DRAFT FOR CONSULTATION

SCHEDULE 2 – THE SERVICES

A. Service Specifications

General guidance for completion: Please ensure that patient accessible language is used throughout and that the completed document is no more than 6 pages long. Guidance notes in blue italic font should be removed before the document is finalised. Text in black font should remain in final document and not be changed.

Service Specification No:	URN 1708
Service	Intestinal Failure (Adults)
Commissioner Lead	*For local completion*
Provider Lead	*For local completion*

1. Scope

1.1 **Prescribed Specialised Service**

This service specification covers the provision of Specialised Intestinal Failure (IF) Service for adults

Description

Specialised IF services are provided by Specialist IF centres. This provision applies to adults (over 18 years of age).

How the Service is Differentiated from Services Falling within the Responsibilities of Other Commissioners

NHS England commissions services for adults with Type 2 and Type 3 IF from commissioned Specialist IF centres.

Clinical Commissioning Groups (CCGs) commission treatment and management of Type 1 IF but do not commission any aspect of Type 2 or Type 3 IF.

The activity is identified through a National Tariff/Currency (to be determined by the Operational Pricing and Currency Development Group)

2. Care Pathway and Clinical Dependencies

2.1 **Care Pathway**

IF 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 of 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.

IF patients can be categorised into three types:

Type 1: Commissioned by CCGs	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, including all units which perform major, particularly abdominal, surgery. Some patients on high dependency units (HDU) and intensive care units (ICU) will also fall into this category.
Type 2: Commissioned by NHSE	This occurs in patients who are usually in hospital and frequently metabolically unstable. It requires prolonged (> 28 days) parenteral nutrition, enteroclycis or fistuloclycis, usually over periods of many weeks or months. It is often associated with complications of abdominal surgery, especially intestinal fistulation and abdominal sepsis. These patients often need the facilities of an ICU or HDU for some or much of their stay in hospital. They may also be discharged with home parenteral nutrition or distal enteral tube feeding/fistuloclycis pending corrective surgery. This type of IF is much less common and should be managed by a multiprofessional specialist team. Poor management is associated with significant and largely avoidable mortality and it may also increase the likelihood of the subsequent development of type 3 IF.
Type 3: Commissioned by NHSE	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. Although the condition cannot be reversed by corrective surgery, a proportion of patients may be candidates for autologous gastrointestinal reconstruction or intestinal transplantation to restore nutritional autonomy.

Note:

- *Type 2 IF patients awaiting definitive surgery will remain defined as "type 2", even when discharged into the community. If they develop intercurrent complications of their IF or IF-related illness prior to planned surgery requiring readmission, the primary responsibility for care arrangements will remain with the Integrated IF Centre (see below for definition of Centres). Admission of these patients will either be to integrated IF Centres or in the event of the need to manage only a complication of HPN, to the local Home PN Centre, subject to agreement between Centres.*
- *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.*
- *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.*

There are 2 types of Centres:

Integrated IF Centre	Treats both Type 2 and 3 patients - see Annex A1. Provides support and advice to Home PN Centres
Home PN Centre	Treats Type 3 IF patients - see Annex A1.

This service specification covers all aspects of care for Types 2 and 3 IF (comprising of both non-elective and elective admissions for medical and surgical care; outpatient follow-up attendances; and including the provision of HPN).

The service comprises the following elements:

- In-patient assessment and management of patients with Type 2 IF
- Provision of specialised IF surgery (as outlined in Annex B)
- Follow-up outpatient attendance(s) post discharge of a Type 2 IF patient, pending provision of specialised IF surgery as detailed above.
- In-patient management of patients with Type 3 IF (management of HPN-related complications or treatment of the underlying disease responsible for IF)
- Ongoing out-patient management of Type 3 IF
- 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
- Provision of HPN (and associated homecare nursing if required) via the NHS Commercial Medicines Unit National Framework Agreement for Home Parenteral Nutrition. HPN can only be supplied via an accredited framework supplier.
- 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.
- For any other patients with the characteristics outlined in Annex A1.

Details of the clinical care roles and associated service infrastructure requirements are outlined in Annex A1 and A2 of this specification.

Designated Centres will make available to patients all literature developed by the National Clinical Network and/or relevant patients groups that have been endorsed by the Commissioner.

Referral processes and sources

- 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.
- Any patient who meets the criteria in Annex A1 should be discussed with/referred to a 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 a 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.
- Outpatient assessment or a period of up to 28 days of inpatient assessment following referral to an Integrated IF Centre of a patient who may not currently be on PN, but for whom an opinion from a specialist IF Centre 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 specialised 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 IF Centre. Patients considered to have type 2 or 3 IF will continue to receive treatment as an IF patient, funded by NHS specialised commissioning. If the patient is considered by the IF Centre not to have IF, funding will revert to the CCG. The patient may either remain at the hospital to which they have been referred, but outwith the care of the IF service, or may be transferred back to the referring hospital for ongoing care, subject to discussion between organizations and patient agreement.
- 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 their IF. The IF 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 needs to be to an Integrated or Home PN Centre, who 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 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 circustances .

- Some IF patients are particularly complex and even experienced clinicians in Integrated IF Centres may require further advice and assistance from colleagues at other Centres within the network. This will initially be supported through transition arrangements and subsequently once Integrated Centres are developed it is expected that such support will be included as part of 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 designated Centre as close as possible to the patient's home.
- The service will also accept referrals from other designated providers of other Specialised 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 fluidity of patient movement between Integrated IF Centres/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 a designated Centre for in-patient 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:

1. If there is a sound clinical reason for the patient to remain in their current hospital due to the patient's primary healthcare issue being other than primary gastrointestinal failure in nature, e.g palliative care with the need for a rapid (humane) discharge; complex burns; infectious disease, brain or spinal cord injury; pseudomyxoma peritonei; , management of complications of specialised upper GI or pancreaticobiliary surgery ; – *note this is not an exhaustive list*.

2. 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 a designated HPN Centre. A discussion between the patient's current hospital and a specialised IF provider should occur and a care plan taking account of their nutritional needs be agreed and documented in the patients' medical records prior to discharge. All HPN at discharge must be prescribed in collaboration with the specialist IF provider, i.e. an Integrated IF Centre or a Home PN Centre.

3. 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

Networks of Care

- It is recognised that services will be developing from different baseline positions in terms of the breadth and depth of service currently available and some services will need to substantially increase their activity levels. Some IF patients are particularly complex, and even experienced clinicians in the new Integrated IF Centres may require further advice and assistance from colleagues at other Centres with greater experience. For this reason a transition phase of 3 years (in the first instance) will be agreed. During the period of transition, two Centres will be identified to act as National Reference Centres. In such cases, support from the National Reference Centres may be requested, either to provide an additional opinion, to support the performance of specialised IF surgery through facilitated training (see Annex B) or, where agreed, to take over the patient's IF care, until such time as they can be transferred back to the referring Centre. Commissioners will facilitate the provision of this support during this transitional period of 3 years by formally recognising two Centres as "National Reference Centres" for these purposes within the national network,

subject to agreement of appropriate tariffs for the provision of these reference services (Annex A0).

- 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. , . Such a network should include shared protocols for PN-related care, arrangements for patient transfer as required and the facility for multi-disciplinary meetings and/or discussions. Such network arrangements should not necessarily be confined to commissioning boundaries. These networks can also be used to help develop new centres.

Exclusions

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

- Type 1 (short-term) IF (< 28 days) remains the responsibility of the patient's responsible Clinical Commissioning Group (CCG).
- Operations/treatments not directly related to IF (see Annex B)
- Transition arrangements for paediatric IF moving to the adult service. This will be addressed and included when paediatric IF services are commissioned
- 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 multiprofessional 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 etc.) 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 are not on PN, may require longer term follow up at the discretion of the specialist Centre, but outwith of specialised IF 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 by the specialist IF service for life, either from the transplant Centre, Integrated IF Centre or local Home PN Centre or a combination of these, to be tailored to individual requirements.

Information Reporting

All designated IF Centres will be contractually obliged to provide accurate and timely reports as follows:

- All designated Centres will return data (frequency to be confirmed) on all patients with type 2 and 3 IF to the national IF Registry.
- 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.

- All designated IF providers 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 not only management of type 2 IF but also HPN and reconstructive surgery.

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: NCBPS12z INTESTINAL FAILURE

When reporting drug activity the indication should be recorded as "Intestinal Failure".

Please note that access to treatment will be guided by any applicable NHS England national clinical commissioning policies.

Interdependence with other Services

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

Co-located services
Services that need to be available on the same site as the specialised service:

- Luminal gastroenterology
- Colorectal surgery
- Adult Intensive Care Medicine
- Venous access
- Enterostomal therapy

Interdependent services
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

- Interventional radiology
- Renal dialysis
- Hepatology
- Plastic surgery
- Gynaecological surgery
- Urological surgery
- Vascular surgery
- Upper GI surgery
- Hepatobiliarysurgery
- Clinical psychology/psychiatry
- Microbiology
- Biochemistry

Related services
These are services that are either at the preceding or following stage of the patient Journey:

- Gastroenterology at District General Hospital (DGH) level (identification of Type 2 IF patients)
- General and/or Gastrointestinal (both Colorectal and Upper GI) surgery at DGH level (identification of Type 2 IF patients)
- Homecare providers of HPN products and services

3. Population Covered and Population Needs

3.1 Population Covered By This Specification

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)

** Note: for the purposes of commissioning health services, this EXCLUDES patients who, whilst resident in England, are registered with a GP practice in Wales, but INCLUDES patients resident in Wales who are registered with a GP practice in England.*

Specifically, this service is for adults with Type 2 or Type 3 IF. This will include (potential or existing) HPN patients, patients undergoing prolonged PN), and patients requiring specialised IF surgery (as outlined in Annex B) or candidates for intestinal transplantation or Autologous Gastrointestinal Reconstruction .

Population Needs

The incidence of major IF surgical procedures is estimated at 10 procedures per million per annum. 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 cessation of PN support

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).

Expected Significant Future Demographic Changes

The incidence of Type 2 IF has been increasing over the last decade, with the biggest area of growth relating to surgical complications. It is anticipated that, at least over the next 5-10 years, this growth will continue. It is estimated that the 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.

Largely as a consequence of the increase in Type 2 IF, the prevalence of HPN (Type 2 and 3 IF) has also been increasing at a rate of approximately 20% per annum. At present there does not appear to be any evidence that this growth is slowing down. It is therefore anticipated that HPN prevalence could be 80 per million within the next 5 years, ie 4000 cases/year.

These estimates have been developed on the basis of figures from the IF Registry and clinical consensus, there being no other formal data or evidence that currently define IF services or patient trends.

4. Outcomes and Applicable Quality Standards

4.1 Quality Statement – Aim of Service

NHS Outcomes Framework Domains

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**	✓

4.2 Indicators Include:

Centres will need to demonstrate compliance with these proposed quality indicators within 2 years of commissioning through their IF Registry returns and other means of reporting, still to be finalised.

Centre	Indicator	Target	Validation
Integrated IF Centre	Refistulation rate at 90 days (Type 2 IF)	< 10%	Audit
Integrated IF Centre	90 day postop mortality (Type 2 IF)	< 5%	Audit
Integrated IF Centre	In-patient IF-related mortality (Type 2 IF)	< 5%	Audit
Integrated IF Centre	In-patient CVC infection rates (Type 2)	<1:1000 catheter days*	Audit
Integrated IF Centre and/or Home PN Centre	All HPN patients to offered assessment at least annually as to their continued need for HPN	100%	Casenote audit
Integrated IF Centre and/or Home PN Centre	1 year survival rate on HPN (Type 3 IF)	>90% (all patients)** ##	Audit
Integrated IF Centre and/or Home PN Centre	5 year mortality rate on HPN (Type 3 IF)	<15% from HPN-related complications ###	Audit
Integrated IF Centre and/or Home PN Centre	Outpatient CVC infection rate (Type 3 IF)	<1:1000 catheter days*	Audit
Integrated IF Centre and/or Home PN Centre	Patient satisfaction scores. Family and Friends	To be developed	
Integrated IF Centre	Waiting list: Number waiting <14 days for transfer to integrated IF Centre after acceptance	>75% ***	Audit
Integrated IF Centre and/or Home PN Centre	IF (including CVC and abdominal sepsis) - related deaths while waiting to transfer to	<5% ***	Audit

	an Integrated IF Centre or Home PN Centre		

* British Intestinal Failure Association (BIFA) Position Paper 2016
** Based on data from European Society for Clinical Nutrition and Metabolism. Clin Nutr 2012; 31: 831-845
*** consensus
excluding patients on HPN for palliative care
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
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

5. Applicable Service Standards

5.1 Applicable Obligatory National Standards

- The provider must adhere to the requirements of the IF Specification, and submit to inspections and quality assurance measures from time to time, as determined by the Commissioners
- The Provider must complete BANS registry for all IF patients in a timely manner
- The Provider must complete Blueteq forms for patient registration for HPN, when it is initiated, when it is discontinued and on annual review
- The Provider must adhere to national guidelines and protocols for care of IF services, to be developed. Where these are not developed, the provider must adhere to international guidelines on the same.

5.2 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, to be updated 2017-2018).
- The Providers must work with homecare providers (contractors), as commissioned by 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 national HPN framework document.

5.3 Other Applicable Local Standards

- The Providers must ensure the standards of care, as set out in Annexes A1/2
- 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. The formal and frequency of the meetings to be organised locally, but no less often than quarterly
- 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.
- 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

6. Designated Providers

To be completed when designation process has been finalised.

7. Abbreviation and Acronyms Explained

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

PN Parenteral nutrition
HPN Home parenteral nutrition
IF Intestinal Failure
CVC Central Venous Catheter

Date published: *<insert publication date>*

ANNEX A0 – DESCRIPTION OF NATIONALREFERENCE CENTRES DURING NETWORK TRANSITION. ROLES RELATING TO SPECIALISED INTESTINAL FAILURE

- The Service will facilitate the provision of training and support during this 3 year transitional period by formally recognising two "National Reference Centres" for these purposes within the national network.

- It is recognised that some IF patients are particularly complex, and even experienced clinicians in Integrated IF Centres may require opinions, advice and surgical assistance from colleagues, especially during the period of transition, from the two current national centres to a nationally commissioned network. 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 a designated 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 B) or to take over the patient's IF care, until such time as they can be transferred back to the referring centre.

ANNEX A1 – DESCRIPTION OF CLINICAL CARE ROLES RELATING TO SPECIALISED INTESTINAL FAILURE

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 – CCG 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,
		2.2 Patients with an uncontrolled high output	Optimal IF management	A1-3, B1-7

		stoma despite standard management*		
		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)	A1-3, B1-7 C1.1-1.3, C2,3
		2.7 Intestinal failure with complex fistulation requiring surgical reconstruction	Optimal IF management with specialist stoma care, interventional radiology (as appropriate) in a specialist surgical 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 a specialist 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, 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 a specialist centre (to include discussion and/or referral to national centres)	Optimal IF management with specialist stoma care, interventional radiology (as appropriate) in a 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 defect of connective tissue (eg Elhers Danlos, Marfans, PXE)	IF surgery in a Integrated IF Centre	A1-3, B1-7 C1.1-1.3, C2-4
		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 Centret	A1-3, B1-7, C1.1-1.3, C2-4
		2.15 Surgery for severe intestinal dysmotility	IF surgery in a Integrated IF Centret	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 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 a Integrated IF Centret	A1-3, B1-67 C1.1-1.3, C2-4
		2.18 Potentially hostile abdomen requiring further expert surgical appraisal or considered possibly not suitable for further surgery	Optimal IF management in a Integrated IF Centret	A1-3, B1-7, C1.1-1.3, C2-4
		2.19 IF due to encapsulating peritoneal sclerosis needing specialist enteroclysis	EPS surgery in a specialized unit (currently only Central Manchester University Hospitals	A1-3, B1-7, C1.1-1.4, C2-4,7

			Foundation Trust)	
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.
		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	Optimal IF management & liaison with other specialist services as necessary	A1-3, B1-7, (C1.5, C2), D1-5

		controlled diabetes)		
		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
	Elective readmissions of Type 3 IF	3.12 Medical and nutritional optimization of PN and hydration (eg 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 – CCG 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	Optimal IF management	A1-3, B1-7 C1.1 -1.3, D1-5

		nutritional/fluid autonomy		
		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.
		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
		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 (eg reviewing PN volumes, lipid/glucose	Optimal IF management	A1-3, B1-7, D1-5

		preparations)		
		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, eg omeprazole 40mg BD, octreotide)

** 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 – CENTRE SPECIFICATION

Code	Description	Sub-code	Subcode description
A1	GI medicine & surgery expertise on site		
A2	NICE compliant nutrition support team		
A3	British Artificial Nutrition Survey (BANS) reporting		
B1	At least 2 nominated intestinal failure surgeons with appropriate on-going interest, practice & junior surgical support		
B2	Nominated specialist IF gastroenterologist & skilled consultant/associate specialist cover in the context of comprehensive medical gastroenterological, endoscopy and hepatology services with junior medical support.		
B3	Enhanced nutrition support team services	**B3.1**	Specialist nutrition nurse specialists with comprehensive cross cover arrangements
		B3.2	Specialist dietitians with experience in intestinal failure management and comprehensive cross cover arrangements
		B3.3	Specialist pharmacists with comprehensive cross cover arrangements. Timely arrangement for tailor made PN or access to compounding facilities
B4	Engaged microbiological services		
B5	Venous access service able to site/replace lines within 24 hours, 7 days a week, with continuous audit of complication rates		
B6	Dedicated ward area for IF patients with an appropriate nursing ratio		
B7	24h on-call arrangements for IP and OP by staff with appropriate expertise in IF management		
C1	High quality supporting clinical teams	**C1.1**	Anaesthetics with a special interest in IF surgery
		C1.2	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 https://www.england.nhs.uk/wp-content/uploads/2015/08/Sepsis-Action-Plan-23.12.15-v1.pdf and Royal College of Surgeons of England/DoH "The higher risk surgical patient 2011" https://www.rcseng.ac.uk/library-and-publications/college-publications/docs/the-higher-risk-general-surgical-patient/, namely: • For patients with septic shock –

			source control immediately i.e. within 3 hours. • For patients with severe sepsis (i.e. with evidence of organ dysfunction – within 6 hours • For patients with uncomplicated infection – within 18 hours
		C1.3	Stoma care & abdominal wound care (experience in management of dehisced abdominal wound)
		C1.4	Interventional radiology expertise in central venous catheter placement and venous stenting in patients with difficult venous access
		C1.5	Support for patients with renal failure requiring haemodialysis
		C1.6	Nominated specialists in psychiatry & psychology
		C1.7	Access to appropriate other surgical specialties (eg gynaecological, urological, upper GI and vascular surgery)
		C1.8	Access to plastic surgery
		C1.9	Access to oncology/palliative care
C2	Good access to and working relations with on-site HDU & ICU		
C3	Critical mass of type 2 IF patients, with at least 10 IF operations carried out per year per centre		
C4	Surgical expertise in abdominal wall reconstruction and fistula repair		
C5	Experience in intestinal transplant selection & assessment		
C6	Experience in intestinal lengthening procedures (AuGIR)*		
C7	Experience in surgical enteroclysis for sclerosing peritonitis*		
D1	Dedicated multi-professional IF outpatient clinics at least every fortnight with capacity for responsive and timely urgent appointments		
D2	HPN experience and on-going critical mass of at least 30 active patients, of which at least 10 are on HPN for >5 years		
D3	Clear processes for patient help and advice by appropriately trained and experienced staff 24 hours a day, 7 days a week		
D4	Clear processes for emergency admission to an appropriate ward 24 hours a day, 7 days a week		
D5	Access to a pharmacy aseptic suite that is able to compound bespoke parenteral nutrition for patients		

*AuGIR – Autologous intestinal reconstruction

ANNEX B – 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

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

* Serial Transverse Enteroplasty
**STEP for short bowel syndrome