

In this submission, the Irish Society for Clinical Nutrition and Metabolism (IrSPEN) focuses on two recommendations for budget 2023. These are to:

1. Establish Ireland's first dedicated inpatient specialist Intestinal Failure (IF) unit at St. James's Hospital to provide care for a complex and high needs cohort of patients who face unacceptably high morbidity and mortality risks. Funding required in 2023 is €6m.
2. Address major gaps in nutritional care within cancer care. Funding required in 2023 is €1.7m.

1. Establish Ireland's first dedicated Intestinal Failure Unit – €6m for full year

Each year approximately 100 patients develop severe acute Intestinal Failure (IF) with a requirement for highly specialised care. IF occurs when a person's intestine cannot digest food and absorb the fluids, electrolytes and nutrients essential to life and normal development. Patients must then be fed artificially via total parenteral nutrition (TPN), which provides liquid nutrition through a catheter or needle inserted most usually into a central vein in the chest.

The treatment is lifesaving, but the risk of serious complications is high if not managed extremely carefully with ongoing support within a dedicated IF unit, resulting in excess emergency hospital admissions, prolonged hospital stay and even death.

This relatively small group of patients with highly complex needs challenge even the most experienced clinicians. If correctly managed within a specialist facility, some patients may be successfully weaned off of PN. A majority, however, will require long term PN, which ideally should be provided as home parenteral nutrition (HPN).

The lack of a specialist inpatient service for adult IF or HPN patients means that hospitals around the country have no tertiary referral centre within the State to which they can refer their highly complex patients that develop severe acute IF, with the line of last resort being to get them transferred as emergency patients to the UK.

It also means that there is no unit to admit the children transitioning to adult services from the national paediatric unit at Children's Health Ireland, Crumlin, which has been in existence since 2000.

What is required

IrSPEN is calling for the immediate establishment of a single dedicated national centre for patients suffering and living with IF at St. James's Hospital. The annual cost for year one of running the centre at 90% capacity is €6.04 million including both staff costs of €2.03 million and non-pay costs.

This is anticipated to serve at least 60% of the national caseload, including the most complex patients currently being treated in hospitals that lack the expertise, resources or training to provide high quality, safe care that meets international standards.

A business case for the establishment of a 12 bed unit at St. James's has also been submitted by St. James's Hospital into the budget 2023 estimates and this also has the support of:

- National Clinical Lead for Gastroenterology and Hepatology, Professor Colm O'Morain
- President of the Irish Society of Gastroenterology (ISG), Prof Deidre McNamara
- Irish Nutrition and Dietetics Institute (INDI)
- Home Parenteral Nutrition Patient Group.

A business case was previously submitted to the Joint Oireachtas Committee on the Future of Healthcare in August 2016, followed by a submission to the Department of Health in 2017. The original case was given support by former Minister for Health, Simon Harris (August 2017 meeting), since which follow up actions stalled.

Lives can be saved and resources better managed

- The absence of a dedicated national IF Unit for adults means that IF patients do not have a safe or adequate service capable of meeting their complex and highly specialised needs. This is contrary to best international practice.
- Under-capacity within the UK IF tertiary centres is associated with 150 avoidable deaths each year, based on NHS audit data. This would equate to 12 avoidable deaths per year in Ireland. As Ireland lacks any provision for adults within a tertiary centre, the true number of avoidable deaths would be significantly higher. Since the start of 2022 alone, three adults on HPN have died.
- Northern Ireland operates a 12-bed intestinal failure specialist tertiary unit for a population of 1.6 million – in contrast to the absence of any unit in ROI for a population of 5 million.
- An audit of IF and HPN patients conducted in ROI in 2016 found that of the 67 IF patients reported to receive prolonged PN within the survey period, 77.4% had experienced at least one major complication whilst 54% had required an average of 2.9 emergency admissions in the previous year, lasting an average of 38 total days per year. These rates of complications are several fold higher in Ireland than in the UK and elsewhere.
- The costs to the health service of inadequate provision of best practice for patients are considerably higher than the savings accrued from provision of specialist care. Audits from international centres have demonstrated savings of 50-60% when patients are given HPN as opposed to PN in hospital. An evaluation undertaken by Crumlin Hospital in 2005 estimated a €95,000 saving per patient per year.

2. Improved access to nutritional care for cancer patients – €1.7m in 2023

IrSPEN recommends that Government allocate €1.7 million in 2023 for the appointment of 19 full-time Dietitians (and per annum thereafter) to address major gaps in dietetic services and improve outcomes for cancer patients.

Doing so would reduce waiting times and ensure more effective interventions, reduced side effects, reduced hospital stays and a better experience and outcomes for many patients. The benefits of nutritional care integrated as part of cancer care is clinically proven across oncology – and particularly relevant to certain cancer types such as oesophageal, stomach, pancreas, lung, liver, colorectal and during high dose chemotherapy and bone marrow transplantation.

This recommendation includes for a additional Dietitian a each of the eight adult and one paediatric cancer centres, plus 10 further dietetic posts to ensure full integration of a Dietitian into the multidisciplinary team.

Current resourcing of dietetics in cancer treatment in Ireland is estimated at 30% of the required level to meet ESPEN (European Society of Clinical Nutrition and Metabolism) recommendations.

There are just 30 whole-time-equivalent Dietitians serving the entire national caseload for invasive cancer excluding non-malignant skin cancer (c.25,000 diagnosed per year, 190,000 prevalent cancer survivors), plus three NCCP cancer specialist Dietitians.

This means that cancer patients are vastly under-supported. Additional investment would enable:

- Inclusion of a dedicated cancer specialist Dietitian within multidisciplinary teams across all cancer centres, from diagnosis through treatment and in survivorship.
- Support for patients as they go through the different treatment modalities, including surgery, chemotherapy, and radiation therapy, since specialist dietetic interventions can be highly effective in helping patients manage side effects and complete treatment with reduced complications.
- Resource to allocate dietetic time to day wards and outpatient treatment settings outside the main cancer centres, where the opportunity to see patients at the earliest possible stage linked to screening offer the greatest potential for preventing escalation of weight and muscle loss that increases the risk of chemotoxicity and treatment-limiting side effects.

Conclusion

This submission aligns with the principles of Sláintecare to both develop national centres of expertise for specialist care and in parallel with more preventative and primary care delivered to patients in community settings.

IrSPEN therefore recommends 1) the establishment of Ireland's first dedicated national adult IF unit and 2) Dietitian staffing to provide best practice nutritional care to cancer patients.

Relative to the benefits the net expenditure required to provide these services is small, while the improved outcomes – based on an overwhelming body of clinical evidence – is very significant.

IrSPEN is available to follow clarify, discuss or meet on any aspects contained in this submission.