
# IrSPEN Submission to Joint Oireachtas Committee on the Future of Healthcare

August 2016

## Executive Summary

1. Given that the background to the establishment of the Joint Committee is the severe pressures on the healthcare system, the unacceptable waiting times for public patients and the poor outcomes relative to healthcare cost, it is clear that a one tier, universal health model can only be achieved if care gaps within the existing services with known, adverse effects on outcome and healthcare utilisation are addressed within the ten year plan. In this context, IrSPEN urges the Committee to commit greater efforts towards the prevention and effective treatment of undernutrition (primarily disease related) and obesity, both major and costly public health problems likely to place increased pressure on scarce healthcare resource within the next decade.

2. Disease related malnutrition is a major source of avoidable risk to patients and an unsustainable source of cost to the health service, with malnourished patients currently using in excess of one third of acute care inpatient bed capacity in Irish hospitals each year, over 90% of whom are admitted from their own home. As most malnutrition is preventable and screening programmes and models of good nutritional care capable of delivering net cost savings, the high prevalence of malnutrition (averaging 30% of inpatients on admission to Irish hospitals) and low priority placed on its prevention merit immediate attention by the Committee. Earlier detection and treatment of community patients with malnutrition could release as many as 450 inpatient bed days per day or 168 000 per year (6% total capacity), yet so far, primary care screening programmes are lacking and community dietetic access severely limited. Future healthcare strategy must focus increased efforts at preventing malnutrition in primary as well as community and secondary care settings.

3. Contrary to the principle of supporting patient self- management, treatment at the lowest level of complexity and the integration of care pathways across care settings, IrSPEN has identified major deficits in the configuration and delivery of clinical services and support for patients discharged from acute care settings on home enteral nutrition (approximately 2800 each year) and on home parenteral nutrition (approximately 35 to 40 per year), both of which IrSPEN urges the committee to address. Current 'ad hoc' services and failure to provide specialist support required by patients on home therapies results in delayed discharges, excess acute admissions for routine problems (eg. tube misplacement, site infections) that could be safely managed at home and in the case of parenterally fed patients managed by non-specialist centres (see below), potentially life threatening line sepsis.

4. Whereas a key deliverable of the Committee is to establish a basis for more equitable access to services based on need, we would draw the Committees immediate attention to the current lack of any suitable service capable of meeting UK / International minimum commissioning standards for patients that develop prolonged / permanent intestinal failure (IF) in Ireland each year (80 – 100), and for those awaiting transition from the national paediatric IF specialist unit based at Our Lady's Hospital for Sick Children. IrSPEN has highlighted this to the HSE as an entirely unacceptable situation that is contrary to all international recommendations and at odds with all developed healthcare systems, including NI (12 bedded unit), the UK and across Europe, costing an estimated 20 lives each year.

5. Given the strategic importance of obesity and diet related disease to healthcare planning, the Committee should align policy and services according to best available evidence regarding the most effective strategies for prevention on the one hand, and treatment of those with severe and complex obesity on the other. In the case of severe and complex obesity, surgical intervention is by far the most clinically and cost effective solution, offering return on investment of 2 – 3 years. In Ireland, access to bariatric surgery is less than 0.1% of the demand based on criteria established by NICE / cost effectiveness data.

The costs associated with malnutrition and obesity are substantial and growing, putting added pressure on services. However, many of the problems are avoidable and large savings achievable. Hence, IrSPEN

urges the Committee to address the current gaps in the provision of nutritional care within their ten year plan.

**Recommendations included:**

1. A national malnutrition steering group or task force should be established at Department of Health level, involving HSE members, patient representatives and relevant expert groups and individuals to ensure that implementation is effective and produces the anticipated outcome and cost benefits. Given the strategic importance of this area and the large potential for savings, IRSPEN is seeking an oral hearing to present its proposals in full and the activities already underway, incorporating health economic modelling on investment costs and potential for savings.

2. IRSPEN urges the committee to address the gaps in service provision and models of care required to support patients discharged from hospital on home enteral and parenteral nutrition therapies. As part of its planning, greater funding and streamlined services and funding arrangements must be put in place to support the ambitions outlined by the Committee for integrated, equitable and efficient healthcare delivery.

3. Patients with intestinal failure in Ireland deserve the same access to specialist dedicated units as those in Northern Ireland, the UK and in developed healthcare systems throughout Europe and beyond. We urge the Oireachtas Committee to support the establishment of a national service, capable of meeting minimum commissioning standards within the UK/NHS as deemed necessary to give this small group of patients with highly complex and challenging requirements the best chance of survival and health. St. James's hospital is proposed as the ideal location for this a national adult specialist unit, and is the subject of a business plan for which the support of this Committee is being sought.

4. Healthcare policy in the area of obesity and malnutrition must differentiate between strategies for prevention and effective treatment, both being important. We urge the Committee to establish a public bariatric programme to allow access to 400 public patients annually with immediate effect, rising to at least 1000 by year ten (2026). Recognizing that allocating limited resources must take budget as well as cost effectiveness into account, a self-funding model is proposed with planned expansion of services subject to delivery of predicted returns on investment over the 10 year plan.

5. The Oireachtas Committee should support specific reporting measures and audit data to highlight the prevalence and impact of malnutrition on outcomes and on the quality of nutritional care provided by healthcare providers.

## Strategic Priorities over the next 10 years

**Action Area 1:** National strategy aimed at significantly reducing the scale and impact of malnutrition on patient outcomes and healthcare costs.

**Background**

Malnutrition and dehydration are known causes and consequences of illness that have significant adverse impacts on health outcomes. As such, their prevention and effective treatment must be integral to all care pathways. However, in practice in Ireland, nutritional care - from detection of risk to the earliest possible correction of any deficits or imbalances and access to nutrition services - is still given low priority relative to its impact across our healthcare system, undermining the effectiveness of medical and surgical interventions and delaying recovery, driving up overall healthcare costs.

At any time, malnutrition affects more than 140,000 chronically ill patients, over half being over 65 years. Although most malnutrition occurs in the community (approximately 97% of those with malnutrition are living in their own home or community settings), most of the €1.4billion annual care costs associated with malnutrition are borne by acute care services, due to more frequent and longer hospital episodes. Without greater focus and resources to achieve consistently high standards of nutritional care and timely access to dietetic services for assessment, treatment and review as appropriate to the patient's needs rather than their ability to pay or geographical location, the cost burden and impact on scarce healthcare resources will only increase further.

**Strategy: why malnutrition must be given significantly greater priority within the 10 year plan :**

- The prevalence of malnutrition is currently around 3.3% of the population but is predicted to increase to between 190 000 and 200,000 (3.7% of population) by 2026, of which 60% will be >65y.
- A secondary analysis of prevalence data obtained from two annual surveys conducted in 27 Irish hospitals applied to 2013 HIPE inpatient data indicates that 36% of the entire acute bed capacity usage was associated with malnourished patients, despite this group representing just 3.3% of the general population. This disproportionate use of healthcare resources by malnourished is predictable, unless systems are in place to ensure early detection and treatment throughout the healthcare system, which they are not.
- Applying results from recent systematic reviews, early treatment of community malnutrition could release 168,000 inpatient bed days arising from reduced hospital admissions. The relative impact would be greater in adults aged over 65 years (4% of bed days) than younger adults (2% of bed days), given that the average LOS for an older malnourished patient is approximately 11.5 days, almost twice that of younger malnourished patients and significantly greater than non-malnourished patients.
- National Screening programmes to detect malnutrition risk factors in old and/or chronically ill and socially isolated patient populations have been shown to be effective in reducing the prevalence and severity of malnutrition, improving outcomes and delivering cost savings.
- Ireland lags behind countries such as the UK and Netherlands in implementing national screening programmes across and within care settings.

**Delivering services as part of an integrated model across primary, secondary and community care:**

- Most malnutrition arises in adults living in their own home (92 – 93%), with the remainder of those affected living in nursing or residential care (around 5%) and hospitals (2 - 3%), on any given point in time. Conversely, an estimated 56 and 58% of the care costs of malnourished patients arise in hospitals, due to higher rates of hospitalisation, higher risks of infection once there and longer average length of stay and up to 90% higher readmission rates. Thus, the

greatest potential to avert costs arising from malnutrition related health or functional deficits arise in the primary care settings, supporting the need for investment in nutrition education of primary care team members, dietetic services, with emphasis on groups at highest nutritional risk, and care pathways and support services for patients receiving nutrition support at home**.**

- IRSPEN supports the establishment of workstreams within the HSE to improve nutrition and hydration of patients. We welcome the valuable role HIQA has played in establishing a framework for self- assessment of nutritional care in both hospitals and nursing homes. However, in establishing a new framework for the future of healthcare, we believe it imperative that policies and quality standards be fully integrated across care settings and sufficiently resourced to address some major gaps and inequities in the current access of patients to appropriate nutritional care. This will have major implications for community /primary care services, which are insufficiently resourced to take pressure of acute care services.

- The vast majority of patients who receive nutritional support are first identified in hospitals and discharged into the community, where dietetic services are lacking to ensure follow up and timely review. If savings are to be achieved and malnutrition prevented or treated at the earliest opportunity, patients should be identified through screening by the GP or practice nurse, and referred to community dietetic services for assessment and treatment if required.

**Funding Model and implications**

Without any regular, large scale survey or auditing of malnutrition prevalence and / or its relationship on outcomes or to differences in the quality of nutritional care, there is no accountability and the HSE is unlikely to invest in its prevention and treatment or to ensure access to dietetic services for those in community / primary care as well as hospitals. Hence, to guide service development and resource allocation as nutrition services are put in place, key performance indicators and metrics should be measured. These metrics should reflect service activity and outcomes.

In recent years, low priority placed on nutritional care of patients coupled with severe pressure on healthcare expenditure produced an environment in which the costs of nutrition support and the need for savings overshadowed the clinical and cost impact of malnutrition or the efficacy and cost effectiveness of medical nutrition. Dietetic services were drastically impacted by an extended moratorium, leaving large areas of the country without any community service for patients requiring assessment or review of their nutrition support.

Given the overwhelming evidence base supporting the efficacy and cost effectiveness of nutritional support, once targeted appropriately and the patient reviewed at regular intervals by a dietitian, it is important that community funded schemes for nutrition support place greater emphasis on value and outcomes and that reimbursement systems ensure access of all patients, including those on LTI schemes, to required nutrition support.

**Recommendation to Joint Committee**

Given the strategic importance of this area and the large potential for savings, IRSPEN is seeking an oral hearing to present its proposals in full, incorporating health economic modelling on investment costs and potential for savings.

**Action Area 2:** Urgent need to address the deficits in community support and coordination of services for patients requiring home enteral (and parenteral) nutrition.

**Background**

Currently in Ireland, c.2000 adults and children are receiving home enteral nutrition (HEN), with c.1900 patients discharged home on tube feeding each year. Clearly, it is in the interests of both patients and healthcare system to ensure streamlined transition of suitable patients from hospital to their own home / community as soon as they are clinically stable, and data consistently shows that HEN can have a transformative impact on quality of life, allowing restoration of normal family life. Compared with the costs of keeping patients in hospital to receive enteral nutrition (average bed day cost of €825 to €1300 in level 4 hospital), care at home delivers major savings for the health service, yet currently, the supports available to maintain patients safely in the community are lacking in the vast majority of areas. In particular, access to community dietetic staff with expertise in enteral feeding is a major problem for patients following discharge, resulting in avoidable admissions for routine procedures that could be managed safely and considerably more cost effectively in the patient's home. Medical nutrition companies play a significant role in patient training in both hospital and home and in providing free of charge equipment (pumps, stands, initial supply) in many areas of the country and this is undoubtedly propping up services where they are non-existent and masking care gaps in community services. Surveys by IrSPEN have confirmed major gaps in services and inconsistencies that all patients on home enteral nutrition and will publish their findings and recommendations later this year.

**Strategy: why this is a strategic priority within ten year planning**

- The number of patients on tube feeds is likely to rise to between 2600 and 3000 by 2026.
- A recent IrSPEN survey of HEN patients has confirmed major gaps in service provision at community level for many patients, with highly variable practices and community arrangements for funding and supply according to the discharging hospital and the area. There is a lack of 'joined up' thinking in both service planning and resourcing by the HSE to ensure safe care for this small but vulnerable patient group, contrary to the principle of supporting patient self- management at home.
- Due to the absence of standards of practice for service providers nationally, the quality of service and support are highly variable and inconsistent.
- Supply arrangements vary greatly across the country, resulting in frequent problems ensuring continuity of supply or in obtaining emergency supplies.
- The failure to ensure adequate care for patients following discharge from acute settings into community care is entirely at odds with an integrated care model, and highlights the urgent need to operate a more effective community care model that keeps patients out of hospital.
- There are clearly missed opportunities for cost saving and improved clinical outcome, as well as quality of life benefits.

**Integrated primary and community care:**

*A Best Practice Example for HEN from INDI (Irish Nutrition and Dietetic Institute) and a model for adoption nationally:*

- In Dublin North City and County, a very successful Community Adult HEN service has been established since 2008.

- Up to the end of 2014, 276 patients have been referred to the service, with an average of 40 new referrals a year. At any one time a caseload of 110 patients are being seen.
- All adult patients on HEN are initially seen within one week of discharge by a dietitian, who is assigned as their main / single point of clinical contact.
- Each patient is reviewed regardless of their location in the community (home, private or public nursing home), at least 3 monthly and ongoing training is provided to each patient/ carer, as well as to their public health nurse/ nursing home staff, GP and professional carers.
- The community dietitians involved have an extended scope of practice that involves changing tubes when necessary at a patient's bedside.
- It has been estimated based on a similar service in the UK, in which patients discharged under the supervision and with access to a community dietitian and speech and language therapist were compared with those discharged home to community services without home visits and specialist dietetic / SLT access. Over a six month period, admissions to hospitals were reduced by over 21%, with significant annual savings possible if applied nationally.

*Unfortunately this ideal level of community based HEN service is not available elsewhere.*

**Funding Model**

Funding of feed: Enteral feeds are available through retail pharmacy through the GMS (General Medical Services), LTI (Long Term Illness), or DPS (Drugs Payments) schemes. The product needs to be reimbursed under the PCRS scheme to be available under these schemes.

Funding of feeding equipment: Inequities exist in the funding and provision of associated feeding equipment (e.g. giving sets, Y-adaptors, replacement tubes, syringes). This process varies according to local procedures and is not standard across the country. Equipment is funded for medical card holders, but not for non-medical card patients which then results in a significant financial burden for these patients.

Gaps in services: Lack of community services are resource dependent. A workforce planning report in the acute and community setting would help identify where staffing shortfalls are impeding service delivery. Education programmes may help to upskill existing staff, where this is needed.

**Recommendations to the Joint Committee**

1. A systematic approach to discharge from hospital to community services should be in place nationally, meeting criteria and best practice international guidelines which will shortly be issued by a special report and guidelines developed by IrSPEN.
2. Services must be streamlined and adequately funded to ensure consistent delivery of quality care for all patients receiving home nutritional therapies, irrespective of discharging hospital or healthcare area, aligned to the principles outlined by the Joint Committee.
3. All home enterally fed patients should have care provided by an experienced multidisciplinary team, both in hospital but especially at home. The committee should ensure that primary care services are configured and resourced to give patients on home therapies equal access to services provided by multidisciplinary team, in this case, the Dietitian being the main clinical point of contact. A skilled workforce with access to appropriate training and CPD is needed to provide this service
4. Funding processes should be streamlined across the country and made easier for HEN patients and carers. Currently, patients above the medical card threshold are likely to face significant financial hardship under existing arrangements (eg. obtaining suppliers of ancillaries not covered within prescription DPS scheme).

**Action Area 3:** Establishment of a national specialist unit for adults with Intestinal Failure in Ireland. **(Special case to be addressed)**

**Background**

Intestinal failure is defined as "the reduction of intestinal function below the minimum necessary for the absorption of macronutrients and/or water and electrolytes, such that intravenous supplementation is required to maintain health and/or growth". This reduced intestinal function can arise for a wide variety of medical and surgical reasons. Between 80 and 100 of these patients will require specialist inpatient care and intensive outpatient care as they are often discharged on home parenteral nutrition (long term intravenous feed at home). Currently in Ireland, no specialist adult service exists for these patients, contrary to standard practice and all international expert recommendations. Thus, they are dispersed across hospitals lacking the expertise, training or service configuration necessary to provide safe care.

**Strategy: why this should be included as a priority within the 10 year plan:**

- The current absence of a National Intestinal Failure Service represents a major risk for patients and a concern for current service providers, with ethico-legal as well as cost implications.
- INDI data indicates that this small but highly complex patient group are dispersed throughout the country across at least 21 hospitals, none specialised or adequately resourced.
- Our Lady's Hospital in Crumlin is the national paediatric centre for IF for the last 16 years, headed by Professor Billy Bourke, yet no adult service has been established to which they can transition or which offers a similar standard of care for those over 18 years of age.
- Based on available evidence, the lack of adult services might be anticipated to be associated with 18 to 20 avoidable deaths each year in Ireland.
- The risks for patients transitioning from a specialist paediatric unit to a non-specialist adult service have already been brought to light by Our Lady's Children's Hospital, Crumlin (OLCHC). Of the three patients that were transitioned to adult acute services, two have subsequently died, resulting in the suspension of transfers pending suitable specialist care being made available.
- In NI, Belfast City Hospital operates a **12 bedded IF specialist tertiary referral unit** for a population of just over 1.6 million.
- The case for establishing a national IF unit for the Republic of Ireland (ROI) is supported by findings from specialist units internationally of dramatically improved morbidity and mortality when compared with treatment at non-specialist hospitals.

**Current Status:**

IrSPEN supports the establishment of a national unit at St. James's Hospital as the ideal location for reasons outlined in a full business case, currently submitted to the HSE for review and urgent consideration.

**Integrated care model**

Establishing a national centre for IF will also facilitate the streamlining of services for HPN patients, which should ideally be managed under the care of a specialist centre.

**Recommendations for Joint Committee**

Patients with intestinal failure in Ireland deserve the same access to specialist dedicated units as those in Northern Ireland, the UK and in developed healthcare systems throughout Europe and beyond. We urge the Oireachtas Committee to support the establishment of a national service, capable of meeting minimum commissioning standards within the UK/NHS as deemed necessary to give this small group of patients with highly complex and challenging requirements the best chance of survival and health. St. James's hospital is proposed as the ideal location for this a national adult specialist unit, and is the subject of a business plan for which the support of this Committee is being sought.

**Action Area 4:** Establishment of national bariatric programme as a component of its strategy to reduce obesity related disease.

**Background**

Whilst the 10 year strategy must address both prevention and treatment of obesity, this submission focuses specifically on the urgent need to increase access to specialist bariatric services for the treatment of severe and complex obesity:

**Strategy: why bariatric services must be prioritised within the 10 year plan**

- Obesity already affects more than a million people and Diabetes more than a quarter of a million people in Ireland, whilst obesity causing diabetes being one of the most serious health problems within the Irish population. By 2026, the proportion of adults classed as obese could reach 37%, with a concomitant rise in type 2 diabetes (T2DM) and other related conditions.
- Bariatric surgery offers the most successful and cost effective treatment option for the treatment of severe and complex obesity, being associated with a 65% remission rate for those with T2DM and complications and a two to three year return on investment.
- Despite its clinical and cost effectiveness, bariatric surgery is severely under-resourced in Ireland, with just two public clinics – one in Galway and one in Dublin. This imbalance between service availability and current demand has created long waiting lists for access to bariatric services.
- Given that obesity and related diseases are projected to increase and that bariatric surgery offers the most clinically and cost effective treatment option for severe and complex obesity, it is imperative that provision is made for more patients to gain access to services. Therefore, there will need to be enough bariatric surgeons, physicians and allied health professionals with sufficient experience to provide this care over the lifetime of this plan.
- The €90,000/hour (€730 million per annum) that the Irish healthcare system currently spends on diabetes is a major burden on existing services, whereas the costs of bariatric surgery for obese patients with T2DM (est €10,000) are recouped within three years from reduced prescription costs.
- An estimated 10,891 (95%CI: 8,228 – 14,416) people aged ≥ 50 years would meet the criteria for bariatric surgery based on BMI and presence of T2DM. Almost 8 times that number would meet criteria based on a BMI alone. Provision of bariatric surgery to those with both severe obesity and diabetes could potentially result in an estimated 7,079 patients having acceptable glycaemic control not requiring medication whereas at present, less than 0.1% of suitable candidates have access to treatment, with significant cost implications for the healthcare system.

**Delivering services as part of an integrated model across primary, secondary and community care:**

- To achieve the best outcomes for patients and have sufficient volumes to develop the experience and expertise of the MDT, it is important to centralize surgical bariatric services in high-volume centres that are geographically located to optimize access to the national population. We support proposals by the IES Bariatric Interest Group that one centre be established in each of the six hospital groups alongside one national paediatric bariatric centre with a full MDT, with associated assessment clinics provided nationally within each of the HSE Hospital Groups. The MDT in each centre should include at least an upper GI surgeon, bariatric physician, a dietician, a specialist nurse, a clinical psychologist, a physiotherapist, and a liaison psychiatrist.

- To ensure access to specialist medical and surgical care for this complex patient group, it is important that centres be based in model 3 or model 4 hospitals with a well-integrated pathway from primary care services to secondary care and back. These pathways should include preventative care, community based interventions, specialist multi-disciplinary bariatric services that include bariatric physicians, and a bariatric surgical service. For those who are referred onto surgical services, post-operative care should be delivered in a chronic disease model of care.

- It is recognised that these care pathways may have different structures in distinct geographical areas. For example in the west of Ireland, the hospital-based bariatric service links with Croi, the West of Ireland Cardiac Foundation, for the delivery of specific domains of bariatric care involving structured lifestyle modification, whereas in Dublin, these services tend to be delivered within the hospital campus.

- To guide service development and resource allocation as the bariatric services develop, key performance indicators and metrics should be measured. These metrics should reflect service activity and outcomes. The development of this data collection strategy should agree with the aims of the National Obesity Strategy. Strong consideration should be given to the development of a National Registry integrated between primary and secondary care to allow regular audit and to ensure appropriate service development

**Funding Model and implications**

The decision to invest in the establishment of a national service model capable of treating a minimum of 400 public patients per annum year one rising to 1000 by year 10 (see proposals below) must take into consideration the cost effectiveness of bariatric surgery versus non-surgical treatments. A UK health technology assessment found that for patients with a body mass index (BMI) ≥40, the incremental cost effectiveness ratios for surgery ranged between £2000 and £4000 per quality adjusted life year (QALY) gained over 20 years. This was well below the £20 000 per QALY threshold for cost effectiveness used by the National Institute for Health and Care Excellence (NICE) and the range historically used by the HSE (between €20000 and €45,000). For patients with diabetes and a BMI of 30-39 the incremental cost effective ratio fell to £1367 per QALY gained, resulting in a probability of cost effectiveness over 20 years of 100%.

Notwithstanding that even with the investment outlined below, services will continue to fall short of demand and pose ongoing challenges in offering equity of access to patients that will benefit from surgery, we propose the following:

**Recommendation to Joint Committee**

1. Sufficient upfront investment to establish 4 additional adult bariatric centres across Ireland in addition to expansion of existing public specialist services in Dublin and Cork, thereby improving access to services in areas where there are none.
2. Service planning to provide access to 400 patients in year 1, 400 in year 2 (2017 and 2018), increasing by 200 patients annually thereafter to 2000 patients by year 10 (2026), subject to being able to demonstrate a return of investment within two years of treatment for patients that received bariatric surgery in preceding years.
3. Access to patients should be offered preferentially to those with complications arising from severe obesity, such as those with T2DM.

**(IRSPEN recommends an oral representation with the committee by the main submitting group / Dr. Francis Finucane / Professor Carel le Roux)**

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