



Irish Society for
Clinical Nutrition
& Metabolism



IrSPEN SPECIAL REPORT No 1:

A Review of Home Parenteral Nutrition in Ireland: Recommendations for Action

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On behalf of IrSPEN's Standards and Guidelines Committee

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Forewords



Professor John V Reynolds – Chairman IrSPEN

This report into the status of Home Parenteral Nutrition Services for patients in Ireland is the first time a review of this sort has been conducted. These patients are highly complex and challenge even the most experienced surgeon and clinical team and yet in Ireland, unlike many other European Countries, we have no national standards or guidelines on how to manage these patients and although many hospitals in Ireland have had a HPN patient, most see very few of these patients very infrequently.

Although Crumlin hospital serves as an excellent example of how a national referral centre for intestinal failure exists for children in Ireland, there is no national referral centre for adults. The more throughputs a unit has, the more experience and expertise it delivers; but this specialism requires resources and training.

This review and the work of IrSPEN aims to improve standards of nutritional care in Ireland and to allow Irish patients to benefit from best practice including the latest advances in therapy to improve quality of life and survival and minimise complications.

The 20 recommendations in this report indicate ways in which the service of HPN in Ireland can be improved, addressing all areas of care from standards, guidelines, access to care, training, planning, audit and clinical governance.

I sincerely hope that this report is the starting point for a serious review of the services provided for these patients in Ireland, and we look forward to working with all relevant organisations to enable implementation of these recommendations.



Professor Aiden McCormick – Past President, Irish Society of Gastroenterology

Ireland has comparable numbers of people with intestinal failure to other European countries and although local expertise may be available a standardised and nationally accepted system for managing these patients is currently lacking.

Although the numbers of people requiring this treatment in Ireland is relatively small, numbers are likely to increase, and it is vital that systems are in place for a clinical pathway for these patients and a focus on fewer centres treating more patients.

Through implementation of the recommendations we hope that the quality of care for this area of nutrition can be standardised to make sure that all patients with these specific and complex requirements can receive the same specialist high quality care.

The ISG welcomes the report, fully supports the recommendations and congratulates IrSPEN for the work they have done in this area.



Carmel O'Hanlon – Chair of Nutrition Support Interest Group of the INDI

Home parenteral nutrition is a life-changing, as well as a life-sustaining therapy for an increasing number of patients in Ireland. This therapy has major financial, social, independence and self-esteem implications for patients, and impacts greatly on their families and friends.

Patients rely heavily on the expertise of the teams which look after them. Key members of these teams include dietitians, nurses, doctors, and pharmacists, and others, with support from home care company personnel. Established teams that work well together reassure patients, reduce feelings of isolation and can help alleviate concerns over HPN complications. Those who work closely with HPN patients know that seemingly small practical improvements can make a significant difference to quality of life of patients and families.

It is incumbent on us as professionals to support our patients and ensure that they have access to and receive all necessary interventions in a timely and standardised way. Proper management of HPN requires streamlined local and national care pathways to promote safe and effective care. The recommendations outlined in this report are a major step in the right direction. This report champions patient-centred care at all levels. The recommendations made must be acted upon if we are to deliver and maintain quality services to HPN patients nationwide.

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Executive Summary

Background

- Home Parenteral Nutrition (HPN) is a life-saving and life-prolonging treatment that offers quality of life benefits for suitable candidates and cost efficiencies for health services when compared with treatment in hospital. However, HPN is complex, demanding and highly specialised, with the potential for serious complications. Hence, experts agree that HPN must be undertaken only by experienced teams in accordance with the highest practice standards, following careful clinical and logistical assessment and planning to ensure that the patient can be safely managed and supported in their home environment.
- This report on HPN was conducted by Irish Society for Clinical Nutrition and Metabolism (IrSPEN) to address the current lack of a coordinated, strategic approach to service provision for Intestinal Failure (IF) and HPN in the Republic of Ireland (ROI).
- Work was conducted over several months, and involved the collation of relevant data obtained from a comprehensive search of the literature, expert reports, practice standards and guidelines for good clinical practice. The report and recommendations draw heavily on the experience and opinion of a specially convened, multidisciplinary advisory panel, all members of which are actively involved in the delivery of services for both adult and paediatric HPN patients in ROI.
- It is important to note that the review did not evaluate the capabilities, quality standards or service delivery provided by individual centres, confining its conclusions and recommendations to addressing deficits in the national configuration and clinical governance of service provision for this highly specialised group of patients.
- In line with the current healthcare strategy which aims *'to improve the quality, access and cost of health services to deliver benefits to every user of Health Service Executive (HSE) services, no matter where they live,'* the key principles underpinning the recommendations in this report are the need to ensure:
 - Equitable access for all suitable candidates with the potential to benefit from HPN in ROI.
 - A consistently high quality of care for all patients receiving HPN in ROI.
 - Cost effective care that allows patients to receive treatment in their own home if possible.
 - Clear guidance and protocols, in line with best practice standards.
 - Recommendations for service reconfiguration based on best practice examples from Ireland (e.g. in relation to paediatric or cancer services) and elsewhere in Europe.

Findings

- Although there are examples of good practice and high quality care, important deficits were identified in the coordination, resource planning and clinical governance of the HPN service provision for adult patients with IF in ROI. These deficits put HPN patients at avoidable risk, and should be addressed without delay.
- In 2010, 45 adult and paediatric patients received HPN, representing a one year period prevalence of 10.1 patients per million population. At any time, there were between 30 and 35 patients on HPN, a point prevalence of 7.5 patients per million of the population. This is significantly lower than in countries in the EU with specialist centres for IF and HPN or a national framework for service provision. Specifically, this represents less than half that in the North of Ireland, less than 40% of that in Scotland, Wales or England, and just 15% of that in Denmark and Germany.

- Under-provision of HPN in ROI appears to be mainly in adult patients with IF associated with benign disease. Based on Scottish data, as many as 45 suitable adult patients with IF in ROI may not currently have access to PN at home, despite the potential benefits for patient and health service. The use of HPN in infants and children in ROI appears to be broadly in line with expected levels of need at present, although the requirement is likely to continue to rise due to advances in neonatal medicine.
- Problems identified with the current systems, when viewed versus expert guidelines recently published by ESPEN and others, are highlighted below:

1) The lack of any recognised IF and HPN specialist centres for adult patients.

This means that there is no tertiary referral centre for smaller hospitals that lack the nutrition support teams (NST) or multidisciplinary teams (MDT) with the specialist training or experience to manage such patients safely and effectively.

2) The dispersal of a small group of patients with highly complex needs across a large number of non-specialist hospitals.

Between 2006 and 2012, a total of 137 patients were discharged on HPN from at least 21 hospitals. Of these, 14 hospitals (i.e. 66%) managed an average caseload of just 1.78 patients, with 9 hospitals discharging just 1 patient over the six year period. Given the evidence of consistently improved outcomes when HPN is managed by an experienced NST with the necessary resources and training to manage IF and HPN according to best practice standards, a move towards fewer centres managing more patients is deemed an important strategic shift underpinning the recommendations in this report.

3) The absence of national standards and protocols.

Currently each hospital that discharges a patient on HPN decides on their own protocols and standards.

4) Community aftercare that is unlikely to meet best practice standards.

This is because GPs and primary care team members lack specialist knowledge of HPN and many hospitals that discharge patients on HPN do not have specialist MDTs, and have not developed outreach services to monitor patients in the home environment.

5) Lack of clinical audit data on patient outcomes.

This means that outcome data cannot be compared between centres or against best practice standards in order to highlight areas of potential or actual risk.

6) Missed opportunities for potential cost saving and improved clinical outcome, as well as quality of life benefits.

All the evidence examining the economic aspects of HPN treatment demonstrates that it is cheaper than in-patient treatment. The estimated cost savings from providing PN at home rather than in hospital is estimated to be between 50 and 65% (Richards DM 1996), in addition to the obvious clinical and psychological benefits of them not needlessly remaining in hospital. An evaluation by Our Lady's Hospital for Sick Children calculated savings of €95,000 per HPN patient per year.

Conclusions

- A distinction needs to be made between the model of care for paediatric HPN patients, adult patients with IF due to benign disease, and patients with malignant disease, since the criteria for patient selection, protocols for monitoring and specialist services will differ.
- Whereas the model of care for paediatric HPN patients is well organised and coordinated around one national tertiary referral centre, there is no framework in place or national specialist centres for the management of adult severe IF and HPN in ROI.
- There has been no auditing of service delivery, outcomes or costs arising from the management of adult IF and HPN in ROI. However, all available data would suggest that the current system poses avoidable risk to patients and results in patchy access to HPN and inconsistent quality of care. Comparison with neighbouring healthcare systems and other European countries strongly suggests that a significant number of patients that meet internationally accepted criteria for HPN provision are not receiving or benefiting from it, at significant cost to patients, their families and the health service.
- Given the low numbers of patients involved and the high level of complexity in their clinical management, it is now recognised that IF and HPN are specialist services that should only be undertaken by acute centres with the expertise, experience and resources to manage such patients safely and effectively. Given the need to achieve a balance between centralising specialist care and ensuring accessibility for patients, ROI needs nationally agreed standards of care and effective referral systems in place to enable high quality care to be delivered within a reasonable distance of a patient's home.
- It is against this background that IrSPEN and the Advisory Group has developed recommendations for the configuration of a national framework and standards aimed at ensuring improved access to a consistently high quality HPN service for suitable candidates.

This report outlines a compelling case for change, and provides actionable proposals aimed at ensuring consistent quality of care and equitable access to this life saving technology for all potentially suitable candidates.

Key Recommendations

Service planning to meet predicted levels of need

1. Sufficient capacity and resourcing is needed within this framework to accommodate up to 3 times the current rates of adult HPN. This is based on estimates in a recent report by a UK expert group that the minimum numbers of Type III IF adult patients likely to require long term PN at home are no less than 14.6 patients per million population.
2. Additional provision should be made for cancer patients for whom HPN is increasingly being used successfully by National Cancer Centres, the latter which accounts for nearly 36% of all HPN in ROI (on database up to December 2012).
3. The need for HPN in paediatric patients, which currently accounts for 15% of HPN cases in ROI (on database up to December 2012) is also likely to continue to increase over the coming years. Hence, the total capacity for both adult and paediatric HPN, for both malignant and non-malignant IF, based on conservative estimates, is likely to exceed 20 patients per million within the coming 5 years.

National service configuration

4. A national framework for the management of patients with IF and HPN needs to be established based on fewer national specialist centres managing larger patient numbers, delivering care as part of a network system. Based on the existing and anticipated prevalence of suitable candidates for HPN, it is proposed that the service configuration for IF and HPN for both IF and malignant disease would involve the establishment of a National Specialist Centre for severe adult IF / HPN. This Intestinal Failure Unit would be a national referral centre for the most complex patients.
 - This National Specialist Centre would be supported by up to 3 regional centres. These hospitals would have the expertise to support the national IF unit and manage patients with IF /HPN, once they are sufficiently stable, ensuring that patients have access to high quality care as close to home as can safely and cost effectively be provided.
 - It is anticipated that the current National Cancer Centre, St. James' Hospital, would be included within this network, given the increasing use of HPN for cancer patients with advanced malignant disease.
 - Our Lady's Hospital for Sick Children in Crumlin remains the national centre for paediatric patients.
5. Within this framework, it is strongly recommended that the management of IF would be transferred over an agreed period of time to these hospitals, each of which would:
 - have necessary resources, specialist expertise in the form of a trained MDT, with defined roles and responsibilities;
 - have the ability and agree to comply with minimum standards of practice and protocols for patient selection, management and clinical governance, to be established by a National Steering Group (see point 7).
6. Smaller hospitals that are unable to meet agreed minimum criteria for the total management of such patients, may be recruited by national centres to provide some aspects of care for patients in their vicinity, should this be clinically appropriate and cost effective for the health service, or offer the opportunity for routine care to be undertaken closer to the patient's home.
7. A National Steering Group should be set up to oversee the development and implementation of such a national care programme / framework, and the clinical governance of any standards or protocols developed. The Steering Group should be led by a Consultant Surgeon or Gastroenterologist specialising in intestinal failure from a national or regional designated HPN provider, and include as a minimum a specialist dietitian, specialist nurse, and specialist hospital pharmacist.

Quality standards and minimum criteria for hospitals managing IF and HPN

8. Key to the implementation of a national framework for IF and HPN, is the immediate commissioning of national standards for the management of patients with IF and HPN provision, to which all regional or national centres for IF and/or HPN would be expected to comply, and against which they would be audited. National standards would need to be developed which take account of:
 - Staffing levels, resource and roles within a MDT.
 - Capabilities and basic /ongoing training.
 - Protocols / criteria for candidate selection for HPN, that take into account the significant differences between patients offered HPN for non-malignant IF and those with malignant disease, the latter who may benefit from HPN in terminal stages of disease, or as a supportive therapy during or while awaiting further treatment.
 - Protocols for the management of the discharge process (to include patient training).
 - Monitoring of patients in the community, according to patient type (e.g. patients with malignant disease may require a different monitoring plan than those with non-malignant IF).
9. In line with recommendations developed by the European Society for Clinical Nutrition and Metabolism (ESPEN), the Association of Surgeons in Great Britain and Ireland (ASGBI) and in countries with national standards, all units involved in IF and HPN should be required to ensure that patients are managed by an experienced and appropriately trained MDT, which as a minimum, must include the lead surgeon/consultant, dietitian, pharmacist and specialist nutrition nurse (or nurse that has completed a recognised course on HPN).
10. Whilst it may be sufficient for supporting regional centres for IF and HPN to manage patients via a MDT, the national specialist centres for IF should be expected to establish a dedicated NST. Given the impact that treatment has on the patient's social and family life, psychologists and social workers should also be available to support the MDT.
11. A nationally accredited HPN training course for NST/MDTs needs to be developed which provides and maintains the necessary level of training required for all future or potential HPN providers.

Audit data & outcome measurement

12. To build on the important work of the Irish Nutrition and Dietetic Institute (INDI) in developing and maintaining a voluntary register of HPN patients within their own membership, a mandatory national HPN register should be established without delay.
13. In addition to obtaining reliable data on the incidence of HPN and relevant patient data to allow monitoring of trends or allow detailed analysis of incidence and practice according to patient type, reporting should also allow for monitoring of outcome data, including number and type of complications, any readmissions to hospital and their cause, and other outcome data.
14. Similar to other countries and the UK, it is recommended that the register be managed by IrSPEN, as the national affiliate of ESPEN and as the only multidisciplinary group specialising in enteral and parenteral nutrition in ROI.
15. Reporting to this national register should be mandatory for all HPN centres, and one of the criteria with which any hospital that manages Type II or III IF must demonstrate a willingness to comply.
16. It is strongly recommended that funding for a national register be provided by the HSE, given that it is an essential tool to good clinical governance.

Clinical governance

17. Management of Type II / III IF patients should be restricted to hospitals that can demonstrate compliance to minimum standards, as outlined in point 1 above.
18. There is an urgent need to establish the respective roles of Directorates within HSE and HIQA in the establishment and implementation of a strategic framework/ clinical pathway and in auditing standards of practice/outcomes.

Patient centred care

19. It is recommended that a survey be conducted of short and long term HPN patients with a view to determining patient experience of existing practice across the country, and to identify any major gaps or deficits that need to be addressed as a priority. Information from this survey should be taken into consideration by the Steering Group in determining protocols for care and standards of practice.
20. There is currently in ROI, no patient organisation specifically for those on artificial home nutrition support. There are currently an estimated 1800 patients on home enteral feeding in ROI at any time, in addition to the small numbers of patients on HPN specified in this report. Efforts should be made to facilitate the establishment of a specialist organisation in ROI, possibly with links to similar organisations in the United Kingdom and Northern Ireland. HPN patients have identified this as a key recommendation.

1. Introduction

1.1 Background

Although HPN is a life-saving and life-enhancing treatment for suitable candidates with intestinal failure (IF), the rate of complications can be high, particularly in inexperienced hands. The consensus amongst expert centres and from recently published guidelines issued by major European and International expert groups (ESPEN, NICE, ASPEN, AUSPEN and others,) is that HPN should only be managed by experienced MDTs that have the capability and resources to train and manage patients according to best practice standards.

Furthermore, given the small number of patients affected and the high degree of specialism required to manage their care with the lowest associated risk of metabolic and catheter related complications, many countries have implemented, or are developing, national frameworks, practice standards and protocols for their care, organised around fewer specialist centres treating more patients.

At present, there is no formal model of care for the management of IF and HPN in ROI, in contrast to many countries in Europe, including the North of Ireland, Scotland, Wales and England, the latter of which is implementing a strategic network system in early 2013.

This review was undertaken by IrSPEN in recognition of the high level of complexity involved in the management of IF and HPN, and the need to address the current lack of a coordinated, strategic approach to candidate selection and service provision in the ROI, at significant cost to patients and the health service.

1.2 Purpose

The primary purpose of this report is to review current use and practices relating to HPN in ROI and make actionable proposals aimed at ensuring safe, consistently high quality of care and equitable access to this life saving technology for all potentially suitable candidates.

Specifically, the aims of this report are to:

- Review the current level and arrangements for HPN in ROI.
- Highlight issues and/or risks associated with the current arrangement, coordination between centres, service delivery and governance for patients with IF who may benefit from HPN, based on assessment versus best practice models of care and expert guidelines.
- Identify opportunities for improvement in the management of HPN patients and the support provided thereafter.
- Make recommendations for a new, national framework for the management of IF and HPN in ROI, taking into account the experiences and guidelines from countries with developed services and specialist centres of excellence.

1.3 Methods

Work was conducted over several months, and involved the collation of relevant data obtained from a comprehensive search of the literature, expert reports, practice standards and guidelines for good clinical practice.

The report owes much to the considerable work of the Nutrition Support Interest Group of the Irish Nutrition and Dietetic Institute (INDI) in their audit of HPN patients between 2006 and 2008, and from 2010 to date. This INDI database has been an invaluable source of information in relation to the prevalence, source of discharge, indications for, and geographical distribution of HPN patients in ROI.

The review was also informed by a benchmarking exercise of 16 countries, providing a basis for comparison with current prevalence and practice in ROI.

Importantly, the report and recommendations draw heavily on the experience and opinion of a specially convened, multidisciplinary advisory panel, all members of which are actively involved in the delivery of services for both adult and paediatric HPN patients in ROI.

It is important to note that the review did not evaluate the capabilities, quality standards or service delivery provided by individual centres, confining its conclusions and recommendations to addressing deficits in the national configuration and clinical governance of service provision for this highly specialised group of patients.

1.4 Principles underpinning IrSPEN recommendations

In line with current healthcare strategy which aims *'to improve the quality, access and cost of health services to deliver benefits to every user of HSE services, no matter where they live'*, the key principles underpinning the recommendations in this report are the need to ensure:

- Equitable access for all suitable candidates that have the potential to benefit from HPN.
- Consistently high quality of care for all patients receiving HPN.
- Cost effective care that allows patients receive medical or clinical care in their own home if possible and clinically appropriate.
- Development and implementation of agreed national standards and protocols for service delivery that are in line with best practice standards, and which can be anticipated to result in reduced complications, improved quality of life, and improved cost effectiveness.
- That recommendations for improved models of care build on the success of Our Lady's Hospital for Sick Children in Crumlin, which has evolved as the principle IF /HPN unit for paediatric patients in ROI, and on that of St. James's Hospital and University College Hospital Galway as National Cancer Centres in their success in advancing the use of HPN for IF in malignant disease.

2. Best practice HPN

2.1 Overview of HPN

What is Parenteral Nutrition?

Parenteral Nutrition (PN) is a means of 'feeding' patients when their gastrointestinal tract does not work. Nutrients and fluid are administered intravenously directly into a central vein, bypassing the normal processes of eating and digestion. It is a life-saving and life sustaining treatment that becomes essential for a small group of adult and paediatric patients that develop IF each year, which can result from major surgical resection due to malignant or non-malignant disease, obstruction, abnormal motility, congenital defects or disease-associated loss of intestinal function. However, because of the nature of PN, it is also complex and highly specialised, with the potential for serious metabolic and catheter related complications. Hence, after more than 45 years since it was pioneered, experts now agree that HPN should only be undertaken by experienced teams in accordance with best practice standards.

Home versus hospital therapy

PN is no longer in itself adequate justification for keeping a patient in hospital. With the development of hospital to home services and care protocols, both by hospitals and medical nutrition companies, many otherwise stable patients who might previously have remained in hospital to receive PN can be safely discharged home. As health providers in the US and in many European countries have already identified, HPN for suitable candidates offers the potential for cost savings for the health service and quality of life benefits for the patient as with home dialysis and home intravenous antibiotic administration.

Intestinal Failure (IF)

Diagnosis of IF can be difficult because of the lack of agreed definitions, but a simple, practical, clinical definition of intestinal failure that is gaining increasing acceptance amongst experts is the 'inability to tolerate 80% of nutritional requirements delivered enterally for a minimum of 48 hours'. Whether a patient will go on to require HPN will depend on whether IF is likely to be temporary or prolonged.

Types of IF as a guide to the need for HPN

Intestinal failure is now generally sub classified into types I, II, or III, depending upon the duration of nutritional support required and the reversibility of the original pathology. This simple classification provides an important basis for determining levels of need and future demand for services nationally, since a distinction can be made between the resources and expertise needed to handle different types of IF, as shown below.

Table 1: Sub-classification of Intestinal Failure used in this document:

IF TYPE	Features	Indication for HPN / referral to specialist centre?
Type I	Less than 28 days duration. Usually occurs post operatively or due to obstruction. May require short term PN.	No.
Type II	Greater than 28 days duration. Usually occurs in severely ill patients, mostly after bowel resection with complications such as intestinal fistulae, sepsis and metabolic disturbance. May require prolonged nutritional /metabolic support pending surgical treatment or spontaneous resolution.	Not generally an indication for HPN but should be managed in specialist IF centre.
Type III	Generally irreversible and occurs as consequence of massive small bowel resection, leading to Short Bowel Syndrome (SBS), or malignant obstruction, or severe motility problems. A small number of patients will become suitable for either small bowel or combined small bowel and liver transplantation.	HPN may be indicated. Specialist centre depending on whether the result of malignant/ non-malignant disease.

Indications for HPN

In countries with developed national service models for IF and HPN management, the underlying conditions for which HPN is most commonly prescribed are:

- Short bowel syndrome
- Radiation enteritis
- Malignant bowel obstruction
- Crohn's disease
- Congenital intestinal disorders
- Severe motility disorders
- Fistulae
- Intractable vomiting and diarrhoea

Changing profile of HPN patient and trends affecting future usage

There has been a significant change in the types of patients being sent home on PN in the last few years, both in age and underpinning diagnosis, largely due to advances in medical therapies, particularly in neonatology and cancer care.

For example, HPN is being used in younger children and neonates in situations where no treatment would have been offered in the recent past, reflecting advances in neonatal medicine and increased survival of preterm infants born before 28 weeks. These include congenital disorders such as extensive necrotising enteritis and long segment Hirschprung's disease – conditions previously considered fatal.

Diagnostic indications have also broadened amongst adult patients. Most significantly, HPN is now more commonly offered to patients with advanced pelvic cancer who are unable to be fed enterally, and who now represent a growing proportion of all HPN patients in many countries, a trend likely to continue.

It is therefore important that service planning, criteria for patient selection, and protocols for home monitoring take such factors into account, since a patient with type III IF that is on long term HPN whose underlying condition is stable will have different monitoring needs than, for example, a patient with malignant disease for whom HPN offers the opportunity to remain at home rather than in hospital in the last months of life.

Notwithstanding the differences in need according to patient type, the following is a general guide to the management of all HPN patients.

How HPN is managed – a general guide

HPN is delivered directly into a large bore central vein, either via subcutaneously tunnelled catheters or implanted ports.

Training is given on how to infuse feeds overnight, allowing the patient to be disconnected during the day so that they can live as 'normally' as their underlying condition permits. Strict adherence to aseptic catheter care techniques is key to preventing infectious complications, reinforcing the need for repeated training sessions with the patient and family both prior to, and following discharge until they are proficient. In specialist centres, this training is generally given by the hospital team, but in many cases, training is given by nurse specialists employed by, or under contract to, the specialist parenteral nutrition company provider.

Feeds and disposables are delivered to the patient's home by the medical nutrition company that manufactures and supplies the feed and ancillaries, and are stored in a separate fridge until used.

The monitoring of patients depends to some extent on the underlying condition and circumstances, but generally they can be monitored less frequently than in hospital. Patients remain in contact with a key member of the hospital nutrition or MDT, and in specialist centres. In ROI this tends to be the nutrition nurse/dietitian in paediatric hospitals, or dietitian in adult hospitals. Local hospital policy determines how often biochemical and other tests are performed and who acts on the results. Outpatient review may be organised at intervals for the patient to be reviewed by key members of the MDT.

All patients with HPN are urged to report any problems without delay, particularly if they develop a fever or other sign of infection. Patients that develop problems are readmitted to hospital, typically for catheter infections, blockages of the catheter, for significant metabolic disturbances, or for reasons related to the underlying medical condition.

Complications and risks

As HPN is delivered into a central vein, there are several serious complications that can arise, although the majority are preventable with proper care and monitoring. Complications are generally categorised as either metabolic or catheter-related.

Metabolic complications

Because the administration of PN is by definition an artificial way of providing nutrients, even small imbalances in the formulation, or a mismatch between substrates provided and an individual's metabolic capability or requirements, can have deleterious effects over time. These can be extremely serious if not corrected, highlighting the expertise required to develop the initial HPN prescription and adjust it based on regular testing of a patient's biochemical and anthropometric response.

Two long term metabolic complications associated with HPN are liver disease and metabolic bone disease. Other rarer complications are known to occur with which a specialist centre will be familiar and best placed to prevent or manage. Advances in PN solutions and feeding protocols are also important in reducing the risk of certain metabolic complications. Persistent electrolyte abnormalities may need to be managed in hospital (as an inpatient or in day-care facilities).

Catheter-related complications

HPN requires a well-functioning central venous access device (CVAD). Whilst these are always placed in the hospital, the CVAD provides potential access for pathogenic organisms to enter the bloodstream. Perhaps not surprisingly, catheter related bloodstream infections (CRBSI) remain the most common complication of HPN, and a major source of avoidable morbidity and mortality.

2.2 Key principles of high quality care

In 2009, the European Society for Clinical Nutrition and Metabolism (ESPEN) developed expert guidelines for HPN in adults as a framework for the development of local policies and procedures.

Within these and other national guidelines for HPN use, there is general agreement that effective and safe HPN requires:

- Considered selection of a person's suitability and support for HPN.
- Accurate assessment of a patients' nutritional requirements.
- Appropriate constitution and compounding of PN.
- Safe intravenous access (including aseptic insertion and catheter aftercare).
- Adequate training of the patient and their carer as well as any other people involved.
- Thorough and ongoing monitoring of a patient's biochemical and anthropometric response.

Expert team

To achieve these goals, ESPEN and other recently published expert guidelines underline the importance of care being provided by a NST, the minimum core composition of which should include a physician (e.g. gastroenterologist, gastroenterology surgeon, clinical biochemist), a specialist nutrition support nurse, senior dietitian and senior pharmacist. More specifically, ESPEN recommendations highlight that 'hospitals that do not have a NST experienced in HPN should not provide the service', based on evidence of significant differences in complication rates between HPN managed by specialist centres with NSTs and others.

Standardised approach to care

ESPEN guidelines and those of other professional expert bodies, including NICE, emphasise the need to establish national standards for the organisation and delivery of care. Whilst the content of these guidelines are beyond the scope of this report, the components of service for which standards or protocols need to be established and agreed nationally include the following:

- The role of the multidisciplinary / NST, and the minimum training that members of the team must receive.
- Selection criteria to determine a patient's suitability for HPN, which differ between adult patients with Type III (non-malignant) and those with cancer, and between adult and paediatric patients.
- Protocols for assessment of a patient's nutritional requirements both initially and at regular intervals.
- Protocols for the insertion and use of CVADs, and the training of patients on their safe use and catheter care.
- Practice standards for training of patients and their carers, both pre and post discharge. Practice standards should specify what the training must cover.
- Procedures and protocols for dealing with complications.
- Funding procedures need to be streamlined across the HSE.

In ROI at present, standards, protocols, training and the support provided to patients before and post discharge are the responsibility of the individual hospital, with no national standards for service delivery or standardisation of practice across discharging units.

2.3 Clinical and cost benefits

Economic evaluation of HPN

All the evidence found examining the economic aspects of HPN treatment demonstrated that it is cheaper than in-patient treatment. The estimated cost savings from providing PN at home rather than hospital is estimated to be between 50 and 65% (Richards DM 1996). An evaluation by Our Lady's Hospital for Sick Children calculated the savings achieved in the 6 years since establishing their HPN service from 2000 and 2006 at over €7.5million, based on savings per patient of €95k per year.

Quality of life and future therapies

Although IF affects a relatively small population, the clinical and personal burden is significant. Early diagnosis and treatment of complications including catheter related infection, central venous thrombosis and hepatobiliary disease minimise mortality and morbidity rates. Safe delivery of HPN relies upon bespoke formulations administered by highly trained patients or carers, supported by a skilled MDT. Five-year survival rates in large centres are reported between 60% and 78% with survival primarily related to underlying diagnosis (Dibb M et al 2013). Therapies that target the underlying problem of inadequate absorptive capacity of the remaining intestine include teduglutide, small bowel transplantation and intestinal lengthening procedures (Hofstetter S 2013).

2.4 The patient's view

During the research for this report a small sample of five patients and carers were interviewed to give feedback on their experience of HPN and issues of concern.

HPN was considered to be a life-saving therapy. Quality of life was perceived to be greatly enhanced by allowing PN to be administered at home, among family and friends. Major lifestyle changes were cited, such as limitations on employment opportunities, independence and financial status. The discharge process was considered to be smooth and efficient, although delays in funding could lead to delayed discharge. The organisation of homecare by hospitals and PN companies was perceived favourably by patients. In the hospital setting, dietitians and nutrition support nurses were commended, and PN company frontline staff were also appreciated. Aftercare services from hospitals and PN companies were considered to be very important. One parent of a child on HPN expressed concern that cut backs in hospital services were noticeable, impacting on school time.

Without exception all patients/carers were anxious about catheter-related blood stream infection (CRBSI) risk. The threat of hospitalisation to treat this and the potential temporary loss of IV nutrition were of particular concern. Training in catheter care was recognised to be essential in the preparation for HPN. Accessing timely interventions by clinicians experienced in HPN in emergency departments was raised as an issue.

A strong feeling of isolation associated with HPN was reported. Small changes, such as the use of a portable pump helped alleviate this for one patient, allowing better social interactions and the possibility of holiday breaks while on HPN. Patients who cannot eat for medical reasons while on HPN, and their families, need extra support to help cope with this. Young children on HPN may have particular issues such as suitability of accommodation, availability of special needs assistants at school if appropriate, and financial assistance and guidance where necessary. Accessing community services where needed for HPN children, can be difficult and may lead to feelings of frustration and isolation.

Patients recommended:

- A HPN support group.
- An Irish HPN website with practical tips.
- Access to counselling for patients and carers.
- Continued improvements in prevention of catheter related bloodstream infections (CRBSI).
- A central point of contact where specialised interventions by clinicians experienced in HPN can be organised in the event of acute complications of HPN, e.g. early signs of CRBSI.
- An advocate for parents of children on HPN, to help access community services, with clear lines of communication to promote seamless individualised care pathways for HPN children, while improving awareness in the community of HPN and its implications on a child's developmental, housing and educational needs.

Overall, Irish HPN guidelines or standards of care should include at their core, the need to support HPN patients and their families in the community.

3. HPN use and practice in ROI versus other country models

3.1 Prevalence of HPN

Ireland

In ROI, there are between 30 and 35 adult and paediatric patients receiving HPN at any time in the ROI, representing a point prevalence of 7.5 per million of the population. During 2010, 45 patients received HPN in ROI, a period prevalence of 10.1 patients per million. Sufficient capacity and resourcing is necessary to accommodate up to 3 times the current rates of adult HPN. This is based on estimates in a recent report by a UK expert group that the minimum numbers of Type III adult patients likely to require long term PN at home are no less than 14.6 per million.

International comparison

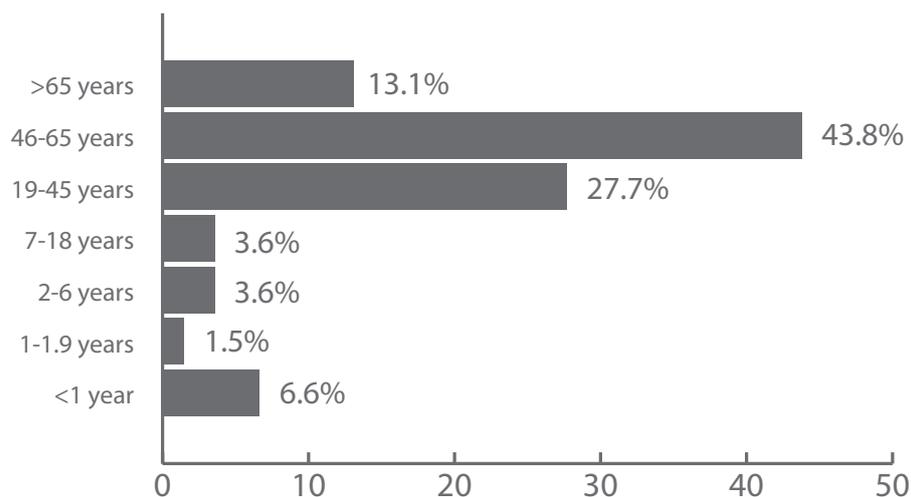
- From audit data obtained from a range of countries, it is clear that there are significant national and regional variations, ranging from 3.25 to 66 patients per million in Europe, with an incidence of 4-6 per million per year for HPN in patients with benign primary diseases. However, this data must be interpreted with extreme caution, since many national registers are voluntary registers that are far from complete: in the UK, the level of under-reporting established by cross checking data with that provided by medical nutrition companies that provide the feed, equipment and support services to HPN patients, was found to be 59% for adult HPN and 89% for paediatric HPN. Hence, in the table below, figures reflect the corrected prevalence figures, as published in the BAPEN BANS 2011 report.
- The prevalence of HPN in ROI is significantly lower than in healthcare systems with specialist centres for IF and HPN or a national framework for service provision, representing less than half that in the North of Ireland, between 33 and 37% of that in Scotland, Wales and England, and just 15% of that in Denmark and Germany (See Table 1). The use of HPN in the US, at 120 per million, is perhaps the highest globally, where the criteria for use in cancer appears to be the source of the very large difference.

Table 2: Prevalence of HPN in UK and Europe

Country	Population (m)	2010 period prevalence per million population	Point prevalence (31 Dec 2010) per million population	National specialist centres
Denmark	5.3	66	47	Yes (3)
Republic of Ireland	4.4	10.1	7.5	No
England	52	unknown	19.3*	Yes (2)
Germany	82	unknown	49	Yes ('few')
Netherlands	17	14.7	unknown	Yes (2)
N. Ireland	1.8	15.6	15.6	Yes (1)
Scotland	5.2	23	17.5*	Yes (11 – network model)
Wales	3.0	unknown	20*	Yes (3)

In ROI, paediatric patients represented 15% of all HPN patients on the INDI register in December 2012. The proportion of those receiving HPN under 1 years of age has increased significantly since Crumlin Hospital first developed its service, largely as the result of advances in neonatal medicine that have seen increased rates of survival of infants born at earlier stages in pregnancy, at which stage the intestine is under developed. See Figure 1 for age distribution of HPN patients.

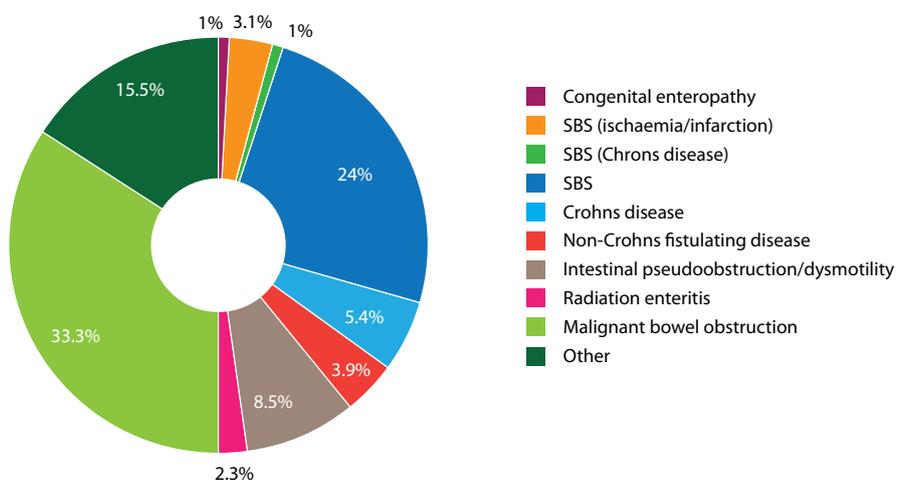
Figure 1: Age distribution of HPN patients (December 2012)



3.2 Indications for HPN and predicted changes

The main indications for HPN in ROI (December 2012) are short bowel syndrome (SBS) (28%) and malignant bowel obstruction (33%) (See Figure 2). This reflects an increase in the last few years in the number of adult cancer patients are being sent home on PN from two hospitals – St. James’s Hospital, and University College Hospital Galway, both of which are National Cancer Centres.

Figure 2: Indications for HPN in ROI (December 2012)



Note: SBS subcategories of ischemia/infarction and Crohn’s disease were added to the database in 2011.

3.3 Source of discharge and service configuration

Tables 3 and 4 below show the number of patients that were discharged on HPN and registered on INDI's HPN database by hospital, from 2006 to 2012. In total, 137 patients were registered as being discharged on HPN from over 21 hospitals across the country, two thirds of which managed just 1.78 patients over that period. It is worth noting that over the past 3 years, some hospitals in the ROI have referred patients to IF centres in the UK (Hope Hospital, Salford and St Mark's Hospital, London) and that each hospital currently have 3 patients each at home in ROI but receiving treatment, follow up and monitoring from hospitals in the UK, co-ordinated with their GP or local hospital. These 6 patients are not reported in the INDI figures below.

Table 3: Hospitals with <5 patients on HPN database*

Hospital (alphabetical order)	HPN numbers on database
Connolly Hospital	1
Cork University Hospital	3
Letterkenny General Hospital	1
Mater Misericordiae	4
Mayo General Hospital	2
Midland Regional Hospital, Tullamore	1
Mid-Western Regional Hospital, Limerick	1
Mid-Western Regional Hospital, Nenagh	1
Our Lady of Lourdes Hospital, Drogheda	1
Sligo General Hospital	1
South Tipperary General Hospital, Clonmel	1
St. Lukes General Hospital, Kilkenny	1
St. Vincents Private Hospital	3
Other	4

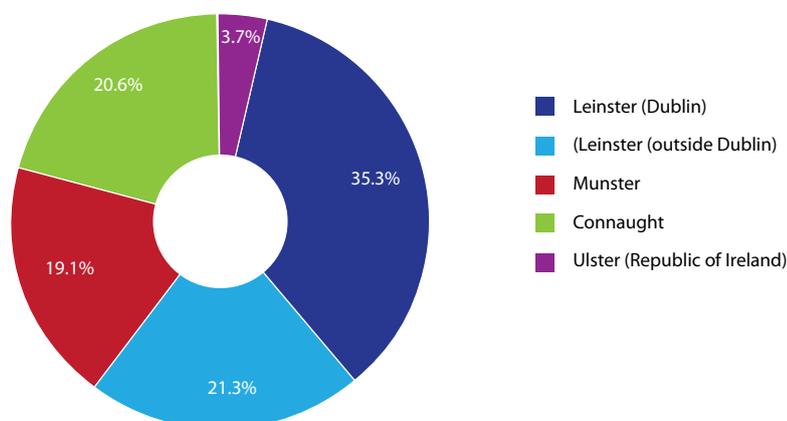
Table 4: Hospitals with ≥5 patients on HPN database*

Hospital (alphabetical order)	HPN numbers on database
AMNCH Hospital	9
Beaumont Hospital	6
Mercy Hospital Cork	11
Our Ladys Hospital for Sick Children Crumlin	19
St. James University Hospital	30
St. Vincents University Hospital	8
University College Hospital Galway	20

*as of December 2012

Most patients (56%) were discharged to Leinster, 19% to Munster and 20% to Connaught (see Figure 3). Approximately 41% of these are male and 59% are female. The majority of patients are between 46 and 65 years of age (see Figure 1).

Figure 3: Location of HPN patients in ROI



3.4 Good practice examples

At Our Lady's Children's Hospital, Crumlin, an HPN programme has been in place for the past 12 years. This provides a paediatric HPN service for the whole country and is run by a fully integrated multidisciplinary NST. More details of the service can be found in Appendix I.

St. James's Hospital has been providing a HPN service for over ten years, with the majority of patients having an underlying cancer diagnosis resulting in intestinal failure. More details of the service can be found in Appendix II.

3.5 Role of medical nutrition companies

Currently in ROI, medical nutrition companies specialising in parenteral nutrition do all the manufacture and the majority of the dispensing and delivery of feeds to patients on HPN.

Service agreements entered into between hospital and companies determine the level and type of services provided for patients. The range and type of support services provided by different suppliers can vary, and non specialist hospitals tend to depend to a greater extent on suppliers to provide aftercare than specialist centres.

Services may include some or all of the following:

- Training of patients and carers pre and /or post discharge, which may take between 4 days and 4 weeks.
- Home supervision of connection/ disconnection by the nurse until the patient / carer is competent.
- Management of the discharge process from hospital to home, which may involve liaison with community funding bodies.
- Provision of bespoke bags of feed, pumps and ancillary equipment to the patient's home. These are likely to include: dedicated PN refrigerator, drip stands, infusion pump, back pack, dressing packs, gloves, syringes, dressings, hand wash, paper towels, filters, giving sets.
- Regular follow up visits with specially trained nurses.
- Phlebotomy services (less frequently required).
- Central line aftercare support .
- 24 hour emergency support.

As there is no primary care support for patients and as so many smaller hospitals without specialist or experienced teams find themselves discharging patients on HPN in different parts of the country in ROI, the level of support required of companies to support adult patients has increased over time. In certain situations, the only home visits are by company personnel.

Whilst suppliers have high levels of expertise to provide logistic or training support, clinical follow up is the responsibility of the discharging hospital, highlighting the importance of limiting the management of IF and HPN to designated and properly resourced centres.

3.6 Barriers to access of best practice care

In the absence of a national strategy for the clinical management of adult IF and HPN in ROI, the key concerns of practitioners and experts consulted in the development of this report, and which form the basis of recommendations for action, are highlighted below:

- The lack of any recognised IF and HPN national or regional centres for the management of adult patients with IF, with no coordination of service provision between discharging hospitals, and no tertiary referral centre for hospitals that lack the resources, specialist training or experience to manage such patients safely and effectively.
- The wide dispersal of relatively few highly specialised patients across a large number of non-specialist hospitals. Between 2006 and 2012, a total of 137 patients were discharged from at least 21 hospitals, approximately two thirds (14) of which managed an average caseload of just 1.78 patients, and 42% (9) having had just 1 patient over the six year period. Given the evidence of consistently improved outcomes when HPN is managed by an experienced NST with the necessary resources and training to manage IF and HPN according to best practice standards, a move towards fewer centres managing more patients is deemed an important strategic shift underpinning the recommendations in this report.
- The absence of national standards and protocols with which discharging hospitals must demonstrate their ability and willingness to comply, leaving each hospital that discharges a patient on HPN to decide on their own protocols and standards. Lack of standardisation is particularly concerning given the large number of hospitals with little experience of IF patients or HPN use or the resources available to deal with the complex problems that such patients may pose.
- Lack of audit data from discharging hospitals on patient outcome, which would allow comparison with best practice standards achieved by specialist units and highlight areas of potential or actual risk.
- Potential over-reliance by hospitals on medical nutrition companies to manage the training, management and ongoing support of patients, which may be masking gaps in the resources, experience, training or support service provision available within the discharging hospital. Whilst medical nutrition companies have high levels of specialist expertise and play an important role in the safe and effective management of patients on HPN, hospitals that discharge patients on HPN must have the necessary specialist expertise, resources and protocols to meet quality standards for the ongoing management of community patients following discharge.
- When compared to statistics from comparable European countries, the low figures of HPN in Ireland suggest there could be patients with type III IF currently not receiving HPN. Identifying and appropriately managing these patients in their home would bring not only a significant cost saving, but improved clinical outcomes, as well as quality of life benefits.

3.7 Conclusions

Despite evidence of an increase in HPN use for both children and adults in the ROI, comparisons with countries that have developed specialist centres and implemented models of care according to best practice standards indicate that there is inequitable access to HPN for adult patients with non-malignant IF across the country.

Low provision or access to HPN is clearly a legitimate cause for concern, since it is almost certainly indicative of patients being kept in hospitals solely for PN, despite having the potential to be managed effectively in their own home. However, it is by no means the only cause for concern.

Whereas several other countries have established a national model for the management of IF and HPN, without exception designed around fewer specialist centres managing greater numbers of patients, in ROI, there is no such framework in place, and no coordination of services. This has resulted in large numbers of hospitals with highly variable level of resources discharging relatively small numbers of adult patients. In contrast, all paediatric patients are referred to Our Lady's hospital in Crumlin, having the only specialist paediatric Gastroenterology team in the country.

Furthermore, in a benchmarking survey of 16 countries in Europe plus Australia, it was established that 75% of countries had a system for educating hospital teams in HPN.

Specifically, and contrary to guidelines produced by ESPEN and others, ROI has:

- No specialist IF / HPN centres for adults.
- No national strategic framework for delivery and coordination of services.
- No agreed national standards of care or guidelines on the management of patient on HPN.
- No NSTs established for IF/HPN in adult centres (a specialist NST is in place in Our Lady's Hospital for Sick Children, which has evolved as a national centre for children on HPN).
- No training course for the education and training of MDTs in ROI.

These deficits are a significant cause for concern, since without an organised model of care and the establishment of specialist centres, access to HPN tends to be patchy and the quality of care variable.

There is clearly a compelling need for change, given the complex and highly specialised needs of this relatively small group of patients.

4. Developing an improved model of care: proposed service configuration

4.1 Levels of need

Adult patients with IF due to benign disease

Sufficient capacity and resourcing is needed within this framework to accommodate up to 3 times the current rates of adult HPN. This is based on estimates in a recent report by a UK expert group that the minimum numbers of Type III adult patients likely to require long term PN at home are no less than 14.6 per million in a similar population. Given similar prevalence of underlying conditions that are likely to result in IF and require HPN, and that rates of HPN in the US are as high as 120 per million, this figure is likely to be conservative, and should be re-evaluated as part of the work of the Steering Group.

Cancer patients

Increasingly patients with chronic intestinal obstruction due to cancer are being sent home on PN. The objectives and issues of HPN can be different for this group of patients. Medical, psychological and ethical issues must be carefully assessed before the decision to send a patient home on PN is made.

Additional provision should be made for cancer patients for whom HPN is increasingly being used successfully by National Cancer Centres, the latter which accounted for nearly 36% of all HPN in ROI (on database up to 2012). Hence, specific guidelines on the selection of patients with cancer for HPN need to be developed depending on their prognosis.

Paediatric patients

The need for HPN in paediatric patients, which currently accounts for 15% of HPN cases in ROI (on database up to 2012), is also likely to continue to increase. Advances in neonatal medicine have seen increased survival rates in very premature and low birth weight infants, at which stage the gut may be poorly developed, leaving them at increased need for parenteral nutrition to support their growth and development. Currently Scotland with a comparable population to ROI has a third more paediatric patients on HPN.

Total capacity

Whilst a more detailed analysis should be conducted by a national steering group, it is estimated that the total capacity for both adult and paediatric HPN, for malignant and non-malignant IF, based on conservative estimates, is likely to exceed 20 patients per million within the coming 5 years.

4.2 Service configuration

There is clearly a need for a balance between the establishment of a National Specialist Centre, and accessibility for patients.

One of the dilemmas facing health services in establishing national centres for services is the difficulty that this can create for patients who may live long distances from the centre. In addition, long waiting lists may develop, causing a backlog of patients in other hospitals that may become more seriously ill whilst on the waiting list to be referred to the national centre. Hence, non-specialist hospitals end up developing a service in an ad hoc fashion, leaving patients with highly variable levels of access and service quality, some areas having no provision and others good provision.

Hence, it is considered impractical to establish a national centre as the only service provider for adult IF as the result of benign disease. Rather, it is proposed to establish a national centre with support from designated regional hospitals that can demonstrate their ability to meet nationally agreed standards of care and take part in audit of clinical outcome. This is largely in line with the service configuration that is in advanced stages of implementation in England, and similar to the network established in Scotland and Wales.

Recommendations

Service planning to meet predicted levels of need

1. Sufficient capacity and resourcing is needed within this framework to accommodate up to 3 times the current rates of adult HPN. This is based on estimates in a recent report by a UK expert group that the minimum numbers of Type III adult patients likely to require long term PN at home are no less than 14.6 per million.
2. Additional provision should be made for cancer patients for whom HPN is increasingly being used successfully by National Cancer Centres, the latter which accounts for nearly 36% of all HPN in ROI (on database up to December 2012).
3. The need for HPN in paediatric patients, which currently accounts for 15% of HPN cases in ROI (on database up to December 2012), is also likely to continue to increase by up to a third over the coming years. Hence, the total capacity for both adult and paediatric HPN, for both malignant and non-malignant IF, based on conservative estimates, is likely to exceed 20 patients per million within the coming 5 years.

Service configuration

4. A national framework for the management of patients with IF and HPN needs to be established based on fewer national specialist centres managing larger patient numbers, delivering care as part of a network system. Based on the existing and anticipated prevalence of suitable candidates for HPN, it is unlikely that more than one adult IF /HPN national specialist centres and one paediatric centre would be required nationally within this network, while specialist cancer referral centres may also make use of HPN, as is the case at present. This proposed national service configuration involves:
 - Our Lady's Hospital for Sick Children in Crumlin to remain as the national centre for paediatric patients.
 - Establish one National Specialist Referral Centre for severe adult IF. This Intestinal Failure Unit would be a national referral centre for the most complex patients.
 - Establish a defined number of regional hospitals (level 4) with the expertise to support the national IF unit and manage patients with IF /HPN, ensuring that patients have access to high quality care as close to home as can safely and cost effectively be provided.
 - It is anticipated that National Cancer Centres, St. James's Hospital and University College Hospital Galway, would be included within this network, given the increasing use of HPN for cancer patients with advanced malignant disease.
5. Within this framework, it is strongly recommended that the management of IF (Type II and III) would be transferred over an agreed period of time to these hospitals, each of which would have:
 - the necessary resources, specialist expertise in the form of a MDT, the composition, training, roles and responsibilities required.
 - agreement with and ability to comply with agreed minimum standards of practice and protocols for patient selection, management and clinical governance.
6. Smaller hospitals that are unable to meet agreed minimum criteria for the total management of such patients, may be recruited by national centres to provide some aspects of care for patients in their vicinity, should this be clinically and cost effective for the health service, or offer the opportunity for routine care to be undertaken closer to the patient's home.

5. Developing an improved model of care: standards, protocols and training

5.1 Minimum standards for service providers to type II and III IF patients

In September 2010 the Association of Surgeons in Great Britain and Ireland (ASGBI) published a report entitled 'The Surgical Management of Patients with Acute Intestinal Failure'. At the outset of the report they state that 'the management of patients with IF necessitates close collaboration between surgical teams, physicians and radiologists. Involvement of a multi-disciplinary NST is essential. Hospitals that do not have a NST or a surgeon with a committed interest to nutritional support should consider referral to centres where these facilities exist'.

This report did not evaluate the capabilities, quality standards or service delivery provided by individual centres. Although it is recognised that there are centres with great experience and knowledge in delivering excellence of care with a well trained and organised MDT, this report focuses on addressing deficits in the national service provided for this highly specialised group of patients.

ROI has:

- no specialist IF / HPN centres for adults;
- no national framework for delivery and coordination of services;
- no agreed national standards of care or national guidelines on the management of a patient on HPN;
- no NSTs established for IF/HPN in adult centres, and no training course for the education and training of MDTs in ROI;
- no national guidelines on staffing level requirements necessary before a patient can be sent home on HPN;
- no nationally agreed training requirements for anyone involved in providing a HPN service;
- no requirement for a hospital to have protocols for the discharge and training of the patient and in many instances this is managed and coordinated by a medical nutrition company;
- no requirement for a hospital to provide a monitoring protocol to the patient and in many instances follow up and monitoring is ad hoc, which poses significant avoidable risk to such a vulnerable patient.

The fact that many hospitals have very infrequent exposure to these patients and may only see only one such patient every 3 to 4 years suggests that local policies may not be in place to give these patients the very specialised and expert care and ongoing monitoring that they need.

This is also reflected in the funding system for HPN. The funding process needs streamlining across the HSE. It varies greatly from region to region, both in terms of who approves the funding and if approved, how long the funding is granted for. This lack of clarity is leading to significant delays in achieving funding approval, resulting in delayed discharge for some patients.

5.2 Competencies and training

There are currently two nutrition support nurses in OLHSC Crumlin, and two adult nutrition support nurses, one in Beaumont (part-time capacity) and one in the Mater hospital. The Irish Nutrition and Dietetic Institute provides a nutrition support course for its members of which HPN is a component part, but this is only available to dietitians and attendance is not compulsory for dietitians working in this area. The Nutrition Support Interest Group of the INDI has also developed general guidelines for managing HPN patients for its members. Unlike many other comparable countries, there is no training course on HPN for health professionals involved in HPN in ROI.

Recommendations

Quality standards and minimum criteria for hospitals managing IF and HPN

7. Key to the implementation of a national framework for IF and HPN, is the immediate commissioning of national standards for the management of patients with IF and HPN provision, to which all regional or national centres for IF and/or HPN would be expected to comply, and against which they would be audited. National standards would need to be developed which take account of:
 - Staffing levels, resource and roles within a MDT.
 - Roles, responsibilities and ongoing training.
 - Protocols / criteria for candidate selection for HPN, that take into account the significant differences between patients offered HPN for non-malignant IF and those with malignant disease, the latter who may benefit from HPN in the terminal stages of disease or as a supportive therapy during or while awaiting further treatment.
 - Protocols for the management of the discharge process (to include patient training).
 - Monitoring of patients in the community, according to patient type (e.g. patients with malignant disease may require a different monitoring than those with non-malignant IF).
8. In line with recommendations developed by ESPEN, the ASGBI and in countries with national standards, all units involved in IF and HPN should be required to ensure that patients are managed by an experienced and appropriately trained MDT, which as a minimum, must include the lead surgeon/consultant, dietitian, pharmacist and specialist nutrition nurse or nurse who has had training in HPN.
9. Whilst it may be sufficient for supporting regional centres for IF and HPN to manage patients via a MDT, the National specialist centres for IF should be expected to establish a dedicated NST. Given the impact that treatment has on the patient's social and family life, clinical psychologists and social workers should also be available to support the MDT.
10. A nationally accredited HPN training course for NST/MDTs needs to be developed which provides and maintains the necessary level of training required for all future or potential HPN providers. As it is likely that the development of a suitable course may take 18 months to 2 years before implementation, it may be appropriate for the HSE to provide funding for members of the core MDT to attend ESPEN accredited courses in the UK / Europe in the interim. IrSPEN is likely to be best placed to coordinate training modules in ROI, as the local ESPEN affiliate.

6. Developing an improved model of care: supporting infrastructure, governance and audit

6.1 Advocacy and patient centred care

One of the most compelling reasons for coordinating services for patients with intestinal failure at a national level is to ensure that this small but highly specialised group of patients receive consistent standards of care, irrespective of which of the designated IF/HPN centres (regional or national) they are treated in.

Although there is little or no audit data to highlight the impact on the quality of care for HPN patients of current, uncoordinated service arrangements in ROI, the expert group responsible for developing a national framework for service provision in the England cited significant deficits in the services when left to individual hospitals to manage such complex patients. Expert units in England (Hope Hospital, Salford and St. Mark's Hospital, London) reported that when they saw patients who had come via the smaller units, their treatment had been sub-optimal. Many smaller units did not have an established MDT, did not monitor their patients in a systematic way and were unable to give audit data on outcomes. On that basis, in 2008, it was decided that collective planning arrangements were urgently required to ensure that standards of care were met by all HPN providers, and that a National Steering Group would be required to oversee the implementation, funding/resourcing and auditing of a national service model.

The model proposed in this report is to provide a network of providers, organised around a national centre that will act as a tertiary referral centre for complex cases. It was decided that a single national centre that would manage all adult IF and HPN would not be practical, and would result in long waiting times for patients and hardship for patients that may have to receive care long distances from their homes.

The decision to adopt a 'network' approach, with regional centres supporting a national centre, makes national coordination imperative, given the need to ensure that all centres have the capabilities, training and service standards to deliver a high quality service, and that all hospitals in the network participate in clinical audit so that any refinements can be made to the service configuration going forward.

Recommendations

National Steering Group

11. A National Steering group should be set up to oversee the development and implementation of such a national care programme / framework, and the clinical governance of any standards or protocols developed. The Steering Group should be led by a Consultant Surgeon specialising in intestinal failure from the national or regional units, and would include representatives from each of the following professions/ disciplines: Surgeon, Gastroenterologist, Dietitian, Nurse Specialist, Hospital Pharmacist, Patient representative. Specifically, the role of the Steering Group would include the following: Establish national practice standards and protocols, set up a national register for clinical audit and take action on the basis of annual results, support or establish training standards, in association with IrSPEN, and liaise with HIQA and the HSE, the mechanisms for which would need to be established.

Audit data and outcome measurement

12. To build on the important work of the INDI in developing and maintaining a voluntary register of HPN patients within their own membership, a national HPN register should be established without delay.

13. In addition to obtaining reliable data on the incidence of HPN and relevant patient data to allow monitoring of trends or allow detailed analysis of incidence and practice according to patient type, reporting should also allow for monitoring of outcome data, including number and type of complications, any readmissions to hospital and their cause, and other outcome data.

14. Similar to other countries and the UK, it is recommended that the register be managed by IrSPEN, as the national affiliate of ESPEN and as the only multidisciplinary group specialising in enteral and parenteral nutrition in ROI.

15. Reporting to this national register should be mandatory for all HPN centres, and one of the criteria with which any hospital that manages Type II or III IF must demonstrate a willingness to comply.

16. It is strongly recommended that funding for a national register be provided by the HSE, given that it is an essential tool to good clinical governance.

Clinical governance

17. Management of Type II / III IF patients should be restricted to hospitals that can demonstrate compliance to minimum standards.

18. There is an urgent need to establish the respective roles of Directorates within HSE and HIQA in the establishment and implementation of a strategic framework/ clinical pathway and in auditing standards of practice/outcomes. This would be one of the roles of the steering group.

Patient centred care

19. It is recommended that a survey be conducted of short and long term HPN patients with a view to determining patient experience of existing practice across the country, and to identify any major gaps or deficits that need to be addressed as a priority. Information from this survey should be taken in consideration by the Steering Group in determining protocols for care and standards of practice.

20. In ROI there is no patient organisation specifically for those on artificial home nutrition. There are currently an estimated 1800 patients on home enteral feeding in ROI at any time, in addition to the small numbers of patients on HPN specified in this report. Efforts should be made to facilitate the establishment of a specialist organisation in ROI, possibly with links to similar organisations in the UK and NI.

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Abbreviations

ASGBI	Association of Surgeons in Great Britain and Ireland
ASPEN	American Society for Parenteral and Enteral Nutrition
AuSPEN	Australasian Society for Parenteral and Enteral Nutrition
BANS	British Artificial Nutrition Survey
CRBSI	Catheter-Related Blood Stream Infection
CVAD	Central Venous Access Device
ESPEN	European Society for Clinical Nutrition and Metabolism
GI	Gastrointestinal
HIQA	Health Information and Quality Authority
HPN	Home Parenteral Nutrition
HSE	Health Services Executive
IF	Intestinal Failure
IrSPEN	Irish Society for Clinical Nutrition and Metabolism
INDI	Irish Nutrition and Dietetic Institute
ISG	Irish Society of Gastroenterology
MDT	Multidisciplinary Team
NICE	National Institute for Health and Clinical Excellence (UK)
NST	Nutrition Support Team
PICC	Peripherally Inserted Central Catheter
PN	Parenteral Nutrition

Definition of Terms

Ancillary equipment: All supporting equipment required for PN including plastics and dressings.

Bespoke bags: Parenteral Nutrition bags tailored to the particular needs of an individual patient.

Central Venous Access Device: A flexible hollow tube, inserted with a guide needle into a central vein.

Enteral Nutrition (EN): The term enteral nutrition comprises all forms of nutritional support that are regulated as 'dietary foods for special medical purposes' as defined by the European Commission Directive 1999/21/EC. It includes oral nutrition supplements (ONS) as well as tube feeding products administered via nasogastric, nasoenteric or percutaneous tubes.

Home Parenteral Nutrition (HPN): Home Parenteral Nutrition refers to the provision of parenteral nutrition in a patient's own home or a community setting. Whilst in most countries, HPN is mainly offered to long term IF patients, it is being used for shorter periods in malignancy from specialised centres.

Intestinal Failure (IF): Intestinal Failure is the main indication for HPN. It can be temporary or permanent and occurs for a variety of medical and surgical reasons. These include obstruction, surgical resection, congenital defects, or disease-associated loss of absorption. IF is characterised by the inability to maintain protein-energy, fluid, electrolyte, or micronutrient balance. Throughout this report we have used the categorisation of the 3 types of IF described by Lal et al in 2006 and used in the HIFNET Strategic Framework document.

- Type I intestinal failure is short-term, self-limiting, often peri-operative in nature and relatively common. Patients are in hospital for the duration of treatment and usually on surgical wards, high dependency units and intensive care units.
- Type II intestinal failure occurs in metabolically unstable patients and requires prolonged treatment which may include in-patient parenteral nutrition over periods of weeks or months. It is often associated with sepsis, and may be associated with renal impairment. Type II IF is rarer than Type I. A proportion of Type II IF patients (approximately half) will stabilise and become Type III IF patients needing long term parenteral feeding who can be managed at home.
- Type III intestinal failure is a chronic condition requiring long term parenteral feeding. The patient is characteristically metabolically stable but cannot adequately absorb sufficient fluid, food or nutrients via the intestinal tract and requires HPN.

Malnutrition: There is no universally accepted definition of malnutrition. The following definition is now widely acknowledged by many, including ESPEN: 'A state of nutrition in which a deficiency, excess (or imbalance) of energy, protein, and other nutrients causes measurable adverse effects on tissue/body form (body shape, size and composition) and function, and clinical outcome.'

Neonate: A newborn baby or a baby in its first 28 days of life

Nutritional assessment: A detailed, more specific and in-depth evaluation of a patient's nutritional state, typically by an individual with nutritional expertise (e.g. a dietitian, a clinician with an interest in nutrition or a nutrition nurse specialist) or by a nutritional support team. This will usually be conducted in the case of nutritional problems identified by the screening process or when there is uncertainty about the appropriate course of action. The assessment process allows more specific nutritional care plans to be developed for the individual patient.

Definition of Terms contd.

Nutrition Support: Nutrition support includes food, ONS, tube feeding and parenteral nutrition.

Nutrition Support Team: A multidisciplinary group with specialist knowledge in clinical nutrition, working together as a team to ensure the implementation of high standard nutritional care. The composition of the team may vary according to their particular role within a hospital, but will typically include a physician, senior dietitian, nutrition nurse specialist and pharmacist.

Parenteral Nutrition: The provision of vital fluid and nutrients into a vein and is used if a patient has temporary or permanent intestinal failure, or if a patient is unable to take or tolerate enough nutrition enterally or orally.

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Appendix 1:

Example of good practice with HPN coordination

At Our Lady's Children's Hospital, Crumlin, an HPN programme has been in place for the past 12 years. This provides a paediatric HPN service for the whole country and is run by a fully integrated multidisciplinary nutrition support team (NST). The team is headed by a paediatric gastroenterologist and includes 2 dedicated nutrition support nurses. Together with a clinical specialist dietitian, the nutrition support nurses provide the day-to-day running of the service. The NST, which also provides PN support for the hospital, also includes a dedicated pharmacist and is supported by the GI department's psychologist and social worker. There also are identified link persons in the clinical laboratory (biochemist) and a paediatric surgeon.

The NST has a formal meeting every 2 weeks at which all current and anticipated HPN patients are discussed. One paediatric gastroenterologist has responsibility for following HPN children in OPD. Strict protocols around the home and hospital management of central lines are rigorously enforced and have contributed to a remarkable decline in central line infections.

In total, 30 children have been managed on HPN over the last 12 years. Ten children have rehabilitated to full enteral nutrition successfully. There are currently 10 children on HPN with various diagnoses. The main indications include short bowel syndrome, intractable diarrhoea and pseudo-obstruction.

Planning

All patients who may require HPN are referred to the GI team for assessment.

Once all alternatives are out ruled then the patient is assessed by the multidisciplinary team for suitability for HPN. This includes medical, nursing, dietetic, social work and psychology assessments of a child's medical condition, parents' involvement and understanding of the HPN requirements.

If agreement to proceed to HPN then:

- A child must be medically stable before training commences.
- The likely duration of training is discussed with the parent(s) who need to commit to the training schedule.
- Stability must be achievable on a nutritionally complete PN bag, pharmacy liaise with the home care company in this regard. Adjustments may be required which are discussed and agreed by the MDT.
- Application is made for a GMS card.

Before training commences:

Assessment of the family's housing situation is needed. Rehousing or alterations may be required which could delay discharge so this should be addressed before training can be scheduled.

The funding application to local HSE area should be supported by letters from the consultant. There can be delays in receiving agreement for funding so again this will delay the date for training.

A meeting with the local community services should be scheduled to advocate for the patient and ensure adequate supports are available. Depending on the family circumstances, help may be needed at times of connection and disconnection, so helpers (not specifically nurses) need to be trained and available on a 7 day basis. The home care company can provide training for these helpers. In addition, home-help hours or nursing hours may be required. Nurses providing respite should not be responsible for the connection and disconnection as this can only be done by those specifically trained for HPN.

The patient may also be on enteral feeds so supply of equipment and feeds needs to be organised through community care and the local pharmacy.

Parents may require financial support such as the Domiciliary Care Allowance.

A child on HPN may need Special Needs Assistant in school.

The patient's details are sent to the home care company to arrange supply of equipment and ancillaries.

Training

HPN training is provided by the nutrition nurses in OLCHC. This is a very intensive period for both parents to ensure they are competent before discharge.

Monitoring

Initially monitoring is done at OLCHC so patients attend every 1 – 2 weeks for review of bloods and medical, nursing and dietetic review. Once stable, bloods are taken every 3- 4 weeks. This can be arranged with the local hospital if possible.

Patients are reviewed in the gastroenterology clinic every 3 months or more regularly if required. Patients are discussed at the MDT meeting regularly to ensure all team members are familiar with their current status.

Ongoing monitoring of growth is required as a child progresses from infancy through to childhood and adolescence. Regular medical, nutritional and psychosocial review is required as the child's needs change over this time period.

Complications

Parents are advised of the possible complications e.g. line occlusion, sepsis. Each patient has a copy of their own line protocol giving details of the line management if sepsis is suspected. A copy of this protocol is also kept in the patient's chart and in the Accident and Emergency Department. Contact details for the GI team are included in the protocol.

Appendix 2:

Example of good practice with HPN coordination

St. James's Hospital has been providing a HPN service for over ten years, with the majority of patients having an underlying cancer diagnosis resulting in intestinal failure, e.g. malignant bowel obstruction or short bowel syndrome. The clinical nutritionists/dietitians work closely with the consultant medical oncologists or gastrointestinal surgeons to manage these patients from referral to discharge and beyond. Over 40 patients have been successfully discharged on HPN since 2003, and in recent years the service has expanded to include patients requiring home intravenous fluids and electrolyte supplementation.

Patient Selection

The decision to proceed with HPN is made by members of the multidisciplinary team (consultant, clinical nutritionist, palliative care, nursing staff, etc.) in consultation with the patient and their family. Initial discussions will focus on the role of HPN within the patient's overall medical or surgical management, anticipated benefits of HPN, limitations of HPN, feasibility of HPN administration, and anticipated time to discharge. This communication is essential to ensure that patients and their families have realistic expectations and understand that HPN may need to be withdrawn should there be a significant clinical deterioration.

It is a requirement for consideration of HPN in oncology patients that the risk of malnutrition outweighs the risk of death from the underlying malignant disease. Where prognosis is very short, HPN is unlikely to confer any additional benefits and is generally not recommended. Patients must be relatively stable medically, so that they can be appropriately managed in the outpatient setting. The patient, or more commonly their family members / carers, must be able to perform the required tasks for HPN administration and must commit to the training required in order to be competent in this.

Discharge Planning

The clinical nutritionists/dietitians coordinate all aspects of HPN discharge planning. They will submit an application for funding to the relevant HSE area, with supporting documentation from the consultant, and will follow up to ensure funding approval is received. They will also liaise closely with the HPN provider company to arrange training and the installation of all necessary equipment and ancillaries prior to discharge. Nursing staff will request dressing of the central venous access device (CVAD) by community nursing services where appropriate, or occasionally the CVAD will be redressed in Oncology Day Care.

The clinical nutritionist will also select the most appropriate PN regimen and duration of infusion for the patient, based on individualised nutritional assessment and care planning. Where patient specific regimens are indicated, these will be formulated and submitted for stability, and often patients may also require additional intravenous fluids. All PN and fluid regimens are subsequently prescribed by the primary consultant. Patients and families / carers are educated on all aspects of their nutrition care plan in advance of discharge, and provided with written information and contact numbers.

Monitoring and Complications

Patients are regularly reviewed in Oncology Day Care or in outpatients by the clinical nutritionist and the medical oncology or surgical team. They will have biochemical and anthropometric monitoring at appropriate intervals, which are determined individually based on the overall management plan for each patient. Where patients are living outside Dublin, it may be possible for them to attend their local hospital or GP for blood tests in between routine appointments, with the results sent to St. James's Hospital for review by the clinical nutritionist and consultant. Oncology patients also have 24-hour access to oncology services by telephone if they are unwell, which is an important feature of our service.

Patients and families / carers are educated on potential CVAD complications as part of their training prior to discharge, and are encouraged to monitor their temperature and contact the hospital if they feel unwell at any time. CVADs are also regularly monitored for sepsis when patients attend for review. Where metabolic complications occur, the HPN or intravenous fluid regimen may need to be adjusted by the clinical nutritionist in close liaison with the consultant medical oncologist or consultant surgeon.

New Developments

The clinical nutritionists in St. James's Hospital have been working closely with VHI Homecare over the last eighteen months to introduce HPN to their existing home clinical service. Patients in the Dublin area that have private health insurance with VHI (some plans exempt) may be considered for this new service where nurses from VHI Homecare will administer PN in their home for up to twelve weeks. This has also been used successfully as a 'bridging' service, which has facilitated earlier patient discharge from hospital while HPN training is completed in the home environment.

There has also been an increase recently in the number of patients discharged on self-administered home intravenous fluids and/or electrolyte replacement. Patients may end up with complex gastrointestinal problems or intestinal failure as a result of multiple oncological treatments, and can have difficulty maintaining hydration and electrolyte status (especially serum magnesium levels). Previously, this would have necessitated hospital admission or frequent visits to Oncology Day Care for replacement, but now these patients can often be managed successfully in the home setting which has numerous cost- and time-saving benefits for the patients and the hospital.



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