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Narrative Review

Building lifelines: A narrative review and pragmatic implementation framework for developing centralised adult chronic intestinal failure services

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SUMMARY

Home parenteral nutrition (HPN) is life-sustaining for patients with chronic intestinal failure (IF), yet access remains inconsistent worldwide. HPN has evolved into a complex, multidisciplinary service that requires coordinated planning, durable investment, and strong governance to deliver safe, equitable care from hospital to home. This narrative review integrates clinical, organisational, and policy evidence and translates it into a pragmatic implementation roadmap for adult chronic IF health systems at different stages of maturity. We synthesise the volume–outcome signal linking higher-centre caseloads and structured nutrition support teams (NSTs) with lower mortality and complications; consolidate contemporary quality standards (minimum volumes, team composition, governance); and appraise health-economic analyses pertinent to HPN.

International exemplars translating guidance into implementable actions enable the development of a four-domain framework to develop cohesive and practical chronic IF services globally: (1) identify and connect the network – map expertise, align professional societies and patient organisations, and establish referral communications; (2) develop the structure - formal centre designation, referral criteria, core infrastructural elements; (3) operationalise care – standardised shared-care/remote-discharge protocols, defined escalation to accredited centres with requisite governance and NST expertise and telehealth-enabled regional support (4) measure and improve – registry participation, routine audit, patient-reported outcomes, and transparent feedback loops. Cross-cutting enablers include robust governance, diagnosis-adjusted reimbursement aligned to NST resourcing, and policy mechanisms (designation, commissioning, funding) that secure access and consistent performance across geographies.

Applied iteratively, this framework supports phased, resource-conscious scale-up of safe, high-quality, and equitable chronic IF/HPN services, aiming to reduce complications and mortality while strengthening patient experience, system resilience, and accountability.

1. Introduction

Intestinal failure (IF) refers to the reduction of gut function below the threshold required for adequate absorption of macronutrients, water, and electrolytes, such that parenteral nutrition (PN) is necessary to sustain health or growth [1].

Type 1 IF, according to the European Society of Clinical Nutrition and Metabolism (ESPEN) classification, is self-limiting (<28 days), and managed in hospital. Types 2 and 3 follow more prolonged, complex and resource-intensive trajectories. Type 3 IF equates to irreversible chronic IF, requiring long-term nutritional, psychosocial, and metabolic management coordinated across

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healthcare sectors [2], with home parenteral nutrition (HPN) facilitating safe discharge and continued nutritional support [3–5].

Adult HPN prevalence demonstrates substantial heterogeneity, ranging from 0.25 to 80 per million inhabitants, but published rates are conditioned by source-specific case definitions and ascertainment, including indication scope (for example, benign chronic IF alone vs inclusion of palliative HPN), denominator choice (total vs adult population), and registry/claims completeness. Accordingly, national estimates are best interpreted as system-level indicators of HPN service provision and data capture, rather than directly comparable measures of chronic IF prevalence (Table 1)[6–8]. Importantly, HPN remains unavailable to patients with chronic IF in several countries worldwide. Indeed, beyond geography and economics, healthcare organisational factors also shape accessibility and quality of HPN care to otherwise eligible patients with chronic IF [9].

Chronic IF prevalence meets rare disease criteria and is infrequently encountered at individual hospitals, constraining clinical expertise. International health policy bodies increasingly recognise chronic IF as a high-risk, resource-demanding condition [10–13] associated with excess mortality and morbidity [14] driven by complications - a proportion of which may be preventable - such as catheter-related bloodstream infections (CRBSIs), intestinal failure–associated liver disease (IFALD), central venous catheter–associated thrombosis (CVC-VT) with subsequent loss of central vascular access. Micronutrient deficiencies, metabolic bone disease and substantial psychosocial burden further necessitate intensive multidisciplinary coordination. These factors contribute to prolonged, costly hospitalisations[15–17] with home-care challenges often precipitating re-hospitalisation.

Observational registry analyses report improved survival and reduced complications in higher-caseload centres with centralised HPN care delivered by structured multidisciplinary nutrition support teams (NSTs). These associations may be influenced by case-mix, referral patterns, workforce capacity, and governance maturity, and should be interpreted accordingly. ESPEN standards recommend minimum patient volumes and NST configurations for chronic IF reference centres ideally supported by formalised training and standardised protocols[3,4,18–20]; however, adoption varies internationally [9].

2. Methods and scope

This narrative review synthesises current evidence and performance standards to inform practical implementation strategies for establishing and/or strengthen chronic IF and HPN services, as a reference template for evolving and established chronic IF teams. Findings are organised into a four-domain implementation framework - network identification, structural definition, operational delivery, and performance measurement – offering feasible, scalable approaches aligned with recognised standards of care and adaptable to local contexts, aimed at developing a cohesive system of centralised chronic IF care across countries.

2.1. Search strategy and sources

We conducted a narrative review of published guidance, registry reports, and health-system policy documents relevant to adult chronic IF/HPN service organisation. MEDLINE/PubMed were searched for publications from 2000 to 2025 using combinations of terms including “chronic intestinal failure”, “home parenteral nutrition”, “nutrition support team”, “registry”, “centre designation”, “service specification”, “commissioning”, “funding”, and “quality of care”. We additionally screened ESPEN-endorsed guidance/position statements and selected national policy documents, where available.

2.2. Synthesis approach

Sources were included if they informed service organisation, governance, referral pathways, outcomes, or economics relevant to chronic IF/HPN. Evidence was prioritised for multicentre registry analyses and national datasets, consensus quality standards, and service specifications addressing governance and network design. Findings were synthesised narratively and mapped to the four domains above. Observational associations were summarised as reported by the original sources, recognising potential confounding and heterogeneity in definitions and data capture.

3. The evidence for centralised specialist care in chronic intestinal failure

3.1. Intestinal failure as a high-risk, low-incidence condition

The combination of low incidence and high complexity in chronic IF increases risks of delays in diagnosis, referral, home-care setup and complication recognition, particularly where referral pathways and specialist infrastructure are unclear, as highlighted in the United Kingdom's (UK) 2019 consultation on severe IF [21]. Robust chronic IF services anchored by NSTs and standardised care pathways reduce these risks, improving patient outcomes, and preserving in-patient hospital capacity [22,23].

3.2. The evidence for centralised models – improved clinical outcomes

Rare disease frameworks—under which chronic IF is increasingly recognised—consistently advocate centralisation to overcome the limited local expertise, care variability and diagnostic delays characteristic of low-incidence conditions [24–27].

This centralisation-outcome benefit is supported by multicentre data by Pironi et al. which analysed 2194 benign type 3 IF adult patients across 51 HPN centres and reported that centre caseload was inversely associated with odds of death during HPN and with major complications (CRBSI and catheter-associated thrombosis) when caseload was included as an independent variable; however, residual confounding cannot be excluded [20]. The mean number of patients included in follow-up per centre was 43.0 $\pm$ 54.1 (median: 19; range: 1–231). Notably, nine centres enrolled fewer than five patients each, underscoring variability in experience and outcome.

Such evidence has informed international consensus on the case for centralisation in service configuration. The 2024 ESPEN position paper on quality-of-care standards in chronic IF recommends that services maintain a minimum caseload of 20 ongoing HPN-dependent adults and 10 new patients annually to preserve NST clinical proficiency and ensure safe, effective HPN care [9].

Comparable multicentre registry volume–outcome analyses are less developed for type 2 IF than for HPN/type 3 IF; nonetheless, centralisation is also recommended for type 2 IF, reflecting the need for coordinated delivery of complex multidisciplinary and surgical care in experienced units, consistent with ESPEN acute IF guidance [28].

3.3. The evidence for centralised models – cost-effectiveness

Chronic IF imposes significant capacity and cost pressures through prolonged hospitalisations, multiple investigations and surgeries required, and intensive multidisciplinary input.

Table 1
International HPN prevalence estimates and service organisation indicators.

Country	Reference	Denominator used in source	Case definition captured in the estimate	Reported prevalence	Registry/designation notes
France	Buhl et al., 2024 [7]; national claims data year 2019	Adults ≥20 years (N = 50,881,948)	Adult HPN identified via reimbursed PPL codes; long-term HPN isolated as HPN >12 weeks (all indications captured by code use)	HPN overall: 25.3/100,000 adults; HPN >12 weeks: 6.2/100,000 adults	Administrative-code ascertainment (claims-based).
UK	Naghibi et al., 2023 [19]; NHSE IF service specification 2023 [21]; homecare cross-check), data year 2015	UK total population 65.12 million (ONS, 2015)	HPS (home parenteral support = HPN + home IV fluids) with adjustment for BANS under-reporting using homecare-company totals	HPS (adjusted period prevalence): 36.1/million; (BANS-only: HPN point 17.6/million; HPN period 20.9/million)	Voluntary national database (BANS) with quantified under-reporting; homecare-company cross-check used.
Italy	Pironi et al., 2017 [82]; SINPE survey data year 2005	"Cases per million inhabitants"; survey covered 16/20 regions (80 % population), representativeness 78 %	HAN survey; HPN defined as nutrition via central/peripheral vein using all-in-one bags; includes mixed indications; adult/paed separated	HPN corrected prevalence: 31.7/million inhabitants	Survey (not a mandatory national registry); demonstrates association between regional regulation maturity and HAN prevalence.
Denmark	Brandt et al., 2016 [16]; holst et al. [83]2024; network estimate circa 2009–2010	Per million inhabitants	'IF-DRIPS' network communication estimate of national IF/HPN incidence and point prevalence	≈80/million (point prevalence)	National network model described (IF-DRIPS); estimate rather than mandatory national registry output.
Spain	Wanden-Berghe et al., 2021 [84]; NADYA-SENPE report 2021, registry year 2019	Total population (Spain; denominator per million inhabitants)	Registry-reported HPN (adults + paeds); adult diagnostic mix includes "palliative oncology" prominently	6.01/Million inhabitants	Voluntary national registry (NADYA-SENPE); multi-centre participation (47 hospitals).
Switzerland	Reber et al., 2021 [68]; (SWISSHPN II), study period 2017–2019; pop year 2019	Swiss adult population (6,835,622 in 2019)	Prospective multicentre adult HPN cohort (not a national registry capture)	Prevalence 5/million adult inhabitants (incidence 3/million also noted)	No national registry; prevalence calculated from study cohort and adult population denominator.
USA	Mundi et al., 2017 [73]; data year 2013	Per million inhabitants (US total population)	National estimate from Medicare + large DME-provider extrapolation; includes adults + children; all indications	79/Million inhabitants	No single national HPN registry; payer/provider-based ascertainment with extrapolation.
Czech Republic	Koudelková et al., 2024 [3]; (REDNUP), data year 2022	Per 100,000 citizens	National registry (adult HPN); includes diagnostic mix with substantial palliative HPN component	5.5/100,000 (point prevalence, 2022)	REDNUP is a national registry across centres providing HPN; incidence also reported (198 new patients; 1.98/100,000 in 2022).
Netherlands	Neelis et al., 2015 [71]; DRIFT registry index date 1st January 2013	Per million total population (adult + child-specific rates also given)	Chronic IF-focused registry capture: Adults with chronic IF receiving HPN via 3 specialised centres; excludes HPN without IF/bridge cases	11.62/Million total (12.24/million adults; 9.56/million children)	DRIFT is a nationwide multicentre registry for intestinal failure and transplantation; chronic IF-oriented capture.
Canada	Fernandes et al., 2012 [85]; Canadian HPN registry context 2012	Population stated as 30 million (not a per-million denominator paper)	Estimated national HPN patient count (not chronic IF-only); registry participation invited across programmes	Not directly reported; ≈13.3/million implied from "~400 patients in 30 million"	National registry established 2006; participation by programs (not necessarily complete national capture).
Australia	Wong et al., 2024 [44]; national survey 2022; published 2024	Not population-based (centre survey)	Survey of Australian HPN centres (caseload, staffing, audit capacity); not a national prevalence dataset	Not reported	Highlights lack of national governance/model; audit capacity limited; decentralised delivery.
Ireland	Bell et al., 2018 [67]; study period Apr 2015–Mar 2016	Per million inhabitants (ROI population)	National survey of adult long-term PN and HPN (type II/III IF definitions applied)	HPN: 9.6/million (long-term PN: 14.6/million)	Centre survey with non-response acknowledged; supports argument for a national IF/HPN centre.
Poland	Folwarski et al., 2021 [86]; NHF data year 2020	Per million citizens (adult HPN)	Exhaustive national payer dataset of adult HPN; mixed indications including cancer	53.26/Million (2020)	Nationwide payer dataset (effectively complete capture within NHF reimbursement); supports long-term trend analysis.
Argentina	Gondolesi et al., 2018 [8]	Total population as stated (41.6 million)	Survey-based counts of patients on HPN (adults + children)	6.75/Million	Based on survey data; highlights limited regional capacity; not a national registry.
Uruguay	Gondolesi et al., 2018 [8]	Total population as stated (3.3 million)	Survey-based counts of patients on HPN	3.60/Million	Survey-based estimate; limited infrastructure described.
New Zealand	Gillanders et al., 2008 [87]; herbison et al., 2021 [88]	Total population 4.1 million (as stated)	Adults (≥18) on HPN recorded in NZ register during 2005	3.4/Million total population	New Zealand register initiated 2004 (AuSPEN initiative) for benchmarking
Chile	Gondolesi et al., 2018 [8]	Total population as stated (16.9 million)	Survey-based counts of patients on HPN	2.95/Million	Survey-based estimate; registry limitations noted.
Colombia	Gondolesi et al., 2018 [8]	Total population as stated (47.4 million)	Survey-based counts of patients on PN/HPN (paper notes definitional uncertainty in narrative)	1.60/Million	Survey-based; paper notes incomplete definition in narrative for PN vs HPN.
Peru	Gondolesi et al., 2018 [8]	Total population as stated (30.65 million)		0.45/Million	Survey-based estimate; highlights early-stage

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Table 1 (*continued*)

Country	Reference	Denominator used in source	Case definition captured in the estimate	Reported prevalence	Registry/designation notes
			Survey-based counts of patients on HPN (some transient PN/HPN noted)		development and access constraints.
Brazil	Gondolesi et al., 2018 [8]	Total population as stated (202.9 million)	Survey-based counts of patients on HPN	0.25/Million	Survey-based; highlights registry/policy development needs.

Table 1. Selected national estimates of home parenteral nutrition (HPN) prevalence and service organisation characteristics, reported as defined by each source. Estimates differ by data year, denominator, case definition thresholds, and ascertainment method (claims, registry, or survey). Accordingly, figures should be interpreted as system-level indicators of identification, access, and data capture rather than directly comparable estimates of chronic intestinal failure (IF) prevalence across countries.
Abbreviations: AuSPEN: Australasian Society of Parenteral and Enteral Nutrition; BANS: British Artificial Nutrition Survey; DME: Durable medical equipment (US homecare reimbursement context); DRIFT: Dutch Registry of Intestinal Failure and Transplantation; ESPEN: European Society for Clinical Nutrition and Metabolism; HAN: Home artificial nutrition; HPN: Home parenteral nutrition; HPS: Home parenteral support (HPN plus home intravenous fluids); IF: Intestinal failure; NADYA-SENPE: *Nutrición Artificial Domiciliaria y Ambulatoria* (NADYA) group of SENPE (Spanish Society of Parenteral and Enteral Nutrition); NHF: National Health Fund (Poland); NHS: National Health Service (UK); ONS: Office for National Statistics (UK); PPL: *Prestation Parfois Longue* (French reimbursement package codes used in claims analyses for home artificial nutrition; as per Buhl et al.); REDNUP: Czech national registry for home nutritional support (home parenteral nutrition registry); ROI: Republic of Ireland; SENPE: *Sociedad Española de Nutrición Parenteral y Enteral* (Spain); SINPE: Italian Society of Artificial Nutrition and Metabolism (*Società Italiana di Nutrizione Artificiale e Metabolismo*); SKVIMP: Czech Society for Clinical Nutrition and Intensive Metabolic Care (*Společnost klinické výživy a intenzivní metabolické péče*).

Centralised, structured chronic IF services and HPN programmes mitigate this burden by reducing complications [20], however, direct evidence for shorter length of stay is limited; analogous centralisations in other specialties report shorter admissions and modest quality-of-life gains [27], but generalisability to chronic IF remains uncertain.

Notably, post-discharge costs remain high: first year of HPN averages €83,000 (€35,000-€256,000), depending on complication rates and care settings [29]. However, a cost-utility analysis by Arhip et al. in 2019, which compared HPN with continued hospital-based management in patients requiring long-term nutritional support, showed that while HPN incurs substantial direct costs—primarily from PN formulations, catheter care, and multidisciplinary monitoring—these are offset by reductions in inpatient days and acute care utilization. The study reported an incremental cost-effectiveness ratio (ICER) of €16,825 per quality-adjusted life year (QALY) gained, which is below commonly accepted willingness-to-pay thresholds in many European healthcare systems[30–35].

Early transition to HPN in stable patients, with NST support, shortens hospital stays and reduces cumulative costs [30], with UK and Canadian prospective cost-utility analyses associating HPN programmes with reduced inpatient burden and improved quality-adjusted survival [36,37]. Higher volume centres likely further curb costs by reducing HPN-related complications and re-hospitalisations [20].

Collectively, clinical and health-economic evidence supports investment in centralised HPN services as a sustainable strategy for managing patients with chronic IF, particularly when embedded within national pathways and with appropriate monitoring infrastructure. The following sections will address four challenges to implementation of this evidence-informed service configuration, drawing on international examples of how such challenges have been overcome.

3.4. Trade-offs of centralisation and how to mitigate them

Centralisation can unintentionally increase patient and caregiver burden when specialist centres are geographically distant, especially in resource-limited settings with weaker transport links. Travel costs, time off work, and reduced informal support may exacerbate inequities and negatively affect quality of life. Therefore, centralisation should be operationalised as centrally governed but as locally delivered as safely possible, using hub-and-spoke models, outreach clinics, telehealth case review, and remote-discharge/shared-care pathways [38–40]. These approaches preserve expert oversight while minimising avoidable travel and facilitating rapid escalation when complications occur.

4. Challenge 1 – mapping and connecting the network

4.1. Establishing and recognizing nutrition support teams

A well-functioning multidisciplinary NST is foundational to IF care. While types 2 and 3 IF require sustained multidisciplinary care, NST involvement in type 1 IF also reduced risks of under or overfeeding, fluid imbalance and CRBSI [1,28,41,42].

ESPEN guidelines emphasise NST roles across hospital and home settings, given chronic IF's multifactorial demands. However, systematic NST implementation remains inconsistent, particularly outside specialised centres. The *ATLAS of Variance* survey across 58 European centres reported that nearly one-quarter of respondents lacked access to a formal NST for chronic IF care [43]. Given likely selection bias, actual access in non-participating centres is probably even lower. Similar challenges exist globally, with <60 % of Australian institutions reporting NST access in a national HPN audit [44].

To translate these gaps into action, Table 2 summarises the most common barriers to NST development in resource-limited settings and the corresponding actionable responses that smaller systems can adopt first. Notably, UK National Institute for Health and Care Excellence (NICE) guidance formalises NST composition for in-patient type 1 IF care and ensures coordinated cross-site care [45], while in Switzerland the Swiss Hospitals Association H+ has adopted clear criteria for NST activity in its mandatory quality improvement programme [46]. Internationally, the ESPEN Practical Guideline on chronic IF and the 2024 International Quality-of-Care Standards provide detailed recommended NST structure and competency for type 3 IF care [9,47].

4.2. The role of national societies, professional advocacy, and policy windows

Effective advocacy raises awareness, secures political attention, and unlocks funding, best achieved through partnerships between clinician-led working groups, patient organisations and international alliances. National professional societies are well positioned to coordinate and align advocacy with health ministry priorities

Table 2
Barriers to Nutrition Support Team development in smaller or resource-limited health systems and pragmatic mitigations.

Barrier category	Manifestation in smaller/ resource-limited systems	Impact on NST development	Actionable mitigations & strategies	References
Workforce gaps (specialised roles)	Shortage of pharmacists, dietitians, specialist nurses, psychologists, social workers	Limited MDT function; delayed PN initiation/monitoring; higher complications	Phase hiring; cross-train with protected time; regional/shared NST rosters; tele-NST; funded fellowships; CPD-protected discipline champions; join LIFE telementoring; start part-time NST and scale with caseload	[44,89,90]
Limited institutional leadership/ incentives	Weak executive sponsorship; no accountability for PN standards	Poor uptake of guidelines/SOPs; inconsistent practice; variable outcomes	Appoint clinical + managerial co-leads; embed NST metrics in quality dashboards; formal PN policy with audit/feedback; recognise NST time in job plans; integrate NST standards and align with ESPEN chronic IF quality standards; routine PN/LOS/complication QI tracking	[9,23,47]
Funding constraints	Insufficient budget for staffing, training, infrastructure, registry	Unable to staff core MDT; limited training; weak data for improvement	Stage-gated business case (bed-days avoided; complication costs); MCB formulary first; pooled procurement; external grants; scale capacity with activity; use QI impact (LOS, readmissions) to unlock funds; tie to accreditation/commissioning levers	[9,44]
Absent national policy frameworks	No defined NST scope, ratios, competencies, network designation	Fragmented services; inequitable access; unstable staffing	Draft national specifications (roles, FTE per caseload, competencies); hub-and-spoke designation; registry/KPIs linked to reimbursement; codify NST in national/institutional policy; adopt ESPEN chronic IF quality standards; mentorship links with established IF centres	[9,23,45,91]

Summary of common barriers impeding NST establishment and scale-up in constrained settings—grouped by workforce, leadership/incentives, funding, and policy—alongside actionable mitigations (e.g., phased hiring, tele-NST, staged business cases, and national specifications). *Abbreviations:* CPD, continuous professional development; CRBSI: catheter related bloodstream infection; ESPEN: European Society for Parenteral and Enteral Nutrition; FTE, full time equivalent; HPN, home parenteral nutrition; IF, intestinal failure; KPI; key performance indicator; LIFE: leading intestinal failure equality; LOS, length of stay; MDT; multidisciplinary team; NST, nutrition support team; QI, quality improvement; SOP, standard operating procedure.

Table 3
Chronic IF/HPN advocacy-to-implementation roadmap.

Priority action	Lead partners	First deliverable (≤90 days)	Aspirational 12 month milestone	Exemplars/ references
Stand up/scale NSTs	Hospital exec; chronic IF clinicians; pharmacy; dietetics; nursing	Appoint NST lead; publish 1-page SOPs (referral, shared care, line care); fix weekly MDT slot & protected time aligned to NICE/ESPEN	NST operating in priority sites; cross-site escalation pathway live; quarterly NST KPIs (PN appropriateness, CRBSI, LOS)	[22,41,45,47]
Form national IF task force	National GI/nutrition society; ministry; patient organisations	ToR, named members, monthly cadence; public email/ contact	Ministry recognition; national workplan with timelines	[43,52,53,59]
Rapid national audit	Task force + registry team	Minimum dataset; survey launched; governance cleared	Gap-analysis with heat-map + priority actions	[43,48,49,58,60]
Consensus guidance & referral criteria	Guideline subgroup; methodologist; patient representatives	Outline & drafting group; 10–12 key recommendations drafted	Final guideline (centre levels, NST standards, referral criteria)	[9,47]
Build/join IF/HPN registry	Society/ministry; IT host; centres	Governance; starter fields; pilot 2–3 sites	National rollout; KPI dashboard (access, safety, LOS/readmissions)	[3,19,60]
Use policy windows	Society policy lead; ministry liaison; patient orgs	Two costed briefs tied to national priorities (e.g., LOS reduction)	Funding/commissioning for designated centres/ HPN coverage	[48,49]
Co-produce with patient groups	Task force + PINNT/Oley/ La Vie/PNDU	Constitute patient panel; adopt co-design template	Patient-authored inputs in guidance; annual experience report	[52,53,55]
Engage ONCA/ ESPEN	Society; centres; patient organisations	Join workstreams; adopt communications assets (e.g., IF day kit)	National IF day; joint statements; benchmarking started	[50,51]
Tie standards to payment/ quality	Ministry/payers; quality bodies	Draft spec linking NST presence & KPIs to contracts	Designated centre list; KPIs in reimbursement	[3,9,19,70]
Training & leadership (CPD/tele-mentoring)	Society education arm; chronic IF hubs; LIFE	Publish CPD schedule; start first mentoring cohort	Annual curriculum completed; active mentor–mentee pairs	[51,89,90]
Routine audit & QI	Registry team; hospital leads; payers	Monthly run-charts (CRBSI, readmits, LOS) with feedback loop	Year-1 QI report; Year-2 targets set	[9,23,60,92]

Advocacy-focused implementation matrix summarising tasks, owners, and time-bound outputs.
Abbreviations.: CPD, continuous professional development; CRBSI: catheter related bloodstream infection; ESPEN: European Society for Parenteral and Enteral Nutrition; HPN, home parenteral nutrition; IF, intestinal failure; KPI; key performance indicator; LIFE: leading intestinal failure equality; LOS, length of stay; MDT; multidisciplinary team; NST, nutrition support team; ONCA: Optimal Nutritional Care for All; QI, quality improvement; SOP, standard operating procedure; ToR, terms of reference.

and reimbursement frameworks. Table 3—chronic IF/HPN advocacy-to-implementation roadmap—summarises staged actions, lead stakeholders, and practical outputs to translate advocacy into operational services.

Country exemplars illustrate different routes to traction. The Argentine Association for Enteral and Parenteral Nutrition (AANEP) coordinated national guideline development and training, whilst key legislative reforms such as *Ministry of Health Resolutions 1548/2007* [48] *and 2574/2011* [49] secured institutional recognition of visceral disability and mandated health insurance coverage for HPN including access to intestinal transplantation [8]. This integrated clinical-legal-professional

strategy provides a replicable model for countries building chronic IF capacity [8].

Countries embarking on this path should consider forming national clinical nutrition and IF task forces co-led by professional societies and patient groups to drive data collection, audits, national guidelines, referral criteria, service standards, and centre accreditation. The ATLAS survey of HPN services across Europe identified the lack of accredited referral centres as a critical limitation, highlighting the need for clear service designation pathways [43].

Policy windows - moments when clinical urgency, political will, and feasible solutions converge - should be leveraged strategically; for example, following adverse events, inequity-revealing service evaluation, or broader reforms in rare disease and long-term care policy. Prepared position papers and analyses aligned to national priorities (e.g., reducing length of stay and avoidable admissions), and cost-effectiveness evidence help secure greater traction.

Beyond national borders, cross-country initiatives such as the *Optimal Nutritional Care for All (ONCA)* campaign demonstrate how collaboration can elevate HPN to national and international health agendas; actions such as ONCA's "Intestinal Failure Day" provide templates for coordinated action across clinical and policy stakeholders [50,51]. At European level, the European Reference Network for rare inherited and congenital anomalies (ERN ERN-ICA) includes an IF domain and provides an additional platform for cross-border expertise sharing, care pathway harmonisation, and referral support for complex cases [12].

Patient-led organisations such as PINNT, Oley Foundation, La Vie par un Fil, and PNDU add lived-experience perspectives, education and lobbying that shape acceptable, accountable services and strengthen funding[52–55]. A multidisciplinary AuSPEN-led working group similarly highlights the value of engaging patients, carers, clinicians, and administrators to mitigate avoidable complications and enhance cross-site coordination [56]. tbox1.

5. Challenge 2 – developing the structure

Transitioning from ad-hoc chronic IF care to a structured national service requires strategic alignment across professional societies, government, and service providers. While early service activity may emerge through individual champions or isolated hubs, formalisation is required for sustainable, equitable HPN delivery. This includes clear governance, referral criteria, protected funding, integration into national frameworks and development of regional/national clinical networks. As outlined, internationally endorsed guidelines and quality standards provide benchmarks and specify key structural and operational elements such as minimum staffing, NST composition and governance mechanisms to guide this transition [9,18]. While such principles are consistent, the instruments used to implement them differ across publicly funded and mixed/insurance-based systems (for example: commissioning specifications versus payer accreditation and coverage criteria).

Interdisciplinary collaboration (e.g. surgery, intensive care, dietetics, pharmacy, nursing, microbiology) requires cross-sector funding and institutional buy-in via joint statements/taskforces [18,23]. The role of homecare providers, PN manufacturers, and insurers should be defined within formal pathways and contracting frameworks [5] with clinical oversight retained by chronic IF centres; in the UK, for example, centre-level accountability is maintained even when homecare is subcontracted, ensuring continuity of care, patient safety, and quality assurance [21].

Planning the number and distribution of chronic IF centres according to population density and geographic needs should be ministry-led, balancing access with maintenance of MDT expertise through minimum caseloads. Engagement of non-tertiary clinicians via shared protocols, telehealth-enabled case discussions, and regionally distributed training supports early referral and equitable, nation-wide access to high-quality chronic IF care, including during local hospital admissions for chronic IF-related complications [57]. In Portugal, early engagement by the Portuguese Society of Clinical Nutrition (APNEP) established a national chronic IF registry that informed policy and service configuration. Subsequent regulatory guidance (*Norma 017/2020*) expanded HPN access beyond domiciliary care zones and formalised patient training pathways for self-administration, enabling more equitable HPN access nationwide[58–60].

Overall, progress from informal chronic IF service to formalised national networks requires more than clinical expertise; it demands coordinated advocacy, inclusive stakeholder engagement, and alignment with international standards – securing quality, safety, scalability, and policy accountability. A number of strategies can facilitate structure development within individual chronic IF services.

Box 1
Practical recommendations for advocating chronic IF/HPN services

- Form a multidisciplinary national working group co-led by clinical societies and frontline clinicians.
- Conduct a national audit to map service gaps and patient unmet needs.
- Draft consensus-based national guidelines and referral criteria.
- Develop or join an IF/HPN registry to generate service data.
- Identify and act on policy windows for funding or commissioning opportunities.
- Collaborate with patient groups to ensure advocacy reflects lived experience.
- Engage with international initiatives (e.g. ONCA, ESPEN) for support and alignment.

5.1. Core institutional features and infrastructure

Following establishment of an NST, safe chronic IF and HPN care depends on institutional infrastructure for reliable PN delivery, complication management, and patient training [18]. These elements must be deliberately developed—even in constrained systems—if services are to scale sustainably.

5.2. Designated inpatient capacity

Dedicated units or, depending on service size, allocating 'ring-fenced' beds within gastroenterology or surgical wards facilitates early multidisciplinary care planning and peer-support within a rare-disease context while concentrating clinical expertise and providing a stepping-stone towards full-service maturity.

Survey data from 30 IF centres across 20 countries (median caseload 128; range 30–380) demonstrated that those managing >100 patients were more likely to have established key infrastructure such as dedicated IF beds (71 % vs 31 %) and structured NSTs [6]. Centres with dedicated beds had higher median caseloads (175 vs 92). These associations between institutional scale and infrastructure readiness are particularly relevant for early-stage systems [6].

5.3. Infrastructure design

Incorporating pre-made multi-chamber-bag (MCB) formulations into procurement is pivotal for all IF services. MCBs provide sterile, standardised formulations that reduce contamination risk and logistical complexity [57]. Access to a certified aseptic compounding units also helpful, particularly when available commercially pre-made MCB PN cannot meet an individual patient's specific nutritional and electrolyte requirements. Where on-site aseptic facilities are lacking, regional or cross-border sterile compounding service partnerships with robust logistics and cold-chain protocols may be required [56]. tbox2.

Aspiring healthcare systems should audit existing infrastructure, while also adopting phased development—leveraging regional partnerships and telehealth-enabled collaboration where resources are limited or out of geographic reach —to deliver coordinated, safe, and timely chronic IF care.

6. Challenge 3 – making the structure work

Developing a safe, sustainable, and equitable IF service requires moving beyond structural designation to consistent, high-quality delivery across the network.

6.1. Operationalising care across the network

Following structural designation, achieving dependable parity of access across both lead centres and satellite partners is paramount. ESPEN recommends referring all chronic IF patients to centres with the necessary infrastructure, governance, and multidisciplinary expertise required for the complex management of long-term intravenous supplementation [23,47].

Several countries have formalised such frameworks. In the Czech Republic, HPN provision is restricted to certified centres with oversight via the REgistr Domaci NUtricni Podpory (REDNUP) registry and the Czech Society for Clinical Nutrition and Intensive Metabolic Care (SKVIMP) to ensure service quality and access [3]. In the UK, NHS England's tiered IF network delineates responsibilities between referring hospitals, HPN centres, and regional IF hubs [21].

For small or resource-limited nations, concentrating HPN provision within one or two designated national centres can build efficiency and caseloads that support better outcomes [8,47,60,61]. As evidenced, international experience corroborates this volume–outcome effect [20]; indeed, in Singapore, a single tertiary centre managed ~95 % of national HPN (41 adults over 15 years) with survival and complication rates comparable to international benchmarks [61]. Where maintaining adequate caseloads remains challenging, cross-border referral, shared-care protocols, and collaboration in complex case management, training, and procurement can bridge early service gaps while local expertise develops.

Box 2
Core service elements essential to delivering safe and sustainable chronic IF care [9].

- Interventional radiology for catheter placement and complication management
- Formal surgical collaboration (e.g. enterocutaneous fistula management or reconstructive surgery)
- Intensive care unit (ICU) or high-dependency unit (HDU) access for metabolically unstable or septic patients
- Patient education and training facilities, equipped for HPN self-care instruction
- Administrative space for MDT coordination and audit
- Timely laboratory and imaging access to support monitoring protocols

6.2. Centre designation and referral pathways

Transparent designation criteria for IF/HPN centres – governance, minimum staffing and infrastructural access [9] – are fundamental to safety and institutional credibility, and strengthens the case for sustained funding [23,47]. This is particularly important given that, as Naghibi et al. observed, HPN prevalence is closely linked to the health economic environment with policy and funding support serving as critical determinants of service growth [19].

Embedding HPN within national frameworks—through insurance coverage and/or commissioning, service specifications, and mandated pathways aligned to locally adapted international guidelines (e.g., ESPEN or ASPEN)—supports sustainability and standardises access and quality. France provides an example of designation-led national structuring for long-term HPN, delivered through a nationally organised network of designated specialist centres defined via *Haute Autorité de Santé* (French National Authority for Health) quality/safety criteria and a national service specification (cahier des charges), implemented through time-limited national designation cycles [62,63]. The 2020 designation cycle identified 12 adult and 6 paediatric centres for five years, supported by earmarked national funding, standardised annual activity reporting, and oversight through an annual national steering committee, consistent with professional society centre directories for 2020–2025 [64].

Policy may also address emergency preparedness and equal access to rural, remote, or low-prevalence regions. UK remote-discharge and shared-care protocols define clinical criteria, infrastructure, and NST support to enable safe home management of complex IF patients without transfer to an IF centre, even in geographically isolated settings [38,39,65]. While supporting evaluations include advanced cancer cohorts, their contribution is chiefly to operational learning—remote-discharge processes, shared-care logistics, and escalation pathways—rather than chronic IF-specific outcome evidence.

Clear referral pathways—for elective chronic IF assessments and urgent HPN-related complications—enable timely escalation and continuity of care. Practical tools such as proformas, centralised triage, and defined review timelines reduce unwarranted delays, while recognising that HPN may encompass heterogenous indications (including palliative/oncology HPN) when designing referral pathways. Early, structured engagement between clinicians from referring hospitals and IF centres, optimises referral timing, improving survival and quality of life (QOL) [66].

Commissioning rounds with feedback cycles helps standardise cross-site processes [21]. Internationally, phased models that begin with a single designated national centre, supported by regional partners for follow-up, have scaled services effectively. In Portugal the pioneer centre standardised referral pathways, training, and protocols across the national IF network, reducing preventable complications during early implementation [60].

In summary, effective HPN services rely on designated centres, clear referral pathways, policy integration, and, where needed, cross-border collaboration. International models show that concentrating expertise, standardising protocols, and securing policy support enable safe, scalable care even in low-prevalence or resource-constrained settings.

7. Challenge 4 – measuring success and ensuring sustainability

Measurement is fundamental to safe, effective, and sustainable chronic IF/HPN services, underpinning governance and clinical quality. Robust monitoring drives improvement, enables benchmarking, and strengthens the case for funding and service expansion. Embedding metrics within governance ensures accountability, transparency, and alignment with national and international standards. For emerging programmes, ESPEN already defines key metrics; the practical task is to build systems to capture, interpret, and act on them [9,23].

7.1. Registry implementation – turning data into direction

Many healthcare systems rely on retrospective audits, regional datasets, or voluntary reporting, each prone to under recording and variable case definitions. Ireland's national point-prevalence study reported 9.6 adults per million population on HPN, though acknowledged incomplete participation by tertiary centres, likely underestimating the true disease burden and complications [67]. International variability in registry implementation drives heterogeneity in reported HPN prevalence and outcomes.

Where implemented, registries shift chronic IF care from anecdote to accountability. Their absence remains a recurring barrier to service development and strategic planning in parts of Europe and Latin America [8,60,68,69]. In the UK, the voluntary British Artificial Nutrition Survey (BANS) historically supported epidemiology but underreported activity (~70 %) [70]. In response, the newer national IF Registry aims for more complete capture of HPN activity and outcomes, with potential prospective linkage to reimbursement to improve completion rates.

In contrast, the Dutch Registry of Intestinal Failure and Transplantation (DRIFT) exemplifies how registries can address historical documentation gaps, reporting an up-to-date HPN prevalence of 11.62 per million, enabling multidisciplinary monitoring across all specialist centres, and supporting timely transplant referral while aligning care and policy through a quality framework [71]. Similarly, the Czech HPN REDNUP registry supports standardisation, reimbursement, quality assurance and long-term complication tracking [3].

For systems establishing chronic IF services, building a national registry—phased or integrated with existing datasets—should be viewed as a strategic enabler of quality assurance, policy development, equity, reimbursement linkage and long-term sustainability. REDNUP, DRIFT and the UK IF Registry provide practical frameworks to inform this process, complemented by ESPEN's guidelines, standards, education and cross-border harmonisation [3,23,71,72].

7.2. The price of sustainability – funding considerations

Sustainable HPN delivery requires sustained, transparent funding for PN solutions, catheter care, home-care logistics, and indirect costs (NST education, monitoring, and data systems) [6,23]. Inconsistent funding remains a major barrier to establishing high-quality services.

Funding models vary widely across health systems, shaped by national policy, economic capacity, and service configuration, with recurrent challenges of limited MDT resourcing and reimbursement misaligned to clinical need. In Australia, nurses were the most frequently funded MDT members (65 % of adult centres), with physicians 59 %, dietitians 29 %, and pharmacists rarely supported. Median clinician time was only 7 min per patient per week, raising concerns for comprehensive care [44].

In the United States, mixed private/Medicare reimbursement produces variability in coverage and care scope [73]. The Czech REDNUP registry demonstrates how a centrally coordinated, certified-centre model can support national negotiations and recognition of HPN cost-effectiveness. Although financial data are not detailed, REDNUP was established to support insurance negotiations and promote economic viability [3].

In contrast, early Portuguese experience relied on institutional budgets without dedicated reimbursement, threatening viability given home-care logistics, catheter maintenance, and PN costs when hospital-based funding is misaligned with community delivery [60].

Poland's long-term national reimbursement (since 1998), coupled with registry-based monitoring, enables detailed cost analysis and responsive planning. Average annual reimbursement was €10,251 per patient (2010–2020), rising to €16,743 when including hospitalisations, rehabilitation and medications, reflecting the complex clinical needs of HPN recipients, including higher rates of hospitalisations, surgical interventions and oncological care.

Although Polish per-patient costs appear lower than other European nations (e.g., €13,364 in Spain, £55,000–65,000 in the UK, and approximately $64,000 in the US), cross-country comparisons can help account for differences in service models, nursing support, complication management, and staffing [30,74–76].

Overfall fair, transparent, diagnosis-adjusted reimbursement aligned with MDT resourcing, supported by robust registries with integrated cost-tracking to inform policy, assess value, and ensure sustainability [44].

7.3. Embedding accountability through governance

Governance underpins the development and continuity of safe, effective, and consistent chronic IF/HPN programmes. Early implementation of robust frameworks accelerates service maturation, supports accreditations, and builds stakeholder trust. International guidance increasingly positions governance alongside staffing, infrastructure, and protocols as a core quality pillar [9,23]. Embedding governance at the structural core of chronic IF services, accelerates quality improvement, strengthens accountability, and align services with international standards.

At the clinical level, regular NST meetings are central to coordinated chronic IF care, supporting clinical decision-making, complication review, protocol adherence, and ongoing patient needs [23]. Routine audit is essential to chronic IF service governance – monitoring CRBSI rates, metabolic complications, inpatient length of stay, unplanned readmissions, and protocol adherence [9]; even small-scale internal audits can catalyse improvement and inform policymaker resource allocation discussions.

Governance also safeguards indications for long-term intravenous supplementation: where parenteral support is proposed, confirmation that IF criteria are met and that HPN is appropriate should sit within the NST, which functions as the gatekeeper for indication assessment and multidisciplinary review, consistent with ESPEN operational recommendations [23,77].

Integrating patient perspectives should be established as a governance priority and recognised as an independent and essential component of care. A systematic review by Sowerbutts et al. highlighted that HPN patients and family members experience significant physical, psychological, and logistical burdens, particularly around home care transitions, emergency planning, and long-term adaptation [78]. Structured tools such as the Home Parenteral Nutrition Patient-Reported Outcome Questionnaire

Table 4
Pragmatic Roadmap for chronic IF/HPN Scale-Up.

Domain	Purpose	First deliverable (≤90 days)	6–12 month milestone	Key tools/references
1) Map the network	Identify people/sites, referral lines & gaps to coordinate chronic IF/HPN	Name national IF lead; rapid map of active HPN/chronic IF caseload & referral routes; publish single triage/contact	National directory of centres/NSTs; standard referral proforma & timelines in use; monthly cross-site case huddles	ATLAS survey to evidence gaps; use a "starter" minimum dataset [43]
2) Agree the structure	Define "what a chronic IF service looks like": Roles, levels, accountability	Adopt NICE NST template (type 1 IF inpatient); adopt ESPEN practical + 2024 QoC for type 3 IF; draft centre levels & hub-and-spoke MOUs	National specification published (staffing, caseload thresholds, IR/compounding/MCB strategy); designated centre list live	NICE NST composition [45]; ESPEN practical & QoC standards [9,18] (caseload thresholds, competencies).
3) Make the structure work	Turn design into daily practice across sites	Lock weekly protected NST MDT; publish 1-page SOPs (referral, discharge to HPN, emergency CRBSI incl. Non-IF sites); stand up tele-NST/shared care	Escalation pathway functioning; earlier discharge to HPN; pooled procurement/MCB active; quarter-on-quarter drop in CRBSI/readmits/LOS	NST oversight improves PN appropriateness; tele-mentoring (LIFE/LIFT-ECHO) [51,89] for capability lift.
4) Measure & improve	Prove safety, access, value; fund growth	Implement "starter" registry fields; monthly run-charts (CRBSI/1000 catheter-days, LOS, readmits, referral→review time); plan for PROs	Quarterly KPI dashboard; annual QI report; KPIs linked to centre designation/payment; join national registry (e.g., APNEP [60])	ESPEN & governance sections; different countries registry exemplars [3,19,60].

Pragmatic actions by domain with ≤90-day deliverables, 6–12-month milestones, and the tools/standards to use.
Abbreviations: APNEP: Portuguese Society of Clinical Nutrition; CRBSI, catheter-related bloodstream infection; HPN, home parenteral nutrition; IF, intestinal failure; MDT, multidisciplinary team; MOU, memorandum of understanding; NICE, national institute for health care excellence; NST, nutrition support team; KPI, key performance indicator; LOS, length of stay; QoC, quality of care; SOP, standard operating procedure.

Box 3
Governance priorities for emerging systems

- Establish formal MDT governance with clearly defined roles and scheduled meetings.
- Integrate CPD and team training.
- Initiate streamlined audits using simplified key performance indicators, with plans to scale toward national registry participation.
- Incorporate patient feedback into service planning, supported by local patient organisations.
- Formalise relationships with intestinal transplant services early for complex chronic IF patients.

(HPN-PROQ) and the Parenteral Nutrition Impact Questionnaire (PNIQ) [79], enable systematic capture of patient-reported outcomes to inform quality improvement and monitor QOL, safety, and treatment [80,81]. tbox3.

8. Conclusion

HPN is life-sustaining for patients with chronic IF, yet access remains uneven across healthcare systems. What was once considered a niche area of clinical practice has now evolved into a complex, multidisciplinary service that demands coordinated, system-wide planning, sustained investment, and robust governance to ensure safe, equitable, and sustainable care delivery.

Countries that have implemented coordinated networks, regardless of population size, demonstrate that outcomes comparable to international benchmarks are achievable, even in low-prevalence settings. Concentrating expertise, embedding governance, and routine measurement move chronic IF care from isolated cases to an accountable quality-assured service.

Progress depends on shifting from piecemeal efforts to national networks led by clinical and political champions and informed by patients, families, and advocacy groups.

The four-challenge framework presented here offers a practical roadmap for healthcare systems at any stage of chronic IF service development (Table 4).

1. Identify and Connect the Network – Map existing expertise, foster collaboration, and establish early communication channels.
2. Agree the Structure – Define "what a chronic IF service looks like" using internationally endorsed standards, such as ESPEN recommendations, adapted to local context [9,23].
3. Make the Structure Work – Translate structure into function through referral pathways, protected MDT time, and coordinated emergency response.
4. Measure and Improve – Implement registries, conduct regular audits, and maintain feedback loops that inform governance and policy.

Applied pragmatically, this framework supports phased, resource-conscious development toward a high-quality national chronic IF service—improving outcomes, QOL, and cost-efficiency while turning fragmented initiatives into a durable system of care.

Author contributions (CRediT) and ICMJE statement

All listed authors meet the ICMJE authorship criteria: each made substantial contributions to the work, drafted and/or critically revised the manuscript for important intellectual content, approved the final version to be published, and agrees to be accountable for all aspects of the work.

- **Trevor Tabone (Corresponding Author):** Conceptualization; Methodology; Data curation; Writing – original draft; Writing – review & editing.
- **Giles Major:** Conceptualization; Methodology; Formal analysis; Resources; Validation; Supervision; Writing – review & editing.
- **Simon Lal:** Conceptualization; Methodology; Formal analysis; Resources; Validation; Supervision; Writing – review & editing.

No individuals who meet authorship criteria have been omitted. No contributors falling short of ICMJE authorship criteria were involved.

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No eligible author has been excluded from the author list.

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Ethical approval, study registration, and permissions

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