	<b>781</b>	<b>413</b>	<b>345</b>	<b>523</b>	<b>611</b>	<b>888</b>	<b>1082</b>	<b>933</b>	<b>1144</b>

### 3.4 Diagnoses and adult HPN

The major change in the diagnosis reported for new HPN registrations over the last 5 years, has been the rise in patients with malignancy. Although the BANS database has not, to date, requested information on the curative nature of the malignancy, evidence from other sources suggests that the vast majority of these patients are likely to have incurable malignancy, in the palliative phase of disease.

The HPN point prevalence for malignancy diagnosis has increased from 6.8% to 11.8% between 2005 and 2015 (Table 3.5 and Table 3.11). Given the short average survival length, period prevalence is a more appropriate measure for this patient group. The malignancy-associated HPN period prevalence during 2015 was 15.5%, which is a near two-fold increase from 8.6% since 2010 (table 3.6). The percentage of new HPN registrations with malignancy as the underlying diagnosis has risen from 11.6% in 2005 to 27.4% in 2015; i.e. cancer accounts for approximately one in four of all new HPN registrations. Ovarian malignancy was the most common cancer, accounting for 22.6% of new malignancy-associated HPN registrations during 2015 (table 3.7).

Crohn's disease remains a leading diagnosis for adults receiving HPN, accounting for 13.8% of newly registered patients, with a point prevalence of 20.8% during 2015. There has, however, been a gradual fall in the overall proportion of established HPN patients with Crohn's disease in the last 15 years; point prevalence data are shown in table 3.8

Mesenteric vascular disease (arterial ischaemia, venous thrombosis and volvulus) also remains a major diagnostic category leading to HPN dependence, accounting for 10.0% of new registrations, with a point prevalence of 16.3% during 2015. The point prevalence for this group of diseases has remained stable during the last 15 years, as shown in Table 3.9. 'Pseudo-obstruction and motility disorders also continue to be common diagnoses, accounting for 7.4% of new registrations, with a point prevalence of 12.8% during 2015 (table 3.10).

**Table 3.5 - Selected diagnostic categories of new adult HPN registrations (all categories not included), 2005 and 2015**

	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015
	n=112	n=101	n=138	n=157	n=148	n=228	n=262	n=351	n=472	n=400	n=420
<b>Malignancy</b>	<b>13</b>	<b>17</b>	<b>16</b>	<b>24</b>	<b>14</b>	<b>32</b>	<b>43</b>	<b>66</b>	<b>116</b>	<b>102</b>	<b>115</b>
<b>Non-malignant gastrointestinal</b>	<b>55</b>	<b>60</b>	<b>68</b>	<b>80</b>	<b>83</b>	<b>121</b>	<b>136</b>	<b>191</b>	<b>233</b>	<b>182</b>	<b>179</b>
<i>Autoimmune enteropathy</i>	1	1	0	1	0	2	5	9	6	6	13
<i>Benign intestinal strictures</i>	1	0	2	3	0	2	9	7	11	3	9
<i>Crohn's Disease</i>	19	27	18	27	32	42	43	62	76	53	58
<i>Perforated Bowel</i>	0	0	0	1	1	6	14	10	21	14	19
<i>Post-necrotising enterocolitis</i>	0	0	1	0	0	1	0	1	0	0	0
<i>Pseudo-obstruction/motility disorders</i>	7	6	11	15	14	25	16	31	47	30	31
<i>Radiation Enteritis</i>	2	6	9	7	5	9	8	5	13	10	5
<i>Ulcerative Colitis</i>	1	3	3	5	3	12	10	22	10	13	2
<i>Vascular Disease - ischaemic</i>	12	9	10	13	17	10	20	33	38	38	24
<i>Vascular Disease - thrombotic</i>	10	6	11	8	9	8	8	6	8	11	9
<i>Volvulus</i>	2	2	3	0	2	4	3	5	3	4	9
<b>Surgery</b>	<b>0</b>	<b>0</b>	<b>4</b>	<b>9</b>	<b>5</b>	<b>29</b>	<b>38</b>	<b>45</b>	<b>63</b>	<b>57</b>	<b>55</b>
<i>Bowel Resection</i>	0	0	0	0	0	1	14	24	36	27	28
<i>Short Gut/Bowel Syndrome</i>	0	0	4	9	5	28	23	18	26	28	27
<i>Total/Partial Gastrectomy</i>	0	0	0	0	0	0	0	2	1	2	0
<i>Obesity Surgery</i>	0	0	0	0	0	0	1	1	0	0	0
<b>TOTAL – ALL*</b>	<b>112</b>	<b>98</b>	<b>138</b>	<b>157</b>	<b>148</b>	<b>228</b>	<b>262</b>	<b>351</b>	<b>472</b>	<b>400</b>	<b>420</b>

\*Total of all new registrations, inclusive of categories not included in this table

**Table 3.6 – HPN period prevalence for primary cancer site (adult patients with malignancy as underlying diagnosis): 2010 - 2015**

<b>Diagnosis</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>	<b>2014</b>	<b>2015</b>
Bladder cancer	0	1	3	5	4	10
Cancer head & neck	2	2	2	2	3	2
Cancer elsewhere than listed	15	18	17	20	20	18
Cancer: colonic	13	14	22	35	36	27
Cancer: gastric	1	4	9	15	19	31
Cancer: GI lymphoma	2	0	1	3	0	2
Cancer: oesophageal	2	2	6	7	4	4
Cancer: orophangeal	0	0	0	0	1	0
Cancer: pancreatic	4	2	5	6	7	11
Cancer: small bowel	11	6	14	27	22	27
Leukaemia	1	2	1	4	2	4
Liver	0	0	1	0	0	0
Lung cancer	0	1	0	1	1	1
Lymphoma	0	2	6	5	5	5
Malignancies not stated elsewhere	0	2	6	11	17	13
Malignant melanoma	0	0	0	0	0	1
Myeloma	0	0	1	2	0	2
Oral	0	0	0	0	0	1
Ovarian cancer	3	14	21	34	26	44
Prostate cancer	0	0	0	1	0	0
Renal cancer	0	0	0	0	0	1
Sarcoma	0	1	3	3	3	6
Thyroid	0	0	1	0	0	1
<b>TOTAL</b>	<b>54</b>	<b>71</b>	<b>119</b>	<b>181</b>	<b>170</b>	<b>211</b>

**Table 3.7 - New adult HPN registrations for all patients with diagnosis reported as malignancy, 2005-2015**

<b>New registrations - Malignancy</b>											
	<b>2005</b>	<b>2006</b>	<b>2007</b>	<b>2008</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>	<b>2014</b>	<b>2015</b>
	<b>n=13</b>	<b>n=17</b>	<b>n=16</b>	<b>n=24</b>	<b>n=14</b>	<b>n=32</b>	<b>n=43</b>	<b>n=66</b>	<b>n=116</b>	<b>n=102</b>	<b>n=115</b>
<b>Gastrointestinal</b>											
Colonic	3	11	4	8	4	5	6	8	21	20	10
Gastric	1	0	0	3	0	0	3	5	10	14	18
GI Lymphoma	0	1	0	1	0	2	0	1	2	0	0
Oesophageal	0	0	1	2	1	0	1	4	6	3	1
Pancreatic	0	2	0	0	0	4	0	4	4	7	5
Small Bowel	2	1	7	5	2	5	2	9	19	10	15
<b>Totals</b>	<b>6</b>	<b>15</b>	<b>12</b>	<b>19</b>	<b>7</b>	<b>16</b>	<b>12</b>	<b>31</b>	<b>62</b>	<b>54</b>	<b>49</b>
<b>Haematological</b>											
Lymphoma	0	0	0	0	0	0	1	4	3	4	3
Myeloma	0	0	0	0	0	0	0	1	1	0	0
<b>Totals</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>5</b>	<b>4</b>	<b>4</b>	<b>3</b>
<b>Head &amp; Neck</b>											
Head & Neck	0	0	0	2	1	1	2	1	1	3	2
Oral	0	0	0	0	0	0	0	0	0	0	1
Oropharyngeal (including orolaryngeal)	0	0	0	0	1	0	0	0	0	1	0
<b>Totals</b>	<b>0</b>	<b>0</b>	<b>0</b>	<b>2</b>	<b>2</b>	<b>1</b>	<b>2</b>	<b>1</b>	<b>1</b>	<b>4</b>	<b>3</b>
<b>Miscellaneous</b>											
Bladder	0	0	0	0	0	0	1	2	4	1	7
Leukaemia	1	0	0	0	2	0	2	0	3	1	3
Lung	0	0	0	0	0	0	1	0	1	0	1
Malignancies Not Stated Elsewhere	0	0	0	0	0	0	2	2	7	10	4
Malignant Melanoma	0	0	0	0	0	0	0	0	0	0	1
Ovarian Cancer	0	0	0	0	1	3	11	16	22	15	26
Prostate Cancer	0	0	0	0	0	0	0	0	1	0	0
Renal Cancer	0	0	0	0	0	0	0	0	0	0	1
Sarcoma	0	0	0	0	0	0	0	0	0	2	4
Thyroid	0	0	0	0	0	0	0	1	0	0	1
Elsewhere than stated	6	2	4	3	2	12	11	8	11	11	12
<b>Totals</b>	<b>7</b>	<b>2</b>	<b>4</b>	<b>3</b>	<b>5</b>	<b>15</b>	<b>28</b>	<b>29</b>	<b>49</b>	<b>40</b>	<b>60</b>
<b>CANCER – Total new patients</b>	<b>13</b>	<b>17</b>	<b>16</b>	<b>24</b>	<b>14</b>	<b>32</b>	<b>43</b>	<b>66</b>	<b>116</b>	<b>102</b>	<b>115</b>

**Table 3.8 – HPN point prevalence of Crohn’s Disease 2000 – 2015**

<b>Year</b>	<b>2000</b>	<b>2005</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>	<b>2014</b>	<b>2015</b>
<b>Patient No.</b>	120	175	153	158	216	241	191	238
<b>%</b>	34.3	27.5	29.3	25.9	24.3	22.3	20.5	20.8

**Table 3.9 – HPN point prevalence of mesenteric vascular disease\* 2000 – 2015**

<b>Years</b>	<b>2000</b>	<b>2005</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>	<b>2014</b>	<b>2015</b>
<b>Patient No.</b>	62	122	80	83	131	162	158	187
<b>%</b>	17.7	19.2	15.3	13.6	14.8	15.0	16.9	16.3

\*includes arterial ischaemia, venous thrombosis and volvulus

**Table 3.10 – HPN point prevalence of pseudo-obstruction and motility disorders, 2000 – 2015**

<b>Years</b>	<b>2000</b>	<b>2005</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>	<b>2014</b>	<b>2015</b>
<b>Patient No.</b>	32	66	79	87	137	152	130	147
<b>%</b>	10.0	10.3	15.1	14.2	15.4	14.0	13.9	12.8

**Table 3.11 – HPN point prevalence of malignancy, 2000 – 2015**

<b>Years</b>	<b>2000</b>	<b>2005</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>	<b>2013</b>	<b>2014</b>	<b>2015</b>
<b>Patient No.</b>	20	43	41	44	75	121	111	135
<b>%</b>	5.7	6.8	7.8	7.2	8.4	11.2	11.9	11.8

### **3.5 Age distribution, location, ability to manage and activity level of HPN patients**

During 2015 the vast majority of new and established HPN patients were under 71 years of age (81.5%); two thirds of patients were between 41 and 70 years of age. The age distribution data have not changed significantly in recent years, as illustrated in Figure 3.5.

The percentage of new registrations ‘initially living in a nursing home’ has remained stable and small (1.1% in 2000, 2.7% in 2005, 0.4% in 2010 and 1.9% in 2015). The majority have been discharged to their own home - 91.4% during 2015. Amongst established patients (point prevalence), the proportion living in nursing or residential homes was 2.6% during 2015, which has remained stable. Patient activity levels are shown in figure 3.6, and have also remained stable.

The percentage of patients who were 'independent' when newly registered was stable between 2000 and 2010, at 50-60%, but there has been a sharp decline between 2010 and 2013 to current levels, which were 26.7% during 2015 (figure 3.7).

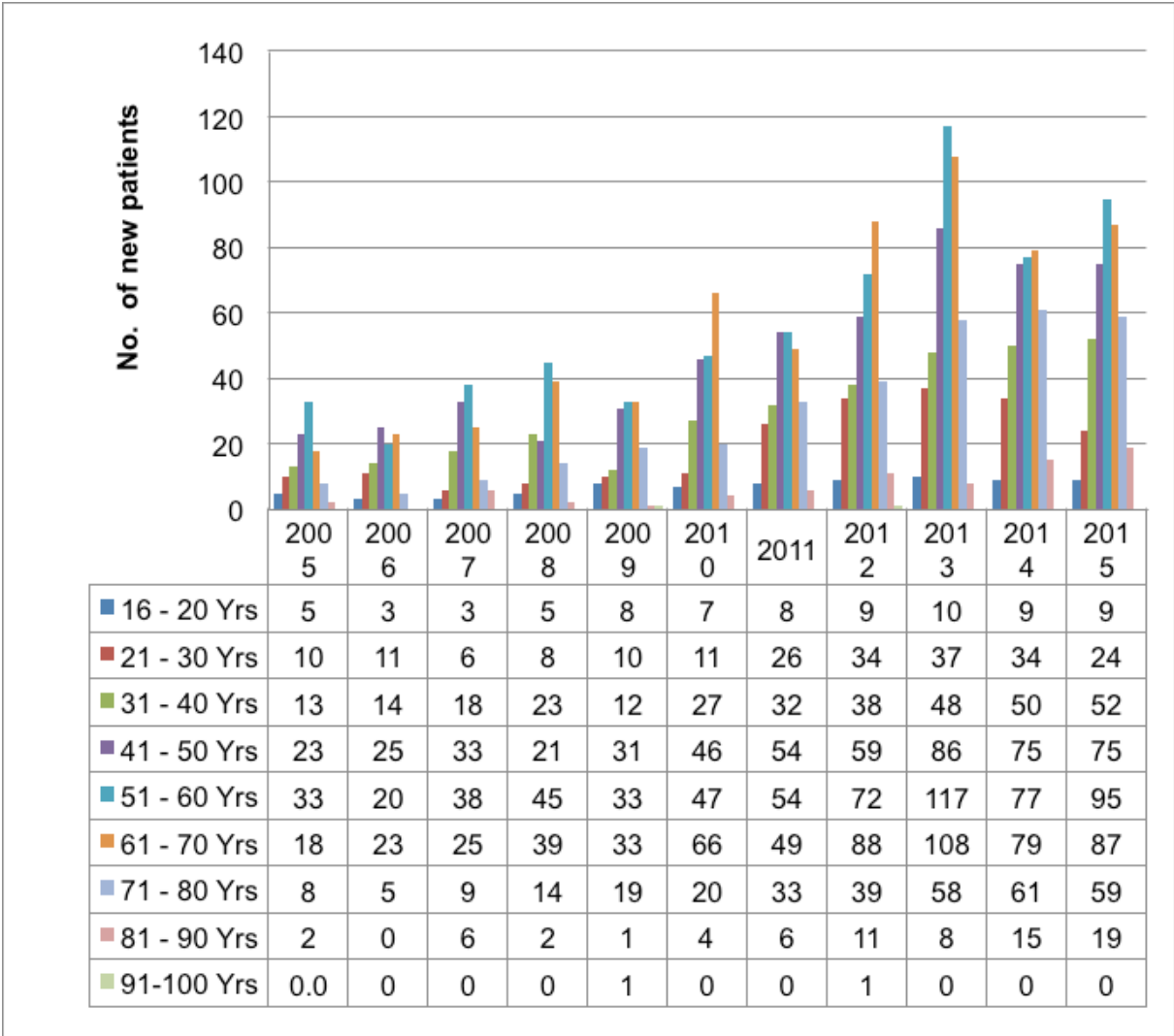


Figure 3.5 - Age distribution of new adult HPN patients in the UK; 2005-2015

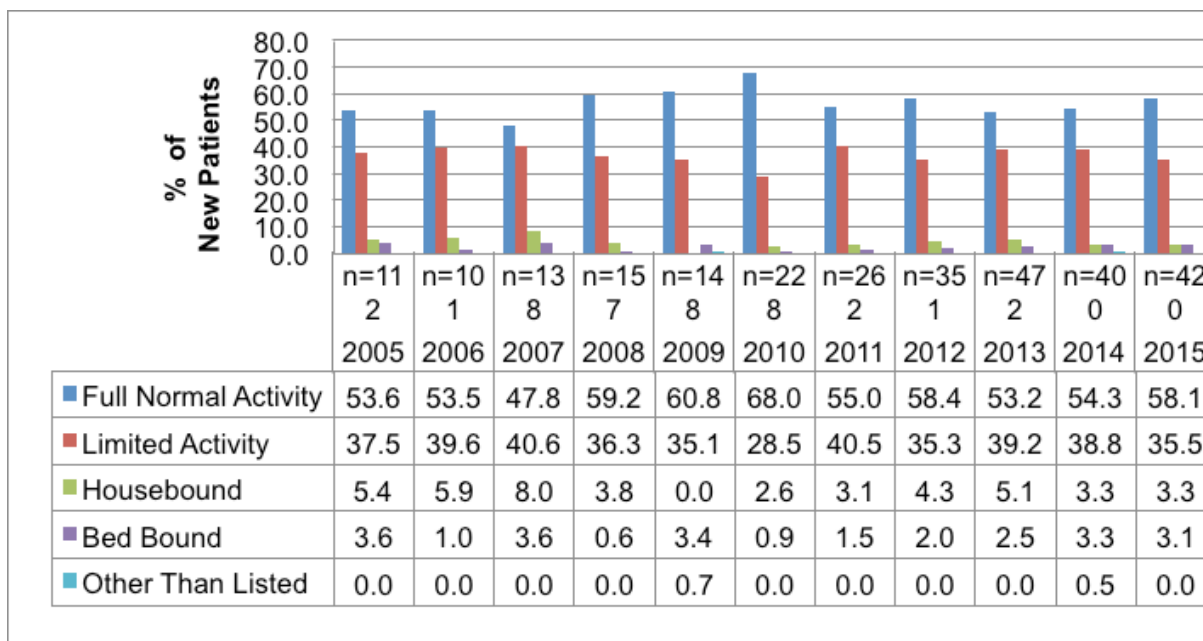


Figure 3.6 - The level of activity for new adult HPN patient registrations, 2005-2015

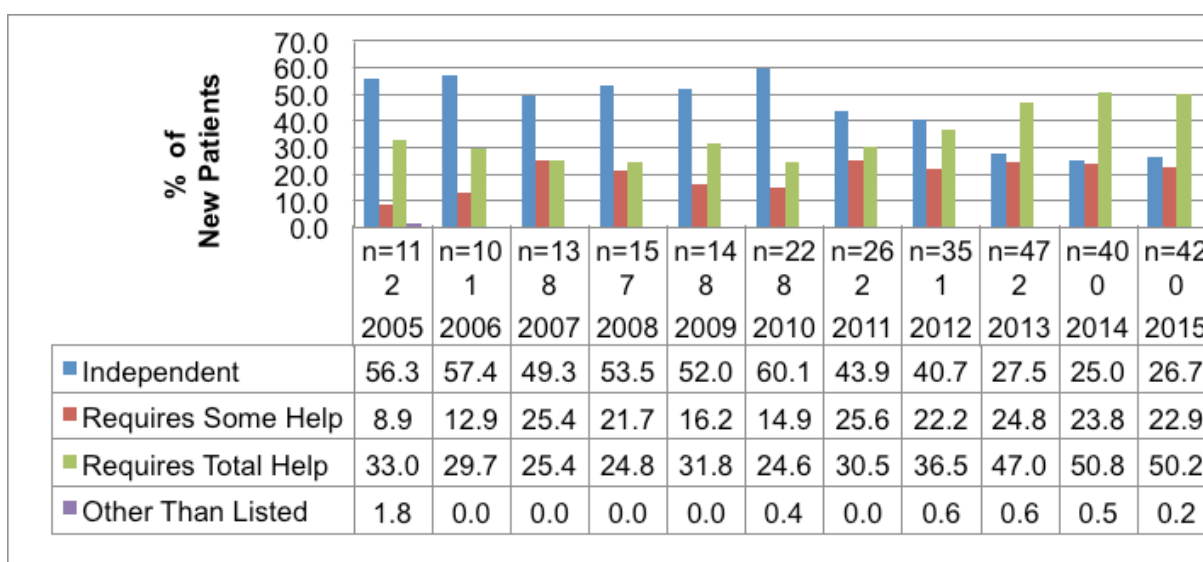


Figure 3.7 - The level of independence for new adult HPN patient registrations, 2005-2015

### 3.6 Access route for adult HPN patients

In the established cohort the point prevalence of HPN administered via a subcutaneous port was 5 – 9% between 2000 and 2009, after which there was a drop to 2.3% in 2010 and, henceforth remained between 2 - 4%; the point prevalence was 2.5% during 2015 (the new patient prevalence was 1.2% during 2015). All other HPN access was via an external catheter. Data have not been collected on the type of external catheter or the number of lumens.



### **3.7 Outcomes for patients receiving HPN during 2015**

1360 patients were registered with BANS during 2015; 84% were still on HPN at the end of the year, 6.5% had reverted to oral nutrition.

25% of HPN patients with malignancy died during 2015, compared to a non-malignancy death rate of 3.3%. This represents a 7% death rate for the entire cohort during 2015.

# Section 4: Adult Home Intravenous Fluids

## 4.1 New registrations, point and period prevalence

BANS has been collecting data on home intravenous fluids (HIVF) in addition to home parenteral nutrition (HPN) since 2011. 75 new adult HIVF patients were registered with BANS during 2015, which represents a consistent increase from 31 patients initially reported during 2011 (see figure 4.1). The reported point and period prevalence for HIVF during 2015 was 207 and 243 patients respectively.

The majority of registrations have been made in England, with small numbers in Wales and Northern Ireland. Intestinal Failure Units in Scotland currently do not report to BANS (see table 4.1).

Expressed in terms of population size, the prevalence of new HIVF cases in 2015 was 1.2 per million of the UK population, with a point and period prevalence of 3.2 and 3.8 cases per million respectively, during 2015.

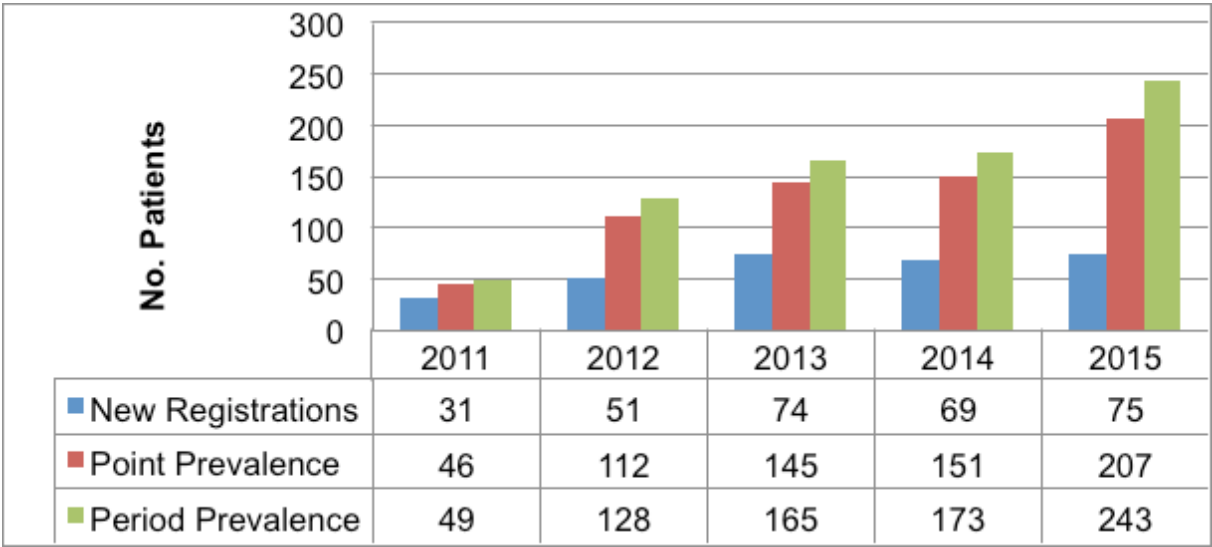


Figure 4.1: Number of new registrations, point prevalence and period prevalence of adult HIVF in the UK, 2011-2015

Table 4.1: Adult HIVF registrations in constituent countries of the UK 2011-2015

	2011	2012	2013	2014	2015
<b>New Registrations</b>					
England	27	49	72	64	73
Scotland	0	0	0	0	0
N. Ireland	1	1	2	0	0
Wales	3	1	0	5	2
<b>Totals</b>	<b>31</b>	<b>51</b>	<b>74</b>	<b>69</b>	<b>75</b>
<b>Point Prevalence</b>					
England	42	106	137	146	203
Scotland	0	0	0	0	0
N. Ireland	1	3	6	0	0
Wales	3	3	2	5	4
<b>Totals</b>	<b>46</b>	<b>112</b>	<b>145</b>	<b>151</b>	<b>207</b>
<b>Period Prevalence</b>					
England	45	122	156	168	239
Scotland	0	0	0	0	0
N. Ireland	1	3	6	0	0
Wales	3	3	3	5	4
<b>Totals</b>	<b>49</b>	<b>128</b>	<b>165</b>	<b>173</b>	<b>243</b>

#### 4.2 Reporting centres

18 centres registered new HIVF patients to BANS during 2015; 16 centres were located in England, with two in Wales. There were no reporting centres from Scotland or Northern Ireland during 2015. A total of 27 centres reported prevalence data (25 centres in England and 2 centres in Wales). See figure 4.2.

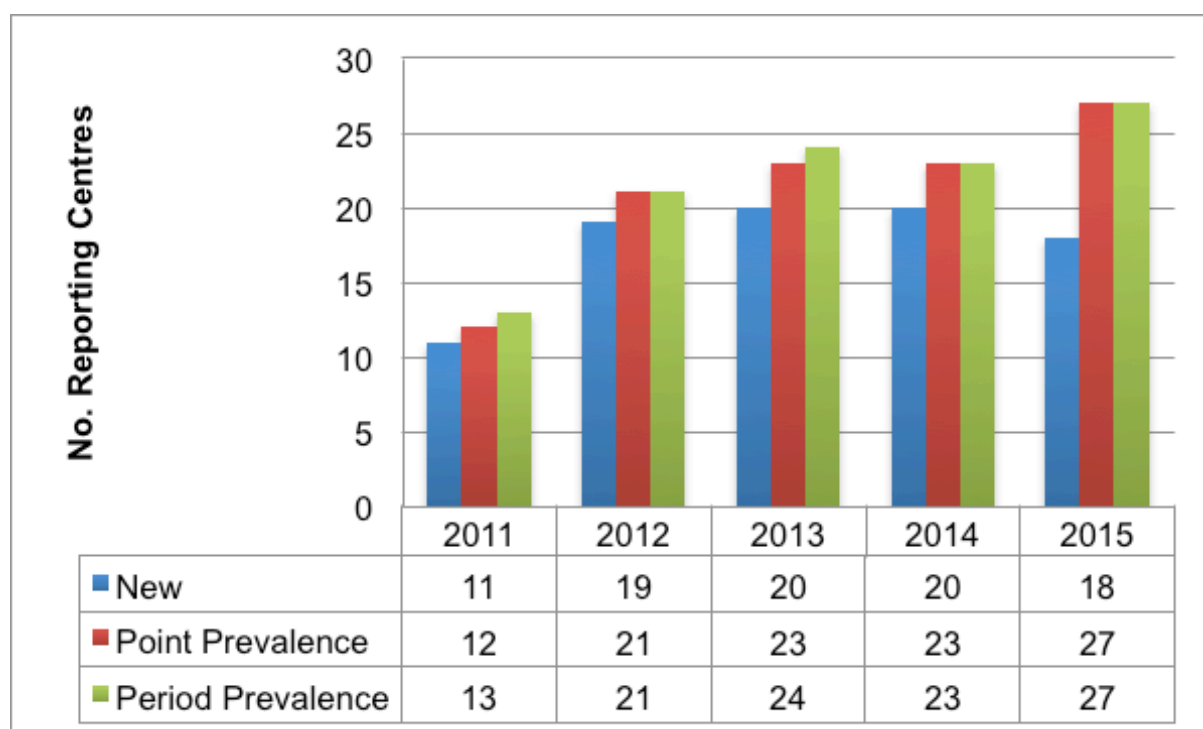


Figure 4.2 - Numbers of adult HIVF reporting centres in the UK for new registrations, point prevalence and period prevalence, 2011 – 2015

### 4.3 Indications for home intravenous fluids

In common with HPN, short bowel syndrome is the most common indication for establishing HIVF (table 4.2). During 2015 48% of patients were commenced on HIVF due to short bowel syndrome, 21% due to Malabsorption, 11% due to fistulae and 11% due to obstruction of the gastrointestinal tract. The remaining 9% of patients had an indication listed as 'other' (i.e. not clearly defined). Table 4.3 demonstrates the indications for HIVF for established patients (point prevalence data).

**Table 4.2 - Indications for new adult HIVF registrations (in percentages), 2011-2015**

Reason for Feeding	2011	2012	2013	2014	2015
Patient No.	n=31	n=51	n=74	n=69	n=75
Short Bowel	67.7	56.9	48.6	47.8	48.0
Fistula	12.9	11.8	6.8	5.8	10.7
Malabsorption	16.1	11.8	33.8	33.3	21.3
Gastro-intestinal Obstruction	3.2	7.8	4.1	5.8	10.7
Disease Related Malnutrition	0	9.8	2.7	4.3	0
Other Than Listed	0	2.0	4.1	2.8	9.3
Totals	100	100	100	100	100

**Table 4.3 - Indications for established adult HIVF registrations (point prevalence; in percentages), 2011-2015**

Reason for Feeding	2011	2012	2013	2014	2015
Patient No.	n=46	n=112	n=145	n=151	n=207
Short Bowel	58.7	50.9	53.8	51.8	52.2
Fistula	13.0	12.5	11.7	9.9	11.1
Malabsorption	23.9	13.4	26.2	27.1	26.1
Gastro-intestinal Obstruction	0	4.5	4.1	4.6	5.3
Disease Related Malnutrition	0	17.0	2.1	4.6	1.0
Other Than Listed	4.4	1.7	2.1	2.0	4.3
Totals	100	100	100	100	100

#### 4.4 Diagnoses and home intravenous fluids

Non-malignant disorders of the GI tract (including Crohn’s disease and mesenteric ischaemia) accounted for 61% of new registrations for HIVF during 2015; this compares to 84%, 76.5%, 66% and 80% for 2011, 2012, 2013 and 2014 respectively (see figure 4.3 and table 4.4).

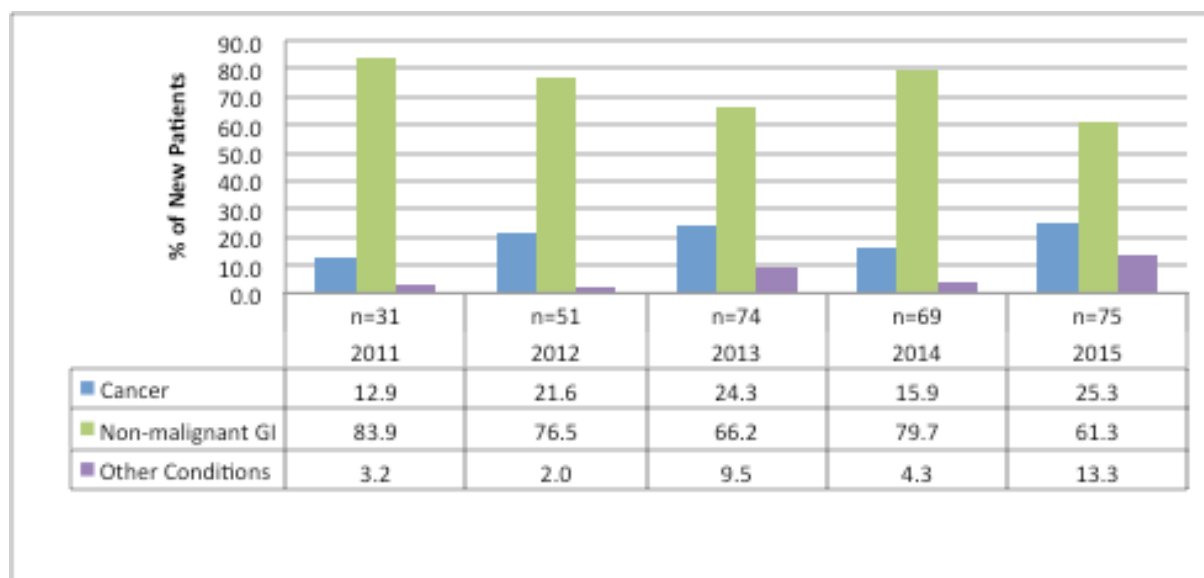


Figure 4.3 Diagnostic categories for new adult HIVF patient registrations; 2011-2015

Crohn’s disease accounted for 17% of all new adult HIVF registrations during 2015; this figure has gradually fallen since 2011, with crohn’s disease accounting 39%, 29%, 20% and 19% of new registrations during 2011, 2012, 2013 and 2014 respectively. Point prevalence data for crohn’s disease are shown in table 4.5.

Mesenteric vascular disease and pseudo-obstruction/motility disorders accounted for only a very small proportion of new HIVF registrations during the period 2011-2015 (see table 4.4).

In common with HPN, one quarter of new HIVF registrations during 2015 had an underlying diagnosis of malignancy (see figure 4.3). GI malignancies are the most common type of cancer, accounting for 42% of new malignancy-associated HIVF registrations during 2015. In contrast to HPN ovarian cancer accounts for only a very small proportion of new HIVF registrations (see table 4.6). The HIVF period prevalence associated with malignancy during 2015 was 17%, which has increased from 8% in 2011 (see table 4.7).

**Table 4.4 Non-malignant GI diagnostic categories for new adult HIVF registrations; 2011-2015**

	2011	2012	2013	2014	2015
	n=26	n=39	n=49	n=55	n=46
<b>Non-malignant gastrointestinal</b>					
Autoimmune enteropathy	1	0	2	1	0
Benign Intestinal Strictures	0	0	2	1	0
Crohn's Disease	12	15	15	13	13
Idiopathic intractable diarrhoea (infancy)	0	0	0	1	0
Perforated Bowel	0	0	4	3	5
Pseudo-obstruction/motility disorders	2	1	2	2	3
Radiation Enteritis	1	2	0	3	2
Ulcerative Colitis	3	2	5	6	1
Vascular Disease - ischaemic	1	6	2	4	5
Vascular Disease - Thrombotic	0	1	0	2	0
Volvulus	0	0	1	1	0
Other GI	0	3	2	6	4
<b>Total</b>	<b>20</b>	<b>30</b>	<b>35</b>	<b>40</b>	<b>31</b>
<b>Surgery</b>					
Bowel Resection	1	4	4	7	12
Short Gut/Bowel Syndrome	5	5	8	8	3
Small Bowel Transplant	0	0	2	0	0
<b>Total</b>	<b>6</b>	<b>9</b>	<b>14</b>	<b>15</b>	<b>15</b>
<b>Other GI Disease</b>					
GI Disease Other Than Listed	0	3	2	0	0
<b>Total</b>	<b>0</b>	<b>3</b>	<b>2</b>	<b>0</b>	<b>0</b>
<b>GI NON MALIGNANT TOTALS</b>	<b>26</b>	<b>39</b>	<b>49</b>	<b>55</b>	<b>46</b>

**Table 4.5 – HIVF point prevalence of Crohn's Disease 2011-15**

Year	2011	2012	2013	2014	2015
<b>Patient No.</b>	20	43	47	49	66
<b>%</b>	43	38	32	32	32

**Table 4.6 Malignancy categories for new adult HIVF registrations; 2011-2015**

	2011	2012	2013	2014	2015
	n=4	n=11	n=18	n=11	n=19
<b>GI Cancer</b>					
Cancer: Colonic	0	2	2	1	2
Cancer: Gastric	0	1	1	3	2
Large Bowel	1	3	5	3	3
Small Bowel	1	2	0	0	1
Totals	<b>2</b>	<b>8</b>	<b>8</b>	<b>7</b>	<b>8</b>
<b>Haematology</b>					
Lymphoma	0	0	2	0	0
Totals	<b>0</b>	<b>0</b>	<b>2</b>	<b>0</b>	<b>0</b>
<b>Head and Neck</b>					
Cancer: Head & Neck	0	0	0	1	1
Totals	<b>0</b>	<b>0</b>	<b>0</b>	<b>1</b>	<b>1</b>
<b>Miscellaneous Cancers</b>					
Bladder Cancer	0	0	2	0	0
Lung Cancer	0	0	1	0	1
Ovarian Cancer	0	1	2	2	2
Prostate Cancer	0	0	0	0	1
Cancer: Elsewhere than stated	2	2	3	1	6
Totals	<b>2</b>	<b>3</b>	<b>8</b>	<b>3</b>	<b>10</b>
<b>CANCER TOTALS</b>	<b>4</b>	<b>11</b>	<b>18</b>	<b>11</b>	<b>19</b>

**Table 4.7 HIVF period prevalence for malignancy; 2011-2015**

Diagnosis	2011	2012	2013	2014	2015
Bladder cancer	0	0	2	1	0
Cancer head & neck	0	0	0	1	1
Cancer elsewhere than listed	2	6	8	6	12
Cancer: colonic	0	3	3	2	5
Cancer: gastric	0	1	1	3	2
Cancer: small bowel	1	2	1	0	3
Large bowel	1	4	7	6	9
Lung cancer	0	0	1	0	1
Lymphoma	0	0	2	2	1
Ovarian cancer	0	1	3	3	6
Prostate cancer	0	0	0	0	1
<b>Totals</b>	<b>4</b>	<b>17</b>	<b>28</b>	<b>24</b>	<b>41</b>

#### **4.5 Age distribution, location, ability to manage and activity level of HPN patients**

The vast majority of new and established HIVF patients are under 71 years of age (76%). The age distribution data are illustrated in figure 4.4

The vast majority of new patients receiving home intravenous fluids were discharged to their own home (93% in 2011, 94% in 2012, 96% in 2013, 99% in 2014 and 97% in 2015); the other patients were discharged to rehabilitation units or nursing homes. Amongst established patients (point prevalence) 98% were living in their own home during 2015.

Patient activity levels are shown in figure 4.5. Typically two thirds of new HIVF patients have been registered as 'full normal activity' since BANS started collecting data on this cohort of patients in 2011, although this figure reduced to approximately 55% in 2013 and 2015. Amongst established patients 73% of patients were categorised at 'full normal activity' during 2015; this figure has been remained stable over the time period 2011-2015.

There has been a sharp decline in the proportion of new HIVF fluid patients registered as 'independent'; 71% of patients were 'independent' during 2011 compared to 21% of patients during 2015 (see figure 4.6). There has been a similar trend amongst established patients – 80% were 'independent' in 2011, 67% in 2012, 49% in 2013, 45% in 2014 and 39% in 2015.



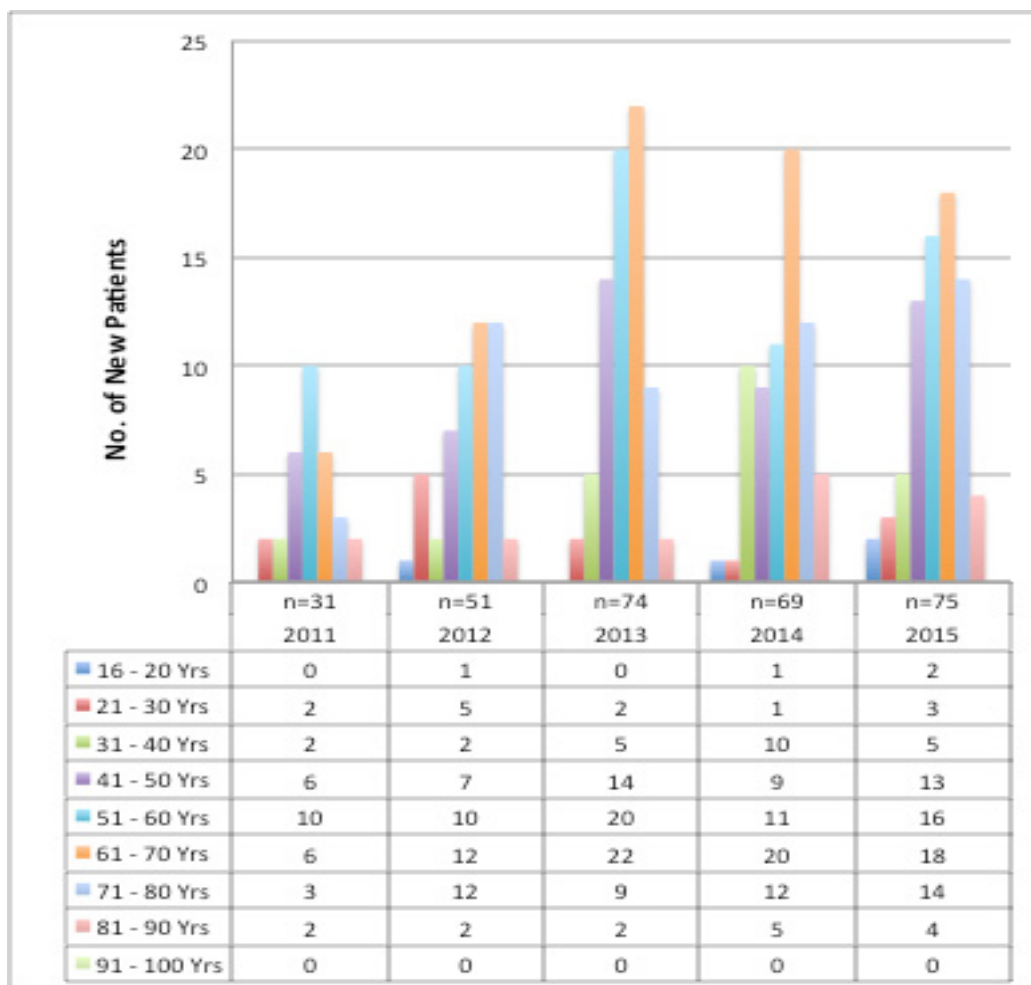


Figure 4.4 Age distribution for new adult HIVF patient registrations; 2011-2015

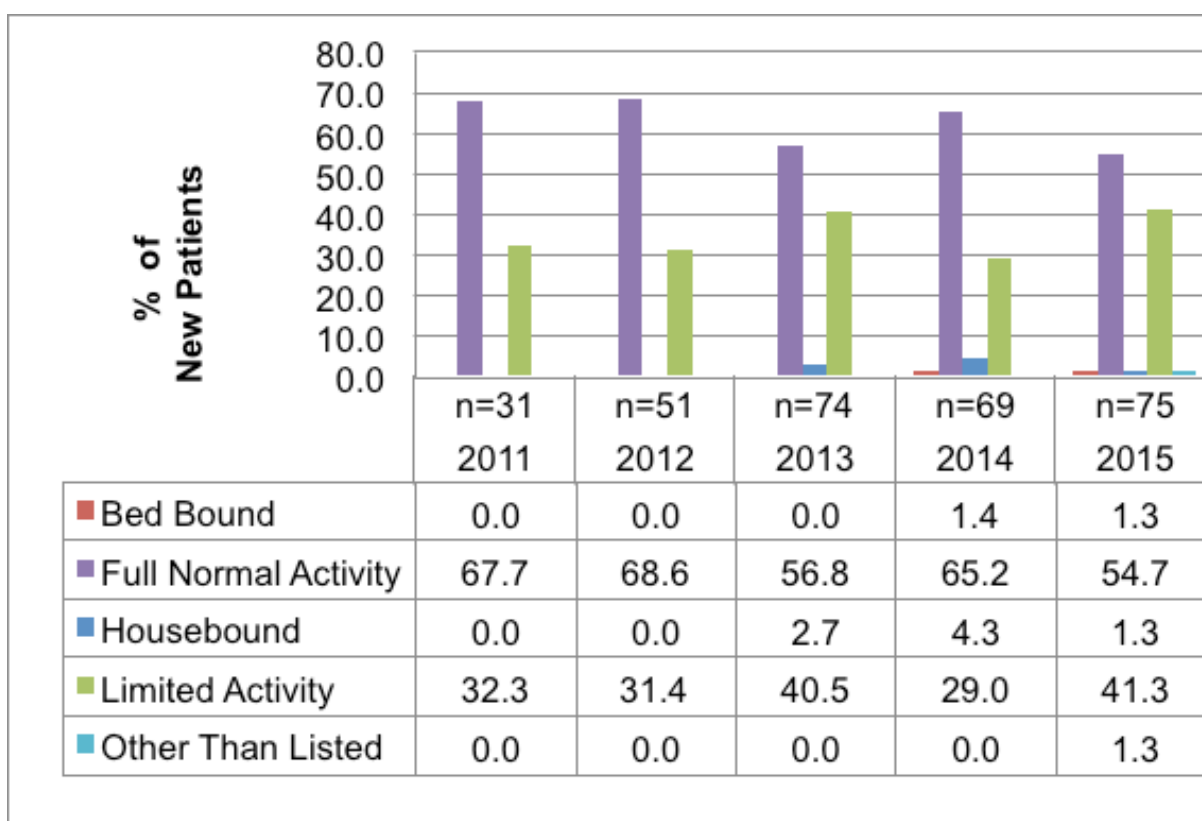


Figure 4.5. The level of activity for new adult HIVF patient registrations; 2011-2015

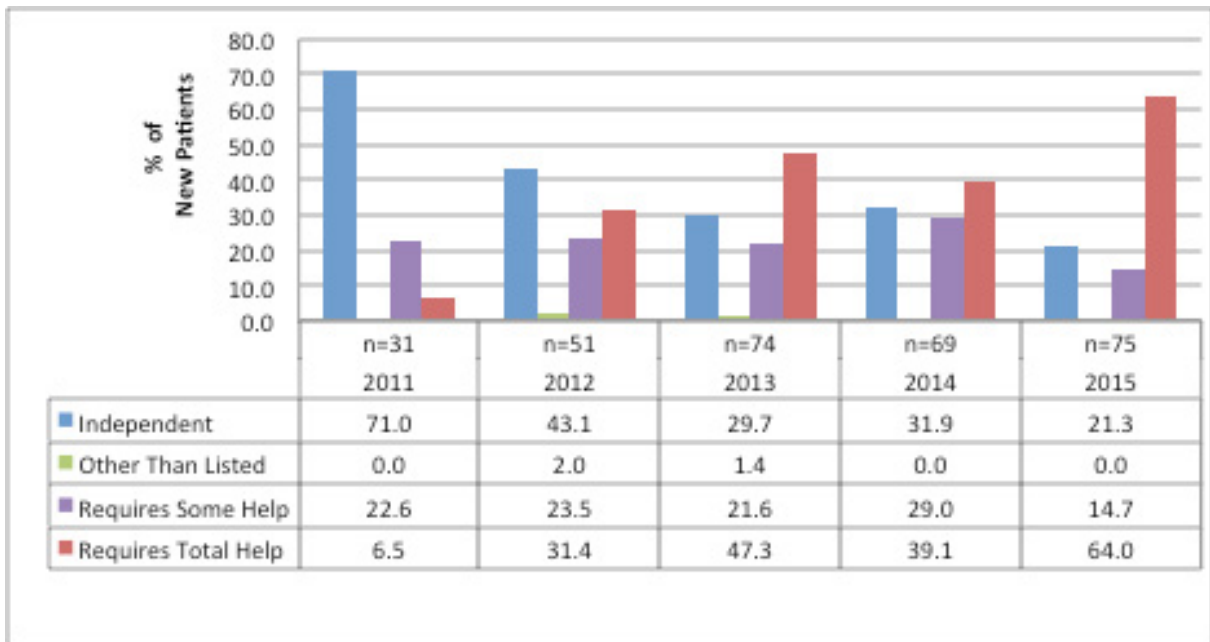


Figure 4.6. The level of independence for new adult HIVF patient registrations; 2011-2015

#### 4.6 Access route for adult HIVF patients

95% of new adult HIVF patients received parenteral fluid therapy via an external catheter during 2011-2015. 90% of established patients received parenteral fluid therapy via an external catheter with the remaining 10% receiving fluids via a subcutaneous port.

#### 4.7 Outcomes for patients receiving HIVF during 2015

243 patients receiving HIVF were registered with BANS during 2015; 85% were still on HIVF at the end of the year, 6.5% had reverted to oral nutrition.

17% of patients with malignancy had died during 2015, compared to a non-malignancy death rate of 4.4%. This represents a 7% death rate for the entire cohort in 2015.



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