

## SCHEDULE 2 – THE SERVICES

### A. Service Specifications

<b>1. Service name</b>	Severe Intestinal Failure Service (Adults)
<b>2. Service specification number</b>	<b>170077S – 230701S</b>
<b>3. Date published</b>	August 2023
<b>4. Accountable Commissioner</b>	NHS England Internal Medicine Programme of Care <a href="https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-a/a07/">https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-a/a07/</a>

<b>5.</b>	<b>Population and/or geography to be served</b>
<b>5.1</b>	<p><b>Population Covered</b></p> <p>Specifically, this service is for adults with Type 2 or Type 3 Intestinal Failure (IF). This will include suspected or diagnosed patients requiring Home Parenteral Nutrition (HPN) or Support (HPS) patients, patients undergoing prolonged Parenteral Nutrition (PN), and patients requiring specialised IF surgery (as outlined in Annex A2) or candidates for intestinal transplantation or Autologous Gastrointestinal Reconstruction.</p> <p>The service outlined in this specification is for patients ordinarily resident in England*; or otherwise the commissioning responsibility of the NHS in England (as defined in ‘Who Pays?: Establishing the responsible commissioner’ and other Department of Health guidance relating to patients entitled to NHS care or exempt from charges)</p>
<b>5.2</b>	<p><b>Minimum population size</b></p> <p>It has been estimated that 10 major surgical procedures per annum per million are required to treat severe IF. The number of patients in England expected to access a Type 2 service annually is approximately 600-700, with an estimated 350-500 undergoing surgical procedures primarily to facilitate restoration of normal gut function and cessation of PN support.</p> <p>The prevalence of patients on HPN in England is about 50 per million. Therefore, the number of patients currently accessing home PN services is 2500, with approximately 30% being on HPN long term (5 years).</p>
<b>5.3</b>	<p><b>Expected Significant Future Demographic Changes</b></p> <p>The incidence of Type 2 IF has been increasing over the last decade, with the biggest area of growth resulting from surgical complications. It is anticipated that over the next 5-10 years this growth will continue. It is estimated that the</p>

	<p>number of Type 2 patients will increase to 1000 per year within the next decade, with a concomitant increase in surgical procedures to 700-800 per year.</p> <p>Largely as a consequence of the increase in Type 2 IF, and patients now being able to be managed long term at home, the prevalence of HPN (for both Type 2 and 3 IF) has also been increasing at a rate of approximately 20% per annum. It is therefore anticipated that HPN prevalence could be 80 per million within the next 5 years, that is 4000 cases/year.</p>										
<b>6.</b>	<b>Service aims and outcomes</b>										
<b>6.1</b>	<p><b>Service aims</b></p> <p>Intestinal Failure comprises a group of disorders with many different causes, all of which are characterised by an inability to maintain adequate nutrition and/or fluid balance via the intestines. It may result from obstruction, abnormal motility, fistulation, ischaemia, surgical resection, congenital defect or disease-associated loss of absorption. The condition is characterised not only by the inability to maintain protein-energy nutritional status, but also by difficulties in maintaining water, electrolyte or micronutrient balance, particularly when there has been a significant reduction in the length of the small intestine. If intestinal failure persists for more than a few days, treatment with intravenous delivery of nutrients and water (parenteral nutrition, PN) is usually required.</p> <p>The service aims to improve patient outcomes and quality of care for people with intestinal failure focussing on all aspects of care for patients with Type 2 and 3 severe IF (see explanation of categorisation in Section 7.1 – Service Model).</p>										
<b>6.2</b>	<p><b>Outcomes</b></p> <p><u>NHS Outcomes Framework Domains &amp; Indicators</u></p> <table border="1" data-bbox="284 1261 1289 1641"> <tr> <td>Domain 1</td> <td>Preventing people from dying prematurely</td> </tr> <tr> <td>Domain 2</td> <td>Enhancing quality of life for people with long-term conditions</td> </tr> <tr> <td>Domain 3</td> <td>Helping people to recover from episodes of ill-health or following injury</td> </tr> <tr> <td>Domain 4</td> <td>Ensuring people have a positive experience of care</td> </tr> <tr> <td>Domain 5</td> <td>Treating and caring for people in safe environment and protecting them from avoidable harm</td> </tr> </table> <p>Centres will need to demonstrate compliance with these proposed quality indicators within 2 years of commissioning through the defined reporting mechanisms.</p>	Domain 1	Preventing people from dying prematurely	Domain 2	Enhancing quality of life for people with long-term conditions	Domain 3	Helping people to recover from episodes of ill-health or following injury	Domain 4	Ensuring people have a positive experience of care	Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm
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Outcome Reference Number	Domain	Rationale	Name of Outcomes/ Description
IF 101	1,2	Safe and effective surgery and aftercare	90-day Post-op mortality
IF 102	1,2	Safe and effective surgery and aftercare	In-patient mortality
IF 103 /4	1,2,4	Safe and effective surgery and care	Proportion of patients that have refistulation within 90-days
IF 104	1,2,4	Safe and effective surgery and care	proportion of patients that have refistulation within1 year
IF 105	1,2	Short term effective care management.	One year survival rates on Home PN
IF 106	1,2	Long term effective care management of patients	5 year survival rates on Home PN
IF107	1,2	Effective training and operational practise	Proportion of patients with CVC infections

Service defined outcomes/outputs

**Applicable Obligatory National Standards**

- The Provider must adhere to national and international guidelines and protocols for care of IF services, where developed. Where these are not developed, the provider must adhere to international guidelines on the same.

**Other Applicable National Standards to be met by Commissioned Providers**

- The Provider must meet the standards, as set out in “The surgical management of patients with acute intestinal failure”, Association of Surgeons of Great Britain and Ireland (ASGBI 2010).
- The Providers must work with homecare providers (contractors), as commissioned by the NHS National Framework, Agreement for the Supply of Home Parenteral Nutrition (referred to as ‘the HPN framework’) to ensure seamless transfer of care between hospital and community. This also includes location of patient/carer training where appropriate.
- The Commissioned Providers are responsible for monitoring the performance of the HPN companies providing services to their patients as per the key performance indicators set out in the HPN framework.

	<ul style="list-style-type: none"> <li>• Providers should comply with the published NHS England Commissioning Policy Statement on <a href="#">Home Parenteral Nutrition</a> in relation to prioritisation of licenced products as a first line prescription.</li> <li>• Commissioned providers should assess on an individual patient basis – using the NHS England HPN Nursing Toolkit - the patient and/or their carers’ capacity and circumstances to support the administration of PN at home, and the need for training and ongoing home nursing support. Where the commissioned provider is delivering the training and home nursing support (as opposed to via a supplier selected from the HPN framework ), it should be delivered in line with the requirements for homecare nursing set out within the s I HPN framework A.</li> </ul> <p><b>Other Applicable Local Standards</b></p> <ul style="list-style-type: none"> <li>• The Providers must ensure the standards of care, as set out in Annexes A1/2.</li> <li>• The Providers must set up care arrangements with other Centres, to facilitate patient care, transfer and discharge. This must include multi-disciplinary team meetings between the Integrated IF Centres and their local Home PN Centres.</li> <li>• The format and frequency of the meetings to be organised locally, but no less often than quarterly.</li> <li>• The Providers must set up care arrangements if IF patients (type 2 and 3) are admitted as an emergency to a local hospital with problems relating to IF to advise on immediate treatment and to transfer them within 14 days.</li> <li>• The Providers must set up care arrangements and communications with local hospitals to advise good and safe provision of PN and nutritional care if admission is for reasons unrelated to IF.</li> </ul>				
<b>7.</b>	<b>Service description</b>				
<b>7.1</b>	<p><b>Service model</b></p> <p>IF patients can be categorised into three types:</p> <table border="1" data-bbox="284 1368 1410 2020"> <tr> <td data-bbox="284 1368 555 1659"> <p><b>Type 1: Commissioned by ICBs</b></p> </td> <td data-bbox="563 1368 1410 1659"> <p>This type of IF is short-term, self-limiting and often perioperative in nature. Type 1 IF is common and patients are managed successfully in a multitude of healthcare settings, especially surgical wards. Some patients on high dependency units (HDU) and intensive care units (ICU) will also fall into this category. Responsibility for PN in hospital sits with ICBs for the first 14 days.</p> </td> </tr> <tr> <td data-bbox="284 1671 555 2020"> <p><b>Type 2: Commissioned by NHS England</b></p> </td> <td data-bbox="563 1671 1410 2020"> <p>Type 2 IF describes patients under a multi-professional specialist team and frequently metabolically unstable. It requires prolonged (meaning &gt; 28 days) parenteral nutrition usually over an extended period of weeks or months. It is associated with complications of abdominal surgery, especially intestinal fistulation and abdominal sepsis and therefore patients often need intensive care unit (ICU) or high dependency unit (HDU) admission during their stay in hospital. They may also be discharged</p> </td> </tr> </table>	<p><b>Type 1: Commissioned by ICBs</b></p>	<p>This type of IF is short-term, self-limiting and often perioperative in nature. Type 1 IF is common and patients are managed successfully in a multitude of healthcare settings, especially surgical wards. Some patients on high dependency units (HDU) and intensive care units (ICU) will also fall into this category. Responsibility for PN in hospital sits with ICBs for the first 14 days.</p>	<p><b>Type 2: Commissioned by NHS England</b></p>	<p>Type 2 IF describes patients under a multi-professional specialist team and frequently metabolically unstable. It requires prolonged (meaning &gt; 28 days) parenteral nutrition usually over an extended period of weeks or months. It is associated with complications of abdominal surgery, especially intestinal fistulation and abdominal sepsis and therefore patients often need intensive care unit (ICU) or high dependency unit (HDU) admission during their stay in hospital. They may also be discharged</p>
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	with home parenteral nutrition or distal enteral tube pending corrective surgery. Type 2 IF patients awaiting definitive surgery will be defined as “type 2”, even when discharged home.
<b>Type 3: Commissioned by NHS England</b>	<p>This is a chronic condition, requiring long term parenteral feeding. The patient is characteristically metabolically stable but cannot maintain his or her nutrition and/or fluid balance adequately by absorbing nutrients or fluid and electrolytes via the intestinal tract. These are, in the main, the group of patients for which Home Parenteral Nutrition (HPN) or Electrolytes (HPE) is indicated. Type 3 IF patients include but are not limited to:</p> <ul style="list-style-type: none"> <li>• Candidates for autologous gastrointestinal reconstruction or intestinal transplantation to restore nutritional autonomy.</li> <li>• Patients with IF related to advanced malignancy and needing HPS. Normally these would be patients with significant intra-abdominal/pelvic disease preventing normal intestinal function. In this situation, to be accepted for HPS, life expectancy is usually at least 3 months.</li> </ul>
<p><i>Note:</i></p> <ul style="list-style-type: none"> <li>• <i>Type 2 IF patients awaiting definitive surgery will be defined as “type 2”, even when discharged home. If they develop intercurrent complications of their IF or IF-related illness prior to planned surgery requiring readmission, the primary responsibility for care will remain with the Integrated IF Centre. Admission of these patients will either be to Integrated IF Centres or if the need is to manage only a complication of HPN, to the local Home PN Centre, subject to agreement between Centres.</i></li> <li>• <i>If definitive corrective surgery is not possible (for whatever reason) and, as a result, the patient remains dependent on PN or fistuloclysis/distal feeding then these patients will be defined as having “type 3” IF from the time at which reconstructive surgery is no longer planned, and thereafter responsibility for IF care will devolve from an Integrated IF Centre to a Home PN Centre, as appropriate.</i></li> <li>• <i>Type 3 IF patients who develop PN-related complications requiring hospital admission will remain as “type 3” and can be admitted to an Integrated IF Centre or Home PN Centre as appropriate.</i></li> </ul> <p>There are two types of Centres:</p>	
<b>Integrated IF Centre</b>	<p>Multidisciplinary team, treating a critical mass of surgical and medical patients and able to provide 24/7 access to type 2 and 3 IF services and support to homecare patients as part of a network.</p>

	Treats both Type 2 and 3 patients - see Annex A1. Provides support and advice to Home PN Centres.
	Integrated Centres will provide network leadership and promote consistent care across the network and support national work to reduce variation in care
<b>Home PN Centre</b>	Multidisciplinary team, treating a critical mass of medical patients and able to provide 24/7 access to Type 3 IF services and support to homecare patients
	Treats Type 3 IF patients and supports home PN care - see Annex A1.
<p>This service specification covers all aspects of care for Types 2 and 3 severe IF (comprising of both non-elective and elective admissions for medical and surgical care; outpatient follow-up attendances; and including the provision of HPN).</p> <p>The service comprises the following elements:</p> <ul style="list-style-type: none"> <li>• In-patient assessment and management of patients with Type 2 IF</li> <li>• Provision of specialised IF surgery (as outlined in Annex A2)</li> <li>• Follow-up outpatient attendance(s) post discharge of a Type 2 IF patient, pending provision of specialised IF surgery as detailed above</li> <li>• In-patient management of patients with Type 3 IF (management of HPN-related complications or treatment of the underlying disease responsible for IF)</li> <li>• Ongoing out-patient management of Type 3 IF</li> <li>• Outpatient or in-patient assessment and management of patients referred who are deemed to be at high risk of having (or developing) type 2 or 3 IF</li> <li>• Provision of HPN (and associated homecare nursing if required) via the NHS Commercial Medicines Unit National Framework Agreement for the Supply of Home Parenteral Nutrition. HPN can only be supplied via an accredited framework supplier <a href="https://www.contractsfinder.service.gov.uk/Notice/2cee30e9-e4b6-4145-8d5b-b37f506337e2">https://www.contractsfinder.service.gov.uk/Notice/2cee30e9-e4b6-4145-8d5b-b37f506337e2</a>.</li> <li>• Regular review of patients on home PN ensuring the least resource required to meet the patient's needs.</li> <li>• Assessment for onward referral to and ongoing lifelong follow-up after Intestinal Transplantation or autologous gastrointestinal reconstruction (AuGIR). The surgical treatment episodes themselves are outside the scope of this specification.</li> </ul> <p>Details of the clinical care roles and associated service infrastructure requirements are outlined in Annex A1 and A2 of this specification.</p>	



	<p>Designated Integrated IF Centres and Home PN Centres will develop patient information and literature developed to be used by the IF Clinical Networks and/or relevant patient groups that have been endorsed by the Commissioner.</p>
<p><b>7.2</b></p>	<p><b>Pathways</b></p> <ul style="list-style-type: none"> <li>• The service will accept referrals only from secondary care clinicians. Patients with prolonged (type 2 or type 3) IF will generally be under the care of either a gastroenterologist; a colorectal surgeon; an intensivist, or an oncologist. All Type 2 IF patients will be referred as inpatients to an Integrated IF Centre.</li> <li>• Any patient who meets the criteria in Annex A1 should be discussed with/referred to an Integrated IF Centre as soon as possible, and within 21 days of commencing parenteral nutrition at the latest. These patients should have a care plan discussed and clearly documented between their current hospital and the designated IF Centre. For inpatients, arrangements will normally be made to transfer patients who have required (or are likely to require) parenteral feeding for more than 28 days to an Integrated IF Centre, or to a Home PN Centre in the case of type 3 IF.</li> <li>• Outpatient assessment or of inpatient assessment for a period of up to 28 days following referral to an Integrated IF Centre of a patient who may not currently be on PN, but for whom an opinion is requested, specifically to determine whether or not a patient has IF. After 28 days at the latest, a decision will be made by the Integrated IF Centre as to whether the patient concerned has type 2 or 3 IF. Confirmation of the diagnosis of IF will be the sole responsibility of the Integrated IF Centre. Patients considered to have type 2 or 3 IF will continue to receive treatment as an IF patient, funded by NHS England specialised commissioning. If the patient is considered by the IF Centre not to have IF, funding will revert to the ICB. The patient may either remain at the hospital to which they have been referred, but without specialised IF care, or may be transferred back to the referring hospital for ongoing care, subject to discussion between organisations and patient agreement.</li> <li>• The service will accept patients with advanced malignancy who have IF and need PN support. Normally these would be patients with significant intra-abdominal/pelvic disease preventing normal intestinal function. To be accepted for PN life expectancy will be anticipated to exceed 3 months. Such patients will remain primarily under the care of an oncologist or palliative care team, as well as their General Practitioner. The IF service will only be responsible (clinically and financially) for the management of IF. The Integrated IF or Home PN Centre will be responsible for the decision to commence (or continue) and to terminate PN, in discussion with the relevant MDT cancer team. Referrals of such patients for consideration for PN will be to an Integrated IF or Home PN Centre, which will either accept transfer of the patient or facilitate remote discharge from the local hospital if this is considered more efficient and clinically appropriate. The Integrated IF or Home PN Centre will be responsible for the care of the PN, including approving the discharge prescription and monitoring arrangements at/following remote discharge under those circumstances.</li> </ul>

- Remote discharge with input from an Integrated IF or Home PN Centre may be appropriate in the specific situation for patients with palliative needs managed in an oncology centre where transfer to a Home PN or Integrated Centre would not be in the patient's best interests. In this situation, once the patient's condition has stabilised and it is preferred by all parties that the patient is discharged from the local service, there must be discussions between the patient's current hospital and the Integrated IF or Home PN centre regarding the patient's medical and surgical history and current clinical status. A joint care plan must be agreed with all relevant clinical teams involved in the patient's care, taking account of their fluid, electrolyte and nutritional needs and this should be agreed and documented in the patient's medical records prior to discharge. HPN must be prescribed by the Integrated IF or Home PN Centre and the prescriber must be confident that they have enough information (for example, relevant fluid balance charts and up-to-date biochemistry results), in order to ensure safe prescribing. If the Integrated IF or Home PN Centre cannot be confident that the patient's nutritional management (including intravenous catheter management) has been optimised in the referring organisation, then the patient must be transferred to the Integrated IF Centre or Home PN Unit prior to discharge on HPN. The referring organisation and the Integrated IF or Home PN Centre should have agreed policies and protocols for safe remote discharge, with audit of outcomes and adverse events related to the delivery of PN.
- Some IF patients are particularly complex and even experienced teams in Integrated IF Centres may require further advice and assistance from other Centres. This will be delivered through networking relationships.
- Patients may be "stepped down" from the Integrated IF Centres to Home PN Centres, as determined by the patient's care needs and the objective of providing care at a commissioned Centre as close as possible to the patient's home.
- The service will also accept referrals from other commissioned providers of specialised severe IF services, particularly when the referring service is not accredited to undertake specific treatment that the patient requires (e.g. AuGIR, transplantation).
- The service will ensure co-ordination of patient transfer between Integrated IF Centres and Home PN Centres, in order to support both the clinical needs of the patient and also the social needs of their family/carers.
- The target transfer time to an Integrated IF or Home PN Centre for inpatient care is 14 working days from acceptance, which will have been deemed to occur following receipt of all relevant clinical information from the referring unit. This will normally include all medical records, including operation notes, histology reports and access to all relevant radiological investigations.

However, there may be a number of situations where it may not be in a patient's best interests to be transferred. These are:



- If there is a sound clinical reason for the patient to remain in their current hospital because the patient's primary healthcare issue is not Intestinal Failure, some examples are: palliative care with the need for a rapid discharge; complex burns; infectious disease, brain or spinal cord injury; pseudomyxoma peritonei; management of complications of specialised upper GI or pancreaticobiliary surgery.
- In cases where a patient's condition has stabilised and arrangements for discharge from the local service are already well-advanced. In this case the hospital concerned must have a dedicated nutritional support team, to be able to maintain safe parenteral nutrition pending outpatient review in the Integrated IF or Home PN Centre. A discussion between the patient's current hospital and the specialised IF Centre should occur and a care plan taking account of their nutritional needs agreed and documented in the patients' medical records prior to discharge. All HPN at discharge must be prescribed in collaboration with an Integrated IF Centre or a Home PN Centre.

There will be occasions when a patient requests care outside of his/her region. Such situations should be considered on an individual basis and accommodated if reasonable.

#### **Transition of patients from paediatric to adult services**

All healthcare services are required to deliver developmentally appropriate healthcare to patients and families. Children and young people with ongoing healthcare needs may present direct to adult services or may be required to transition into adult services from children's services.

Transition is defined as a 'purposeful and planned process of supporting young people to move from children's to adults' services. Poor planning of transition and transfer can result in a loss in continuity of treatment, patients being lost to follow up, patient disengagement, poor self-management and inequitable health outcomes for young people. It is therefore crucial that adult and children's NHS services, in line with what they are responsible for, plan, organise and implement transition support and care (for example, holding joint annual review meetings with the child/young person, their family/carers, the children's and adult service). This should ensure that young people are equal partners in planning and decision making and that their preferences and wishes are central throughout transition and transfer. NICE guidelines recommend that planning for transition into adult services should start by age 13-14 years at the latest, or as developmentally appropriate and continue until the young person is embedded in adult services.

#### **Care for teens new to IF services.**

Ordinarily, adult services would take patients from aged 18 years and over, however, for those patients aged 16-18 years, and recognising that intestinal failure might continue for many months or years, services are asked to consider the needs of the patient about whether they are most appropriately treated in an adult or a paediatric setting.

#### **Exclusions**

The following forms of treatment are out of the scope of this service specification:

- Type 1 (short-term) IF (< 28 days) remains the responsibility of the patient's responsible Integrated Care Board (ICB)
- Parenteral nutrition Type 1 (short-term) IF (14 days or less) remains the responsibility of the patient's responsible Integrated Care Board (ICB)
- Operations/treatments not directly related to IF (see Annex A2)
- IF patients domiciled outside England.

### **Discharge criteria and planning**

Patients discharged home from Integrated IF Centres and HPN Centres will have their treatment plan agreed and recorded by a multi-professional IF MDT prior to discharge. The MDT will include clinicians (physicians and surgeons, as appropriate to the patients clinical need), dietitians, pharmacists, nurses (including, where relevant, nutrition, stoma and wound care nurses) and clinical psychologists. All health professionals involved in other aspects of the patients care (for example in specialties not immediately related to IF, e.g. respiratory medicine, orthopaedic surgery, urology) and who will need to be made aware of the relevant episode of IF care will receive a summary of the discharge plan.

Patients who have fully completed their treatment for Type 2 IF, and who do not require treatment for Type 3 IF will normally be followed-up as outpatients for up to 90 days post-discharge and then referred back to local services. The patient's GP and referring Centre will be provided with a discharge summary when the patient leaves hospital and at the point of transfer back to local services. Some patients, e.g. those with short bowel syndrome, or intestinal fistulas who do not require PN, may require longer term follow up at the discretion of the Integrated IF or Home PN Centre, but without specialised funding.

Patients with Type 3 IF that has fully resolved will be followed-up as outpatients for up to one year following weaning. At that stage they will be discharged back to local services and a final discharge summary will be sent to their GP and referring Centre.

Type 2 patients who do not progress to definitive surgery and who therefore become defined as having Type 3 IF may have their follow up transferred to a more local Home PN Centre, subject to patient agreement and establishment of an agreed care plan between the two Centres.

Patients with Type 3 IF that has resolved either as a result of intestinal transplantation, AuGIR or pharmacological methods to enhance intestinal adaptation will be followed up for life, either from the Transplant Centre, Integrated IF Centre or local Home PN Centre or a combination of these, tailored to the patient's individual requirements.

Trusts will also need to consider whether patients might be trained on self administration and maintenance of their PN and lines whilst in hospital, or whether training support is needed in their home environment. Trusts may purchase that training time from one of the homecare providers accredited on the HPN Framework, or may utilise other resources, provided the standards of training and nursing identified in the HPN framework are met.

<p><b>7.3</b></p>	<p><b>Clinical Networks</b></p> <p>Robust local networks of care will be developed between Integrated IF Centres, Home PN Centres and other local hospitals. This will facilitate seamless care transition. Networks should include standardised referral proformas, shared protocols for PN-related care, arrangements for patient transfer as required and the facility for multidisciplinary meetings and/or discussions. Such network arrangements should not necessarily be confined to commissioning boundaries. It is anticipated that networks will work collaboratively at a national level to produce standardised clinical practice across England.</p>
<p><b>7.4</b></p>	<p><b>Essential Staff Groups</b></p> <p>See Annex A2</p>
<p><b>7.5</b></p>	<p><b>Essential equipment and/or facilities</b></p> <p>See Annex A2</p>
<p><b>7.6</b></p>	<p><b>Interdependent Service Components – Links with other NHS services</b></p> <p>The services required by the different Centres are articulated in Annex A1 and A2 based on the following depending on whether a Centre is designated as an Integrated IF Centre or a Home PN Centre.</p> <p><b>Co-located services</b></p> <p>Services that need to be available on the same site as the specialised service:</p> <ul style="list-style-type: none"> <li>• Luminal gastroenterology</li> <li>• Colorectal surgery</li> <li>• Adult Intensive Care Medicine</li> <li>• Venous access</li> <li>• Enterostomal therapy</li> </ul> <p>The following are services that are commonly required during the spell of care provided by the specialised service; however, there is no absolute requirement for this service to be based on the same healthcare delivery site as the specialised service. However, where services are not immediately available on site, there should be transparent, robust and formal contractual arrangements for timely access to these services by the specialised IF service:</p> <ul style="list-style-type: none"> <li>• Interventional radiology</li> <li>• Pharmacy aseptic services</li> <li>• Renal dialysis</li> <li>• Hepatology</li> <li>• Plastic surgery</li> <li>• Gynaecological surgery</li> <li>• Urological surgery</li> <li>• Vascular surgery</li> <li>• Upper GI surgery</li> <li>• Hepatobiliary surgery</li> </ul>

	<ul style="list-style-type: none"> <li>• Clinical psychology/psychiatry</li> <li>• Microbiology</li> <li>• Biochemistry</li> </ul> <p><b>Related services</b></p> <p>These are services that are either at the preceding or following stage of the patient journey:</p> <ul style="list-style-type: none"> <li>• Gastroenterology at District General Hospital (DGH) level (identification of Type 2 IF patients)</li> <li>• General and/or Gastrointestinal (both Colorectal and Upper GI) surgery at DGH level (identification of Type 2 IF patients)</li> <li>• Homecare providers of HPN products and services</li> <li>• Bowel Transplant Services.</li> </ul>
<p><b>7.7</b></p>	<p><b>Additional requirements</b></p> <p>All Integrated IF and Home PN Centres will be contractually obliged to provide accurate and timely reports as follows:</p> <ul style="list-style-type: none"> <li>• All centres will return data on all patients with type 2 and 3 IF to the national IF Registry in line with the requirements set out in Schedule 6 (Contract management, Reporting and Information Requirements) of the NHS Standard Contract, and as guided by the Association of Coloproctology of Great Britain and Ireland here: <a href="https://www.acpgbi.org.uk/resources/1095/uk-national-if-registry-data-additions">https://www.acpgbi.org.uk/resources/1095/uk-national-if-registry-data-additions</a>.</li> <li>• All patients discharged to the community on PN will be registered with Blueteq to ensure the PN provision is from a recognised homecare provider, adhering to the standards and practice separately contracted for by NHS England. Blueteq continuation forms for extended nursing support, and continuation with PN provision will also be required</li> <li>• All centres will participate in the National IF Audit Programme (undertaken by/at the behest of the National Clinical Network). This programme and network is currently in development but will include both management of type 2 IF and also HPN and reconstructive surgery.</li> </ul> <p>Following the Identification Rules, activity and finance reported through the Secondary Uses Service (SUS) and Aggregate Contract Monitoring report should be reported against the Service Line:</p> <p style="text-align: center;"><b>NCBPS12z INTESTINAL FAILURE</b></p> <p>When reporting drug activity the indication should be recorded as “Intestinal Failure”.</p>
<p><b>7.8</b></p>	<p><b>Commissioned providers</b></p> <p><b>Integrated Surgical and Medical centres</b> (Integrated Centres)</p> <p>Newcastle Upon Tyne</p> <p>Leeds Teaching Hospitals</p> <p>Northern Care Alliance (Salford)</p>

	<p>University Hospital Birmingham  University Hospital Coventry and Warwick  Nottingham University Hospital  Cambridge University Hospital  London North West University Hospital (St Marks)  Central London IF Partnership (UCLH, GSTT, Barts)  Oxford University Hospital  University Hospital Southampton  University Hospital Bristol and Weston</p> <p><b>Medical Management Centres</b> (HPN Centres)  Lancashire Teaching Hospital  Yorkshire and Humber IF Service (Sheffield, Hull)  Liverpool University Hospital  University Hospital Leicester  St Georges Hospital  Norfolk and Norwich University Hospital  Royal Berkshire  Portsmouth University  Royal Devon and Exeter.</p>
<p><b>7.9</b></p>	<p><b>Links to other key documents</b></p> <p>NHS England Commissioning Policy Statement on <a href="#">Home Parenteral Nutrition</a>.  HPN can only be supplied for home use via an accredited framework supplier  <a href="https://www.contractsfinder.service.gov.uk/Notice/2cee30e9-e4b6-4145-8d5b-b37f506337e2">https://www.contractsfinder.service.gov.uk/Notice/2cee30e9-e4b6-4145-8d5b-b37f506337e2</a></p> <p><i>References supporting the quality outcomes:</i></p> <ul style="list-style-type: none"> <li>• British Intestinal Failure Association (BIFA) Position Paper 2016</li> <li>• Based on data from European Society for Clinical Nutrition and Metabolism. Clin Nutr 2012; 31: 831-845</li> <li>• Dibb M et al. Survival and nutritional dependence on home parenteral nutrition: Three decades of experience from a single referral centre. Clin Nutr 2017; 36:570-576</li> </ul> <p>Lloyd D, et al. Survival and dependence on home parenteral nutrition: Experience over a 25-year period in a UK referral centre. Aliment Pharmacol Ther 2006; 24:1231–1240</p>

## 8. Abbreviations and Acronyms

The following abbreviations and acronyms have been used in this document:

AuGIR	Autologous Gastrointestinal Reconstruction
CVC	Central Venous Catheter
EPS	Encapsulating Peritoneal Sclerosis
HPN	Home Parenteral nutrition
PN	Parenteral nutrition
IF	Intestinal Failure
LILT	Longitudinal Intestinal Lengthening and Tapering
MDT	Multidisciplinary Team
PXE	Pseudoxanthoma Elasticum
STEP	Serial Transverse Enteric Plication



## ANNEX A1 – IF and HPN Centre requirements

This Annex describes the particular service pathway elements for Specialised Intestinal Failure (IF) care. This is described on the basis of three factors:

The ‘who’ – the characteristics of need of the patient

The ‘what’ – the intervention(s) required to meet that need

The ‘where’ – the specified standards that need to be in place to effectively deliver those interventions.

These roles will be used as the basis of currencies for specialised intestinal failure activity as they describe patient pathways with similar need and similar resource inputs.

### Integrated IF Centre Service Requirements

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
Type 1 IF (Non-Specialised – ICB Commissioned)	Short term IF (<28 days)	1.1 Short term ileus.	Optimal nutritional management	A1, A2, (A3 optional)
Type 2 IF Specialised	PN with complications or PN whose duration (> 28 days) is causing concern	2.1 Patients requiring continued PN who have had more than two episodes of central venous catheter blood stream infection	Optimal IF management	A1-3, B1-7,

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
		2.2 Patients with an uncontrolled high output stoma despite standard management*	Optimal IF management	A1-3, B1-7
		2.3 Patients with catheter-related central venous thromboses leading to problems of access for PN** administration (e.g. direct IVC## or atrial catheters, venous recanalisation or vascular reconstruction)	Optimal IF management & appropriate vascular intervention	A1-3, B1-7, C1.4,
		2.4 Medical management patients with persistent or deteriorating metabolic complications (significant liver or renal dysfunction, recurrent acidosis, poorly controlled diabetes)	Optimal IF management & liaison with other specialist services as necessary	A1-3, B1-7, (C1.5, C2)
		2.5 Patients requiring long term in-patient PN with severe psychiatric co-morbidity (including personality disorders), needing intensive liaison psychological medicine services which cannot be provided locally	Optimal IF management & involvement of specialist psychiatric services	A1-3, B1-7, C1.6
		Intra- abdominal sepsis, fistulation and/or open abdomen)	2.6 Recurrent / persistent severe abdominal sepsis requiring prolonged PN	Optimal IF management with specialist stoma care, interventional radiology (as appropriate)

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
		2.7 Intestinal failure with complex fistulation requiring surgical reconstruction	Optimal IF management with specialist stoma care, interventional radiology (as appropriate) in an Integrated IF Centre	A1-3, B1-7 C1.1-1.3, 1.7, C2-4
		2.8 Dehisced abdominal wound or open abdomen needing reconstruction of both GI tract & abdominal wall	Optimal IF management with specialist stoma care, interventional radiology (as appropriate) in an Integrated IF Centre	A1-3, B1-7, C1.1-1.3, C2-4
		2.9 High output enterocutaneous fistula(s) or stomas (>1500ml/day) despite standard management*	Optimal IF management	A1-3, B1-7, C1.1-1.3, C2-4
		2.10 Need for distal limb enteroclysis or fistuloclysis	Optimal IF management with specialist stoma care and interventional radiology (as appropriate).	A1-3, B1-7, C1.1-1.3, C2-4
		2.11 Recurrent intestinal fistulation after failed surgical treatment of Type 2 IF in an Integrated IF Centre (to include discussion and/or referral to National Reference Centres)	Optimal IF management with specialist stoma care, interventional radiology (as appropriate) in an Integrated IF Centre	A1-3, B1-7, C1.1-1.3, C2-4
		2.12 IF Surgery in a patient with radiation enteritis or an inherited	IF surgery in an Integrated IF Centre	A1-3, B1-7 C1.1-1.3, C2-4

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
		defect of connective tissue (e.g. Ehlers Danlos, Marfans, PXE)		
		2.13 Persistent IF with significant co-morbidity (heart, renal & liver failure) requiring tailored PN	Optimal IF management	A1-3, B1-7, C1.1-1.3,1.5, C2-4
	Patients requiring intestinal reconstruction	2.14 With or without abdominal wall reconstruction	IF surgery in an Integrated IF Centre	A1-3, B1-7, C1.1-1.3, C2-4
		2.15 Surgery for severe intestinal dysmotility	IF surgery in an Integrated IF Centre	A1-3, B1-7, C1.1-1.4, C2,3
		2.16 Intestinal lengthening – AuGIR (tapering, lengthening, STEP & Bianchi/LILT procedures)	IF surgery in a nationally commissioned Integrated IF Centre (currently only Salford Royal NHS Foundation Trust)	A1-3, B1-7, C1.1-1.4, C2,3, 4,6
	Surgical re- appraisal	2.17 Severe intra- abdominal adhesions requiring further expert surgical appraisal or considered possibly not suitable for further surgery	Optimal IF management in an Integrated IF Centre	A1-3, B1-67 C1.1-1.3, C2-4
		2.18 Potentially hostile abdomen requiring further expert surgical	Optimal IF management in an Integrated IF Centre	A1-3, B1-7, C1.1-1.3, C2-4

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
		appraisal or considered possibly not suitable for further surgery		
		2.19 IF due to encapsulating peritoneal sclerosis (EPS) needing specialist enterocysis	EPS surgery in a specialized unit (currently only Cambridge and Central Manchester University Hospitals Foundation Trusts)	A1-3, B1-7, C1.1-1.4, C2-4,7
Type 3 IF Specialised	Evaluation, initiation & training of new HPN patient	3.1 Patients on long term parenteral nutrition who could be considered for continued home care	Optimal IF management	A1-3, B2-7, D1-5
		3.2 Patients with significant intestinal resection leaving a short bowel with or without colonic continuity, and thereby loss of nutritional/fluid autonomy	Optimal IF management	A1-3, B1-7, D1-5
		3.3 Patients with an uncontrolled high output stoma or fistula (>1500 ml/day), where surgery is deemed unsuitable, despite standard management*	Optimal IF management	A1-3, B1-7 C1.1 -1.3, D1-5
		3.4 Patients with severe intestinal dysmotility or extensive mucosal disease leading to malabsorption who cannot meet their nutritional requirements enterally	Optimal IF management	A1-3, B1-7 D1-5.

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)	
		3.5 Severe intestinal dysmotility requiring specialist psychological support	Optimal IF management & specialist psychiatric input	A1-3, B1-7 C1.6, D1-5	
		3.6 Patients with advanced malignancy with loss of intestinal function	Optimal IF management in liaison with oncology and palliative care	A1-3, B1-7 C1.6, 1.9, D1-5	
	Non-elective readmission of Type 3 IF or Type 2 patient awaiting surgery ***		3.7 Patients with central venous catheter blood stream infection	Optimal IF management & appropriate vascular intervention	A1-3, B1-7, D1-5
			3.8 Patients with catheter-related central venous thromboses	Optimal IF management & appropriate vascular intervention	A1-3, B1-7, C1.4, D1-5
			3.9 Patients with other catheter-related complications	Optimal IF management & appropriate vascular intervention	A1-3, B1-7, C1.4, D1-5
			3.10 Medical management patients with persistent or deteriorating metabolic complications (significant liver or renal dysfunction, recurrent acidosis, poorly controlled diabetes)	Optimal IF management & liaison with other specialist services as necessary	A1-3, B1-7, (C1.5, C2), D1-5
			3.11 Other non-elective admissions of Type 3 patients	Optimal IF management & liaison with other specialist services as necessary	A1-3, B1-7, (C1.5, C2), D1-5



IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
	Elective readmissions of Type 3 IF	3.12 Medical and nutritional optimization of PN and hydration (e.g. reviewing PN volumes, lipid/glucose preparations)	Optimal IF management & appropriate vascular intervention	A1-3, B1-7, D1-5
		3.13 Changing or replacing venous access	Optimal IF management	A1-3, B1-7, C1.4, D1-5
	MDT and outpatient management	3.14 Established HPN	Optimal IF management	A1-3, B2-7 D1-5
Potential IF patients (type 2 or 3)	Patients whose clinical and nutritional care requires evaluation by a specialist IF service prior to determining their IF status	4.1 Up to 28 days of in-patient assessment, by which time a decision on IF status is made	Optimal IF management	A1-3, B1-7
Intestinal transplant		5.1 Transplant assessment	Transplant assessment	A1-3, B1-67 C1,2,3,5
		5.2a Transplantation & perioperative care	Intestinal transplantation -	Transplant unit
		5.2b Transplantation & perioperative care	Multivisceral transplantation	Transplant unit
		5.3 Out-patient post- transplantation follow up	Optimal post-transplant care	A1-3, B1-7, C1,2,3,5

## Home PN Centre Requirements

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
Type 1 IF (Non-Specialised – ICB Commissioned)	Short term IF (<28 days)	1.1 Short term – e.g. ileus.	Optimal nutritional management	A1,A2,(A3 optional)
Type 3 IF Specialised	Initiation & training of new HPN patient	3.1 Patients on long term parenteral nutrition who could be considered for continued home care	Optimal IF management	A1-3, B1-7, D1-5
		3.2 Patients with significant intestinal resection leaving a short bowel with or without colonic continuity, and thereby loss of nutritional/fluid autonomy	Optimal IF management	A1-3, B1-7 C1.1 -1.3, D1-5
		3.3 Patients with an uncontrolled high output stoma or fistula (>1500 ml/day), where surgery is deemed unsuitable, despite standard management*	Optimal IF management	A1-3, B1-7, D1-5.
		3.4 Patients with severe intestinal dysmotility or extensive mucosal disease leading to malabsorption who cannot meet their nutritional requirements enterally	Optimal IF management	A1-3, B1-7 D1-5.

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)	
		3.5 Severe intestinal dysmotility requiring specialist psychological support	Optimal IF management & specialist psychiatric input	A1-3, B1-7 C1.6, D1-5	
		3.6 Patients with advanced malignancy with loss of intestinal function	Optimal IF management in liaison with oncology and palliative care	A1-3, B1-7 C1.6, 1.9, D1-5	
	Non-elective readmission of Type 3 IF ***		3.7 Patients with central venous catheter blood stream infection	Optimal IF management & appropriate vascular intervention	A1-3, B1-7, D1-5
			3.8 Patients with catheter- related central venous thromboses	Optimal IF management & appropriate vascular intervention	A1-3, B1-7, C1.4, D1-5
			3.9 Patients with other catheter-related complications	Optimal IF management & appropriate vascular intervention	A1-3, B1-7, C1.4, D1-5
	3.10 Medical management patients with persistent or deteriorating metabolic complications (significant liver or renal dysfunction, recurrent acidosis, poorly controlled diabetes)	Optimal IF management & liaison with other specialist services as necessary	A1-3, B1-7, (C1.5, C2), D1-5		

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
		3.11 Other non-elective admissions of Type III patients	Optimal IF management & liaison with other specialist services as necessary	A1-3, B1-7, (C1.5, C2), D1-5
	Elective readmissions of Type 3 IF	3.12 Medical and nutritional optimization of PN and hydration (e.g. reviewing PN volumes, lipid/glucose preparations)	Optimal IF management	A1-3, B1-7, D1-5
		3.13 Changing or replacing venous access	Optimal IF management & appropriate vascular intervention	A1-3, B1-7, C1.4, D1-5
	MDT and outpatient management	3.14 Established HPN	Optimal IF management	A1-3, B2-7 D1-5
Potential type 3 IF patient	Patients whose clinical and nutritional care requires evaluation by a specialist IF service prior to determining IF status	4.1 Up to 28 days of in-patient assessment, by which time a decision on IF status is made	Optimal IF management	A1-3, B2-7 D1-5

## Notes

\* Standard management - Fluid restriction & electrolyte mix; antimotility agents (loperamide up to 64mg QDS, codeine phosphate up to 60mg QDS); antisecretory agents (PPI, e.g. omeprazole 40mg BD, octreotide)

Date published August 2023

\*\* IVN - Intravenous nutrition

\*\*\* Option of protocol-led care with hub and spoke Home PN Centre

# Complex fistulation - >1 separate enterocutaneous fistulas, fistulation involving other organ systems e.g. upper or lower GI tract, genito-urinary or biliary tracts, fistulation into an open abdominal wound, recurrent fistulation after a previous attempt to resection

## IVC - Inferior vena cava

## ANNEX A2 – INTEGRATED AND HPN CENTRE SPECIFICATION

Code	Description	Sub-code	Subcode description
<b>A1</b>	GI medicine & surgery expertise on site		
<b>A2</b>	NICE compliant nutrition support team		
<b>A3</b>	British Artificial Nutrition Survey (BANS) reporting		
<b>B1</b>	At least 2 nominated intestinal failure surgeons with appropriate on-going interest, practice & junior surgical support		
<b>B2</b>	Nominated specialist IF gastroenterologist & skilled consultant/associate specialist cover in the context of comprehensive medical gastroenterological, endoscopy and hepatology services with junior medical support.		
<b>B3</b>	Enhanced nutrition support team services	<b>B3.1</b>	Specialist nutrition nurse specialists with comprehensive cross cover arrangements
		<b>B3.2</b>	Specialist dietitians with experience in intestinal failure management and comprehensive cross cover arrangements
		<b>B3.3</b>	Specialist pharmacists with comprehensive cross cover arrangements. Timely arrangement for tailor made PN or access to compounding facilities
<b>B4</b>	Engaged microbiological services		
<b>B5</b>	Venous access service able to site/replace lines within 24 hours,		



Code	Description	Sub-code	Subcode description
	7 days a week, with continuous audit of complication rates		
<b>B6</b>	Dedicated ward area for IF patients with an appropriate nursing ratio		
<b>B7</b>	24h on-call arrangements for IP and OP by staff with appropriate expertise in IF management		
<b>C1</b>	High quality supporting clinical teams	<b>C1.1</b>	Anaesthetics with a special interest in IF surgery
		<b>C1.2</b>	Interventional radiology (experienced in abdominal abscess). This must be, available to provide source control within a time frame specified by NHS England “Improving outcomes for patients with sepsis”, 2015 and Royal College of Surgeons of England/DoH “The higher risk surgical patient 2011”, namely: <ul style="list-style-type: none"> <li>• For patients with septic shock – source control immediately i.e. within 3 hours.</li> <li>• For patients with severe sepsis (i.e. with evidence of organ dysfunction – within 6 hours</li> <li>• For patients with uncomplicated infection – within 18 hours</li> </ul>
		<b>C1.3</b>	Stoma care & abdominal wound care (experience in management of dehisced abdominal wound)
		<b>C1.4</b>	Interventional radiology expertise in central venous catheter placement and venous stenting in patients with difficult venous access

Code	Description	Sub-code	Subcode description
		<b>C1.5</b>	Support for patients with renal failure requiring haemodialysis
		<b>C1.6</b>	Nominated specialists in psychiatry & psychology
		<b>C1.7</b>	Access to appropriate other surgical specialties (e.g. gynaecological, urological, upper GI and vascular surgery)
		<b>C1.8</b>	Access to plastic surgery
		<b>C1.9</b>	Access to oncology/palliative care
<b>C2</b>	Good access to and working relations with on-site HDU & ICU		
<b>C3</b>	Critical mass of type 2 IF patients, with at least 10 IF operations carried out per year per centre		
<b>C4</b>	Surgical expertise in abdominal wall reconstruction and fistula repair		
<b>C5</b>	Experience in intestinal transplant selection & assessment		
<b>C6</b>	Experience in intestinal lengthening procedures (AuGIR)*		
<b>C7</b>	Experience in surgical enteroclysis for sclerosing peritonitis*		
<b>D1</b>	Dedicated multi-professional IF outpatient clinics at least every fortnight with capacity for responsive and timely urgent appointments		
<b>D2</b>	HPN experience and on-going critical mass of at least 30 active		

Code	Description	Sub-code	Subcode description
	patients, of which at least 10 are on HPN for >5 years		
<b>D3</b>	Clear processes for patient help and advice by appropriately trained and experienced staff 24 hours a day, 7 days a week		
<b>D4</b>	Clear processes for emergency admission to an appropriate ward 24 hours a day, 7 days a week		
<b>D5</b>	Access to a pharmacy aseptic suite that is able to compound bespoke parenteral nutrition for patients		

\*AuGIR – Autologous intestinal reconstruction

## ANNEX A3 – DEFINITION OF A SPECIALISED INTESTINAL FAILURE SURGICAL PROCEDURE

To qualify as within the definition as a '*specialised procedure for the management of Intestinal Failure*' the patient must fully meet the criteria in one or more of the boxes below:

1. Have had a prolonged period of parenteral nutritional support or enteroclysis (more than 28 days) **prior to** abdominal operations (i.e. in a patient who already has intestinal failure).

### AND EITHER

2. Enteric fistulation associated with:
  - a. Open abdomen (laparostomy); or
  - b. Other intra-abdominal organs (i.e. upper or lower GI, urinary, gynaecological, hepato-pancreatico-biliary); or
  - c. Abdominal sepsis requiring radiological or surgical drainage; or
  - d. Significant co-morbidity - specifically:
    - i. Collagen synthesis disorders such as Ehlers Danlos, Marfan's, and Pseudoxanthoma Elasticum;
    - ii. Radiation enteritis
  - e. Recurrent fistulation following previous surgical attempts to repair

### OR

3. Hostile abdomen (without fistulation) associated with:
  - a. Open abdomen (laparostomy); or
  - b. Re-operation for adhesions/sclerosing peritonitis; or
  - c. Abdominal sepsis requiring surgical drainage; or
  - d. Significant co-morbidity - specifically:
    - i. Collagen synthesis disorders such as Ehlers Danlos, Marfan's, and Pseudoxanthoma Elasticum;
    - ii. Radiation enteritis
    - iii. Encapsulating Peritoneal Sclerosis (EPS)<sup>+</sup>

4. Abdominal surgery **in an established IF centre** where planned operative intervention would deliberately result in a period of intestinal failure as part of a planned programme of staged surgical reconstruction (e.g. creation of a proximal jejunostomy).

5. Abdominal surgery where the primary aim of the surgery is to restore intestinal continuity allowing cessation of parenteral nutritional support, including HPN and fistuloclysis, and/or otherwise improve quality of life specific to intestinal failure.

6. Abdominal surgery requiring complex abdominal wall reconstruction (component separation, plastic surgical flaps, prosthetic implants, abdominal wall transplants in a patient with intestinal failure undergoing surgery as specified in categories 2, 3, or 5 above.

7. Abdominal surgery for autologous GI reconstruction (tapering, lengthening, reversed loops STEP\* and Bianchi/LILT\*\* procedures) or intestinal transplantation

+ In specialised centres currently commissioned to treat EPS (see Annex A1 section 2.19)

\*Serial Transverse Enteroplasty

\*\*Longitudinal Lengthening and Tapering

#### **ANNEX A4 –DESCRIPTION OF NATIONAL REFERENCE CENTRES.**

- Commissioners will facilitate the provision of training and support by recognising the two commissioned “National Reference Centres” for these purposes within the national arrangements.
- It is recognised that some IF patients are particularly complex, and even experienced teams in Integrated IF Centres may require clinical advice and surgical assistance from colleagues. Examples of such situations would include: Intestinal fistulation in a totally dehisced abdominal wound, requiring simultaneous intestinal and abdominal wall reconstruction; failed corrective surgery for Type 2 IF in an Integrated IF Centre (e.g. recurrent fistulation or persistent abdominal sepsis after reconstructive surgery); any patient with type 2 or 3 IF where the clinical level of complexity is considered by an integrated IF centre or HPN centre to exceed their expertise or resources. In such cases, support from a more experienced centre may be requested, either to provide an additional opinion, to support the performance of specialised IF surgery (see Annex 2) or to take over the patient’s IF care, until such time as they can be transferred back to the referring centre.



**Change form for published Specifications and Products developed by Clinical Reference Group (CRGs)**

**Product name: Service Specification: Severe Intestinal Failure (Adults)**

**Publication number: 170077S – 230701S**

**CRG Lead: National Programme of Care Senior Manager – Internal Medicine**

**Description of changes required**

The development of a revised Severe Intestinal Failure (Adults) service specification started in 2017, and the specification was published in draft format in 2019 to support provider selection of Adult Intestinal failure services. Stakeholder testing and public consultation on the proposals were undertaken in 2017 and 2018 respectively. Since that time, provider selection has been completed and the format for NHS England national service specifications has also been updated. This change form reflects changes to the specification published in draft format in 2019.

<b>Describe what was stated in original document</b>	<b>Describe new text in the document</b>	<b>Section / Paragraph to which changes apply</b>	<b>Describe why document change required</b>	<b>Changes made by</b>	<b>Date change made</b>
Draft document was in the 2017 specification format	Content has been transferred to the new specification format, which has included re-ordering sentences, and rephrasing in order to ensure the specification continues to follow a logical dialogue	Whole document	Update to format of the specification template	Internal medicine Programme of care	October 2022 and May 2023
Various terms for referring to the NHS National Framework Agreement for the Supply of Home Parenteral Nutrition HPN	References changed to 'NHS National Framework Agreement for the Supply of Home Parenteral Nutrition HPN' or 'HPN framework'.	Whole document	To ensure consistent wording	Head of Acute Programmes	June 2023

<p>Clinical metrics and outcome indicators listed in section 4.2</p>	<p>Clinical outcomes revised, metrics and indicators removed from specification document.</p>	<p>Old document – section 4.2; new document section 6.2</p>	<p>Updated outcomes included within the specification as well as the removal of metrics which will be published separately in keeping with revised Quality metrics reporting process</p>	<p>Internal medicine Programme of care with Quality and Nursing Team (QNT)</p>	<p>May 2023</p>
<p>Applicable service standards</p>	<p>Refreshed wording to include national and international guidelines</p>	<p>Paragraph 6.2</p>	<p>To ensure reference to BIFA / BAPEN / ESPN Guidelines</p>	<p>Internal medicine Programme of care</p>	<p>May 2023</p>
	<p>New inserted text: Providers should comply with the published NHS England Commissioning Policy Statement on Home Parenteral Nutrition [LINK] in relation to prioritisation of licenced products as a first line prescription. Commissioned providers should assess on an individual patient basis – using the NHS England HPN Nursing Toolkit - the patient and/or their carers’ capacity and circumstances to support the administration of PN at home, and the need for training and ongoing</p>	<p>Section 6.2</p>	<p>To reference newly published commissioning policy statement and new nursing toolkit.</p>	<p>Internal Medicine Programme of care</p>	<p>June 2023</p>

	home nursing support. Where the commissioned provider is delivering the training and home nursing support (as opposed to via a supplier selected from the NHS Commercial Medicines Unit National Framework Agreement for Home Parenteral Nutrition), it should be delivered in line with the requirements for homecare nursing set out within the NHS Commercial Medicines Unit National Framework Agreement for Home Parenteral Nutrition				
	<p>New inserted text:</p> <p>Regular review of patients on home PN ensuring the least resource required to meet the patient's needs.</p>	Section 7.1	To encompass principles of new commissioning policy statement	Internal medicine programme of care	June 2023
<p><b>Exclusion:</b> Transition arrangements for paediatric IF moving to the adult service. This will be addressed and included when paediatric IF services are commissioned</p>	<p>Transition of patients from paediatric to adult services All healthcare services are required to deliver developmentally appropriate healthcare to patients and families. Children and young people with ongoing healthcare needs may present direct to adult services or may be required to</p>	Section 7.2	This is standard text to be included in the majority of NHS England service specifications to reflect the importance of good transition planning and	Internal medicine Programme of care	April 2023

	<p>transition into adult services from children's services.</p> <p>Transition is defined as a 'purposeful and planned process of supporting young people to move from children's to adults' services'. Poor planning of transition and transfer can result in a loss in continuity of treatment, patients being lost to follow up, patient disengagement, poor self-management and inequitable health outcomes for young people. It is therefore crucial that adult and children's NHS services, in line with what they are responsible for, plan, organise and implement transition support and care (for example, holding joint annual review meetings with the child/young person, their family/carers, the children's and adult service). This should ensure that young people are equal partners in planning and decision making and that their preferences and wishes are central throughout transition and transfer. NICE guidelines recommend that planning for transition into adult services should start by age 13-14 at the latest, or as developmentally</p>		<p>reflects NICE guidelines.</p>		
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	appropriate and continue until the young person is embedded in adult services.				
Service is identified as specific for adults aged over 18 years	<b>Care for teens new to IF services.</b> Ordinarily, adult services would take patients from aged 18 and over, however, for those patients aged 16-18, and recognising that intestinal failure might continue for many months or years, services are asked to consider the needs of the patient about whether they are most appropriately treated in an adult or a paediatric setting.	Section 7.2	Teenagers and young adult patients who are starting their Intestinal failure journey at aged 16-18 may be using the service for many years. This amendment reflects that there should be no hard dividing line between paediatric and adult service, to ensure that patient care remains most appropriate for the individual.	Internal medicine programme of care	June 2023
Homecare nursing for training was not mentioned in previous version of the specification	Trusts will also need to consider whether patients might be trained on self administration and maintenance of their PN and lines whilst in hospital, or whether training support is needed in their home environment. Trusts may purchase that training time from one of the	Section 7.2	A self-administration assessment is already expected practice but new wording emphasises the importance of the	Internal Medicine Programme of Care	June 2023

	homecare providers accredited on the HPN Framework, or may utilise other resources, provided the standards of training and nursing identified in the framework are met		assessment to support self-sufficiency and reduce reliance on homecare training, which might result in delays to discharge from hospital.		
The Provider must complete Blueteq forms for patient registration for HPN, when it is initiated, when it is discontinued and on annual review	All patients discharged to the community on PN will be registered with Blueteq to ensure the PN provision is from a recognised homecare provider, adhering to the standards and practice separately contracted for by NHSE. Blueteq continuation forms for extended nursing support, and continuation with PN provision will also be required	Section 7.7 Additional requirements.	New text to explain revised Blueteq requirements linked to the new Commissioning Policy for continuation of PN and for extension of nursing support. Providers are required to complete Blueteq forms for patients prescribed high cost drugs.	Internal medicine Programme of care	May 2023
<b>Commissioned Providers</b> To be completed when procurement intervention has been finalised	<b>Commissioned providers Integrated Surgical and Medical centres</b> (Integrated Centres)	Section 7.8	New text to reflect the outcome of the	Internal Medicine Programme of Care	May 2023

	<p>Newcastle Upon Tyne Northern Care Alliance (Salford) Leeds Teaching Hospitals NHS Trust University Hospital Birmingham University Hospital Coventry and Warwick Nottingham University Hospital Cambridge University Hospital London North West University Hospital (St Marks) Central London IF Partnership (UCLH, GSTT, Barts) Oxford University Hospital University Hospital Southampton University Hospital Bristol and Weston</p> <p><b>Medical Management Centres (HPN Centres)</b></p> <p>Lancashire Teaching Hospital Liverpool University Hospital Yorkshire and Humber IF Service (Sheffield, Hull) University Hospital Leicester St Georges Hospital Norfolk and Norwich University Hospital Royal Berkshire Portsmouth University Royal Devon and Exeter.</p>		<p>provider selection process.</p>		
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<p>Transitional arrangements (relating to service stability while moving to the new specification)</p>	<p>Updated wording: Description of National Reference Centres Commissioners will facilitate the provision of training and support by recognising the two commissioned 'National Reference Centres' for these purposes within the national arrangements. It is recognised that some IF patients are particularly complex, and even experienced teams in the integrated IF Centres may require clinical advice and surgical assistance from colleagues.</p>	<p>Annex 4</p>	<p>To reflect passage of time since National Reference Centres were initiated, removing the transitional nature of support offered.</p>	<p>Internal medicine Programme of care</p>	<p>May 2023</p>
<p>“The surgical management of patients with acute intestinal failure”, Association of Surgeons of Great Britain and Ireland (ASGBI 2010, to be updated 2022).</p>	<p>“The surgical management of patients with acute intestinal failure”, Association of Surgeons of Great Britain and Ireland (ASGBI 2010,).</p>	<p>Section 6.2 Other Applicable National Standards to be met by Commissioned Providers</p>	<p>There are no current plans to update the professional standards, which remain relevant to the current service</p>	<p>Internal Medicine Programme of Care</p>	<p>July 2023</p>
<p>All centres will return data on all patients with type 2 and 3 IF to the national IF Registry in line with the requirements set out in Schedule 6 (Contract management, Reporting and Information</p>	<p>All centres will return data on all patients with type 2 and 3 IF to the national IF Registry in line with the requirements set out in Schedule 6 (Contract management, Reporting and Information Requirements) of the NHS Standard Contract, and as guided by the Association of Coloproctology of Great Britain and</p>	<p>Section 7.7</p>	<p>To support from the Association of Coloproctologists of Great Britain and Ireland, the need to submit clinical data to the IF database</p>	<p>Internal Medicine Programme of Care</p>	<p>July 2023</p>



Requirements) of the NHS Standard Contract.	Ireland here: <a href="https://www.acpgbi.org.uk/resources/1095/uk_national_if_registry_data_additions">https://www.acpgbi.org.uk/resources/1095/uk_national_if_registry_data_additions</a>		to support clinical audit.		
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