The Annual Meeting of the Clinical Nutrition and Metabolism Group of the Nutrition Society with the British Association for Parenteral and Enteral Nutrition, in conjunction with the 24th Congress of the European Society for Parenteral and Enteral Nutrition, was held at the Scottish Exhibition and Conference Centre, Glasgow on 4 September 2002

The Pennington Lecture*

Recent developments in the delivery of home parenteral nutrition in the UK

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The British Artificial Nutrition Survey 2001 recorded 507 home parenteral nutrition (HPN) patients (Crohn's disease 31.5 %, vascular disease 19.7 %, cancer 6.9 %). Parenteral nutrition was administered via tunnelled central line (92 %) and supplied by a commercial homecare company in 89 % of cases. The majority of HPN patients live at home (95.5 %) with an independent life (74 %), normal activity (59.2 %) and 92 % survive 1 year. However, there is good evidence that the geographical distribution of HPN patients is uneven (prevalence no patients to thirty-six patients per million of the population) suggesting inequity of access. Patients are increasingly concerned about the distances travelled to main centres and variable standards of more local support. Funding issues continue to cause difficulties as commissioning of health care transfers from Health Authorities to Primary Care Trusts. The two nationally-funded intestinal failure units provide HPN services to 220 HPN patients. HPN-related readmissions have displaced those awaiting admission for intestinal failure treatment, for which the waiting list mortality in one unit has risen to 14 %. The government has now recognised HPN as a specialised service distinct from intestinal failure and that existing medium-sized HPN units should be encouraged to take on HPN patients from intestinal failure units and smaller units. In Scotland a Managed Clinical HPN Network supported by the Scottish administration now cares for seventy-two patients under common protocols. The challenge for the future is how to provide high-quality care to all who need it in the rest of the UK.

Home parenteral nutrition: Intestinal failure

Patients with intestinal failure require replacement therapy just as do patients with other organ failure. Mediumto long-term intestinal failure is most commonly a result of short bowel syndrome, although some patients have intact but non-functioning guts. Intravenous nutrition provided at home in a manner analogous to home haemodialysis now offers patients hope of prolonged and improved quality of life. As with many novel treatments, innovative and inspired clinical leadership has led to the provision of home parenteral nutrition (HPN) in many centres in the UK. To date, no centre has been officially recognised as a provider of HPN and there is no nationally-coordinated HPN service. Using data from the British Artificial Nutrition Survey (BANS; Elia *et al.* 1999, 2001, 2002) the British Association for Parenteral and Enteral Nutrition (BAPEN), chaired

by Professor Chris Pennington, recognised in 1999 that the delivery of HPN in the UK is associated with inequity of access and highly variable quality of care. The present review describes the basis for these concerns and the progress made towards rectifying them. Much of the data on HPN is derived from the annual surveys performed by the BANS, a constituent body within BAPEN. Both BAPEN and BANS are multidisciplinary organisations that include representation from patients (Patients on Intravenous and Nasogastric Nutrition Therapy).

Historical perspectives

The first patients discharged home on intravenous nutrition in the UK were at St Mark's Hospital, London

*This lecture was established in memory of the late Professor Chris Pennington, University of Dundee, President of ESPEN 2002. **Abbreviations:** BANS, British Artificial Nutrition Survey; BAPEN, British Association for Parenteral and Enteral Nutrition; HPN, home parenteral nutrition; IFU, intestinal failure unit; NSCAG, National Specialised Commissioning Advisory Group. **Corresponding author:** Dr Barry J. M. Jones, fax +44 1384 244262, email B.J.M.J@btinternet.com

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and Hope Hospital, Salford in 1978. A central register of such patients began to be kept almost immediately in Salford. In 1996 this function was transferred to BANS, which has conducted ongoing surveys of HPN ever since. In 1980 Sir David Cuthbertson opened a four-bed intestinal failure unit (IFU) at Hope Hospital. This IFU was expanded to a twelve-bed unit, which was opened in 1997 by Professor John Lennard-Jones, who had initiated a similar service at St Mark's Hospital. The two IFU were officially recognised in 1998 when funding was obtained from the National Specialised Commissioning Advisory Group (NSCAG) at the Department of Health. It is important to note that these centres were funded for type 2 intestinal failure and not type 3 intestinal failure requiring HPN (where type 1 is classified as short-term intestinal failure as after abdominal surgery when IF is self limiting; type 2 is intestinal failure in severely-ill patients with major resections of bowel and septic, metabolic and nutritional complications requiring complex multidisciplinary intervention with metabolic and nutritional support to permit recovery; type 3 is chronic intestinal failure requiring long-term nutritional support; see Shaffer, 2002) although this treatment forms a major component of the overall care of 55 % of the patients with intestinal failure. HPN has now been provided from as many as fifty centres around the UK, although some hospitals have only limited or sporadic experience of this complex treatment. No officially-recognised HPN units exist in England as yet, but in Scotland and recently in Wales much progress has been made.

BAPEN was founded as a result of the King's Fund report (Lennard-Jones, 1992), and not long afterwards BAPEN published quality criteria for HPN services (British Association for Parenteral and Enteral Nutrition, 1994).

Home parenteral nutrition characteristics and trends 1996–2001

BANS reports (Elia et al. 2001, 2002) indicate that point prevalence (the number of patients receiving HPN on a given day, i.e. the census day) and period prevalence (the number of patients receiving HPN over a given period, in this case 1 year; point prevalence is less than period prevalence since duration of treatment is often < 1 year, so the total number of patients fed over the whole year is greater than the number at any one time) of adult HPN have shown a steady rise each year (Fig. 1), although the numbers of new patients have remained stable over the last 3 years. In 2001 507 patients received HPN and 407 patients were being fed at any one time in twenty-nine centres. These estimates are unlikely to represent the absolute number of HPN patients because of underreporting estimated at 20 %. In Scotland the Managed Clinical HPN Network has recorded a point prevalence of seventy-two patients from no less than sixteen centres in a population of 5.5 million (Baxter et al. 2002). A BANS survey of pharmaceutical advisors in 1998 (Elia et al. 1999) found that about one-third of patients from thirtyeight Health Authorities in the UK were not registered with BANS. A similar exercise would now be difficult following the demise of Health Authorities in England, but it seems likely that a point prevalence of 500 and a period prevalence of 600 might be realistic estimates of the true position across the UK in 2001.

Indications by diagnosis

BANS data (Elia et al. 2001, 2002) indicate that Crohn's disease remains the most common indication for HPN, but the percentage of HPN patients with Crohn's disease has fallen from 37.5 to 21.8 in relation to new referrals and from 44.6 to 31.5 in relation to point prevalence. No new patients had HIV, reflecting improvements in treatment of this condition. Vascular disease leading to small bowel infarction is rising. Cancer of the gastrointestinal tract and other cancers account for 14·1 % of the new referrals but only 6.9 % of the point prevalence, suggesting that survival time in this group is short. There is no evidence that the proportion of HPN patients with cancer as the main indication is rising. There continue to be major differences between the UK and mainland Europe and USA in relation to HPN provision for cancer. However, cancer is a major contributor to the numbers of patients undergoing home enteral tube feeding in the UK and represents 25.3 % of all new registrations, mainly for head and neck, oro-pharyngeal and oesophageal cancers (Table 1).

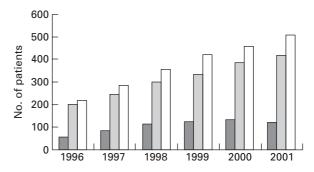


Fig. 1. British Artificial Nutrition Survey data for home parenteral nutrition (HPN) in 2001. (■), New registrations; (■), point prevalence (the no. of patients receiving HPN on a given day, i.e. the census day); (□), period prevalence (the no. of patients receiving HPN over a given period, in this case 1 year; point prevalence is less than period prevalence since duration of treatment is often <1 year, so the total number of patients fed over the whole year is greater than the number at any one time). (From Elia *et al.* 2002.)

Table 1. Home parenteral nutrition (HPN) associated with cancer; new registrations 2001 (Elia *et al.* 2002)

Cancer	HETF (%)	HPN (%)
	1111 (70)	11/11 (70)
Head and neck	8.5	0
Oropharyngeal	8.4	0
Oesophageal	5.3	2.5
Stomach	1.0	0.8
Pancreatic	0.1	0.8
Small bowel	0.1	1.7
Colonic	0.3	5.0
GI lymphomata	0.1	0
Other	1.4	3.3
Total	25.3	14·1

GI, gastrointestinal; HETF, home enteral tube feeding.

Indications by reason for nutritional support

Short bowel syndrome continued to be the main indication for HPN in new patients in 2001 (46.7%), with malabsorption (11.7%), fistula (10%), gastrointestinal obstruction (10%) and swallowing disorders (5.8%) making up the remainder (Elia *et al.* 2001, 2002). There was a higher representation of short bowel (61.3%) in the estimates for point prevalence.

Age

The commonest age range for new patients on HPN is 41-60 years, accounting for 50 % of the new HPN patients (Elia et al. 2001, 2002). Between 1996 and 2001 there was an upward age shift overall and within the 41-60 years age range. Patients between 71 and 90 years now represent $14\cdot1$ % of the new registrations. Point prevalence in this age-group is only $6\cdot9$ %, suggesting that the survival rate in this group is not good. As established HPN patients become older, or older patients are referred for HPN, the support required will increase. This situation has implications for carers and commissioners of care. Ethical dilemmas will be inevitable.

Dependency

The ability of HPN patients to manage their HPN independently has changed dramatically, reflecting a change in practice across the UK. The rate of independent living amongst new registrations has fallen from 75 % in 1996 to 55.8 % in 2001, and this trend is reflected in the fall in point prevalence (from 83.2 % to 74 %; Elia et al. 2001, 2002). Those requiring total help, including their HPN administration, have risen from 8.9 % to 21.7 % over the 6 years, although this increase has not yet filtered through to the point prevalence estimates, perhaps because some patients eventually achieve independence. These findings suggest that the threshold for selection of patients for HPN has changed to include those previously rejected on the grounds that quality of life and availability of support were not sufficient to justify HPN. The observation that the mean age of HPN patients has shifted upwards confirms these findings.

Residence

In the 4 years that this statistic has been audited there is already a trend away from patients living in their own home to living in nursing homes in which 5.8 % of new registrations now reside (Elia *et al.* 2001, 2002). This trend has major resource and training implications.

Activity levels

New patients are more likely to be bed bound or housebound than they were 6 years ago, and limited or full activity is less evident now than in 1996, but the majority of HPN patients are still able to demonstrate limited or full activity (Elia *et al.* 2001, 2002). These estimates should be contrasted with those for home enteral tube feeding.

Venous access

Data for venous access routes have shown a slight trend away from subcutaneous ports to tunnelled catheters with an external section (Elia *et al.* 2001, 2002). There is little difference between the estimates for new registrants and those for point prevalence, suggesting that there is no net trend towards switching from a port to an external section line as sepsis complicates port placement.

Homecare company involvement

It is generally considered good practice to involve a commercial homecare company in the provision of HPN solutions and equipment. There has been a clear trend towards use of such companies over the last 4 years (from 74·1 % to 89·2 %; Elia *et al.* 2001, 2002). However, even in Scotland the largest centre has found it difficult to obtain funding for commercial homecare support of its twenty-five HPN patients.

The evidence for inequity of access to home parenteral nutrition

In 1999 BANS data (Elia *et al.* 1999) demonstrated a wide variation in point prevalence of HPN by region and by Health Authority. However, an additional survey of pharmaceutical advisers to Health Authorities revealed underreporting of about 20 % compared with BANS data from the individual reporters within National Health Service Trusts. With this additional data, variation in prevalence between Health Authorities of origin of no patients to thirty-six patients per million of the population was demonstrated. There is a < 1 in 1000 possibility of this variation occurring by chance alone. Such variation cannot be explained by similar variation in the underlying disease processes that lead to intestinal failure and HPN. It follows that many patients who should receive HPN do not, which is the basis on which the thesis of inequity of access is founded.

In Scotland all patients receiving HPN in 2001 have been identified, giving a point prevalence of fourteen patients per million of the population. This estimate exceeds the overall UK rate of approximately eight patients per million of the population, as assessed by BANS, even allowing for underreporting in England and Wales (Table 2).

Table 2. Point prevalence of home parenteral nutrition (no. of patients receiving home parenteral nutrition on any given day i.e. census day)

	Rate (per million of the population)
Scotland	14
UK*	7⋅5
UK†	9
England: North West region, 2000	14
West Midlands region, 1999	3.4
Denmark	12.7
USA (no records since 1992)	30–40

^{*}British Artificial Nutrition Survey 2001 (Elia et al. 2002).

[†]Pharmaceutical advisors 1998 (Elia et al. 1999).

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Further evidence is available from the patterns for intestinal failure referrals to the two nationally-funded IFU (Fig. 2). Their remit is to provide an intestinal failure service for the whole of England and Wales. It will be seen later that such a remit will be impossible to achieve without major changes to the provision of HPN. Referrals to both units are predominantly from adjacent regions. If patients with intestinal failure are going to other centres, it is not reflected in the HPN data for those centres, except in Northern Ireland and Cambridge. Thus, large areas of the country apparently do not place as many patients on HPN. The treatment of intestinal failure must vary, therefore, according to the geographic area in which the patient suffers their cause of intestinal failure. These data suggest that HPN is not being offered in many hospitals as an interim or long-term measure for patients with intestinal failure. The reasons may be: there is no local available HPN service; ignorance of the success of HPN; the distances involved if referral is made to a major centre. There is anecdotal evidence of older patients with acute small bowel infarction leading to short bowel syndrome not being considered for HPN because of the logistics involved.

Evidence for variation in standards of home parenteral nutrition

HPN is a specialised form of nutritional care with possible life-threatening complications. If care is to be effective, it should be provided from centres with adequate expertise. It is generally accepted that optimal nutritional care is provided through a multidisciplinary team (Lennard-Jones, 1992; British Association for Parenteral and Enteral Nutrition, 1994). BANS data from 209 centres in 144 hospitals reveal that only 41 % of respondents have a nutrition support team and that this percentage has not risen for several years (Elia *et al.* 2002). These data may overestimate the true proportion of hospitals with a nutrition support team, since not all hospitals participate in BANS data collection. There has been a slight increase to 79 % in the number of teams with a nutrition nurse. At the latest count in May 2002 there were seventy-two nutrition nurse

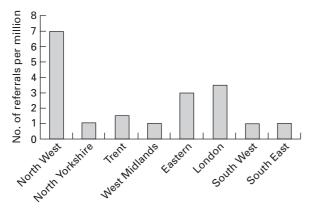


Fig. 2. Population-adjusted combined intestinal failure referrals for 2000–1. Data from the two UK nationally-funded intestinal failure units, at St Mark's Hospital, London and Hope Hospital, Salford. (From S Gabe, personal communication.)

specialists from fifty UK centres registered as members of the National Nutrition Nurse Group of BAPEN. It is known that parenteral nutrition catheter-related sepsis rates are unacceptably high when there is no nutrition support team. Surprisingly, ten of thirty-eight HPN centres report that they do not have a nutrition support team, although some centres deal with eight to twenty-nine HPN patients.

The most recent BANS survey indicates that many hospitals do not even record and audit their catheter sepsis rates. Those hospitals that can report in-patient sepsis rates returned estimates of 0–87 %! If a hospital has a poor in-patient parenteral sepsis rate it is unlikely to achieve a high standard with HPN. Some hospitals have very limited exposure to HPN, with twelve of thirty-eight having only one patient and five centres having only two patients (Elia *et al.* 2002). Patient surveys have revealed perceived inadequacies of care in relation to knowledge of line care, management of catheter sepsis, variable training and post-discharge support and information (Wheatley, 2002). Centres that do not use commercial homecare companies to provide community support may offer a less than optimal service.

Relationship between home parenteral nutrition and intestinal failure

It is important to recognise that not all patients with intestinal failure or short bowel syndrome will require HPN. Not all patients needing HPN require intestinal failure services when they have completed their surgical experience in their local hospital. The NSCAG-funded national IFU are funded for type 2 intestinal failure (Shaffer, 2002). This group comprises patients with sepsis, fistulas, peri-operative problems or complications of feeding requiring more than routine care of their central catheter. Multidisciplinary surgical support, stoma care and nutritional support will be essential. By comparison, patients with type 3 intestinal failure will be on medium- to long-term parenteral nutrition but will no longer be in need of the services provided to patients with type 2 intestinal failure. For many patients, infirmity, age, distance or diagnosis may limit the ease with which HPN can be initiated in a major centre such as the two IFU. Thus, patients with cancer need HPN in conjunction with their local cancer services and cannot be transferred away to a distant unit. Older patients who have suffered small bowel resection after infarction find travel to distant units difficult and may not be offered HPN if it is not available more locally.

Intestinal failure unit experience

The two IFU each admit about sixty patients with type 2 intestinal failure per year, but have now reached saturation point with >100 HPN patients each. Admission of new intestinal failure referrals for complex assessment, initial nutritional and metabolic stabilisation, and often highly complex surgery is now severely affected by readmissions of established HPN patients. Only 55 % of the patients admitted to an IFU subsequently require HPN, but 66% three readmissions are for HPN-related problems and not intestinal failure. As a result, waiting list mortality has risen to 14 % at Hope Hospital, whereas mortality of those

admitted is only 2–4 %. The time available for IFU staff to deal with each patient is therefore limited. It has become clear to both the IFU and NSCAG that a policy for offloading HPN patients is required to allow the IFU to provide a more nationally distributed service for intestinal failure problems and to train new HPN patients for discharge to other units. As already stated, both IFU attract most of their patients from regions closest to them. Recruiting from more distant regions cannot be considered unless a new policy for HPN is forthcoming.

Funding issues

Funding has always been a difficulty for those wishing to offer HPN. From 1995 to 2002 Health Authorities acted as commissioners of care and could cross-charge other Health Authorities. Following the government's document Shifting the Balance of Power (Department of Health, 2002), funding and commissioning of health care passes to new Primary Care Trusts. However, there is no instruction from central government concerning the necessity for Primary Care Trusts to provide for individual specialised services such as HPN. There is no guarantee that funds will be available for HPN in a cash-strapped health economy. A major HPN centre wishing to return a patient to the Primary Care Trust responsible for the care of that patient may find unacceptable bureaucratic delays prevent expeditious discharge, thereby compounding the saturation problems already discussed. It should be considered unacceptable to train a patient for HPN to a given standard within a certain time only to find that discharge is delayed for lack of available funding. Since April 2002 there is accumulating anecdotal evidence of delayed decision making by Primary Care Trust commissioners who have no previous experience of this type of treatment. Discharge from hospital is often delayed while trying to find the appropriate authority to sanction funding for individual patients. This situation is unacceptable.

The government commissioned the London Regional Specialised Commissioning Group to formulate national definitions of specialised services. These definitions included 'high cost-low volume' services such as HPN (London Regional Specialised Commissioning Group, 2001). The definition was agreed after extensive consultations and published in November 2001.

It has subsequently been made clear by the Department of Health that the existence of the specialised service definition for HPN is for guidance of commissioners only (E Jessup, personal communication).

Comparisons with paediatric home parenteral nutrition

In 2001 twelve centres reported thirteen new patients and a total of seventy-eight on HPN in the year as a whole. The age distribution shows relatively few on HPN in the age-group 13–15 years (point prevalence 8·7 %). It is not clear how many of these patients will go on to require HPN as adults (> 16 years), but this is an important issue as there are no recognised centres for juvenile HPN patients undergoing the transition from their specialist paediatric centre to an adult centre. Such patients often have special problems such as HPN-related liver disease or psycho-social difficulties.

Interestingly, commercial homecare companies are used less frequently for paediatric patients (61.5% v.89.2% for adults) and subcutaneous ports are used more frequently (23.1% v.5.8% in adults; Elia *et al.* 2002).

Distances travelled

Data from Hope Hospital show that patients are travelling considerable distances for routine attendances and emergencies. Of these patients 45 % travel > 80·5 km and 21 % are > 60 years old. Patients have recorded even greater distances in a national survey performed by Patients on Intravenous and Nasogastric Nutrition Therapy in 2001 (Wheatley, 2002). The mean distance travelled for a routine appointment was 135 km and for an emergency it was 114 km. Each trip cost the patient £16·48 and a family member or carer accompanied 50 % of the visits. These data show that the present service is not very 'patient friendly'.

Patient survey data

The Patients on Intravenous and Nasogastric Nutrition Therapy 2001 survey (Wheatley, 2002) revealed the affection and confidence that patients have for their major centre, but 78 % would like to receive their care nearer to their home. However, 30 % were dissatisfied with the service given to them at their local hospital. It is clear that patients wish to have more locally-available high-quality care similar to that which they receive in more remote major centres.

Progress in Scotland

It will be apparent that organisational changes are required to rectify the many problems prevailing in the delivery of HPN. The shortcomings of the service in Scotland were recognised by Chris Pennington and others in 1998. The publication of the Acute Services Review of the National Health Service in Scotland (Scottish Executive, 1998) saw the development of managed clinical networks as the most important strategic issue, with the role of lead clinician being pivotal. With active involvement of the Scottish Executive Health Department and the Clinical Standards Board for Scotland, the new Scottish Managed Clinical Network for HPN was founded in 2000 under the leadership of Professor Chris Pennington. By November 2001 the network had held its first annual business and educational meeting followed by its first annual report. The stated aims were:

- 1. to ensure equity of access;
- to ensure that patients are managed according to evidence-based nationally-agreed procedures and protocols;
- 3. to enable provision of HPN in a cost-efficient manner;
- 4. to allow audit of practice and outcomes, and hence provide a basis for improving quality of care;
- 5. to encourage multi-professional care.

Before the inception of the managed clinical network, there were five known centres in Scotland treating forty HPN patients. Following the appointment of a coordinator, sixteen centres with seventy-two patients were identified, with the highest point prevalence in the UK of fourteen

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patients per million of the population (Baxter *et al.* 2002; Tait & Baxter, 2002). Joint protocols (Baxter & Tait, 2002) have been developed, agreed and circulated to participating centres, some of which have only one patient. Remote hospitals are supported by visits from the coordinator and training of local staff. Catheter sepsis rates have shown a slight reduction. Harmonisation of delivery of nutrition bags, ancillary equipment, documentation, patient-held records and patient information are in progress and audit is active (McKee *et al.* 2002). It is envisaged that economies of scale may be achieved by negotiation with homecare companies. It is clear that this project has been ground breaking and sets the standards for the rest of the UK to follow. However, progress will not be possible without the commitment and involvement of government agencies.

Welsh Managed Clinical Network

As in Scotland, the presence of strong devolved government in Wales has led to support for HPN as a specialised service. An embryo network is now being formed with Cardiff, Swansea and Wrexham as the involved centres. They will continue to work in close cooperation with the national intestinal failure centres.

England

With its much higher population, centralised government and the major changes in funding arrangements since April 2002, it has proved difficult to move forward. The policy of 'shifting the balance of power' devolves decision making to Primary Care Trusts. Strategic Health Authorities are only just beginning to become effective and Primary Care Trust specialised service consortia have not yet acquired the expertise or capacity to deal with all the issues relating to specialised services. During this difficult period BAPEN and the two IFU have been in negotiation with the Department of Health and some progress has been made.

First, the Department of Health has now recognised the distinction between intestinal failure and HPN services. This recognition is enshrined in the Specialised Services Definition no. 12 (HPN; London Regional Specialised Commissioning Group, 2001), which sets out the basic requirements for an HPN service and states that intestinal failure is separately funded by NSCAG.

Second, the Department of Health have noted that the national IFU are unable to subserve their designated role because the service is blocked by large numbers of HPN patients no longer requiring type 2 intestinal failure services. Initially, it was thought that more national IFU would be commissioned, but this policy has now changed. The Department of Health is now keen to build up a 'subnational service for HPN using existing strengths in networks or 'hub and spoke' arrangements according to local needs' (E Jessup, personal communication). It has also been noted that existing units will not be able to take on patients from the two national IFU or from smaller less-viable centres without investment. This constraint particularly applies to specialist nurses.

The way is now clear for BAPEN and other interested parties to move forward in England. It is now possible to

aim for effective organisational restructuring similar to that in Scotland.

A 'sub-national' home parenteral nutrition service

There are approximately twenty units capable of providing HPN in England. Assuming a national point prevalence of fourteen patients per million of the population (700 patients), that the two national IFU continue to care for about eighty HPN patients each, and that Scotland has seventy-two HPN patients and Wales forty, the remaining 428 could be distributed between a network of twenty centres. Some teaching hospitals could probably take thirty or more patients, whereas smaller District General hospitals could support fifteen to twenty patients each. All centres would require increased investment. If every centre received funding for one more nurse, the expenditure would be relatively modest by comparison with creating new IFU. Smaller units have demonstrated quality of care comparable with that provided in major centres (Ransford & Jones, 2000). Other resource implications relating to availability of beds and clinicians able to provide such a service would need to be addressed.

BAPEN has been invited by the Department of Health to set standards for HPN to enable Primary Care Trusts commissioners to take well-informed decisions about the priority needed for HPN and to assess whether they are purchasing a high-quality service. All potential HPN centres should now be approaching their commissioners to seek endorsement and funding of their service.

Conclusions

It is clear that there is inequity of access to HPN and that quality of care is not uniform or satisfactory in many parts of the UK, particularly in England. There is much enthusiasm amongst professional staff and patients for change. The model of care now developing in Scotland provides a benchmark against which to compare services elsewhere in the UK. The proposal to develop a 'subnational' service for HPN will benefit the national intestinal failure service and permit equity of access and improved quality of HPN care. The recent agreement by government to support and develop existing HPN centres provides a great opportunity to move forward. Much of this progress should be attributed to Professor Chris Pennington, whose death in May 2002 has deprived Scotland and BAPEN of an inspired leader.

Acknowledgements

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