This Service Specification is not in force for contractual purposes but will be used within the national procurement of this service during 2019/20.

SCHEDULE 2 – THE SERVICES

A. Service Specifications

Service Specification No:	**170077S** **This Service Specification is not in force for contractual purposes but will be used within the national procurement of this service during 2019/20.**
Service	Severe Intestinal Failure (Adults)
Commissioner Lead	*For local completion*
Provider Lead	*For local completion*

1. Scope

Prescribed Specialised Service

This service specification covers the provision of specialised severe intestinal failure (IF) service for adults.

Description

Specialised IF services are provided by specialist intestinal failure 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 severe Type 2 and Type 3 IF from commissioned specialised 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

Care Pathway

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 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. Some patients on high dependency units (HDU) and intensive care units (ICU will also fall into this category. Responsibility for par enteral nutrition in hospital sits with CCGs for the first 14 days.
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 an extended period o weeks or months. It is associated with complications of abdominal surgery, especially intestinal fistulation and abdominal sepsis. These patients often need the facilities of an ICU or HDU during 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 severe IF is much less common and should be managed by a multi-professional 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. 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 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.

- 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	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.
	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
Home PN Centre	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.

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).

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 A2)
- 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 https://www.contractsfinder.service.gov.uk/Notice/2cee30e9-e4b6-4145-8d5b-b37f506337e2
- 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.

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

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 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 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.

- 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 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 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 out with specialised IF care, 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 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 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.

- Remote discharge with input from an Integrated IF or HPN Centre may be appropriate in the specific situation for patients with palliative needs managed in an oncology centre where transfer to an HPN 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 organization, then the patient must be transferred to the Integrated IF Centre or HPN Unit prior to discharge on HPN. The referring organization and the Integrated IF or HPN 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 initially be supported through transitional arrangements and subsequently once Integrated IF 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 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.

Networks of Care

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 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.

Transitional Arrangements

It is recognised that service change could impact on service stability whilst the new model is developing the breadth and depth of service required. Some IF patients are particularly complex and developing IF teams may require further advice and assistance from colleagues at other Centres with greater experience. For this reason, a transition phase of 3 years will be agreed. During the period of transition, two Centres will be selected to act as National Reference Centres. In such cases, support from the National Reference Centres may be requested, this could include providing an additional clinical opinion, to support specialised IF surgery through facilitated training (see Annex A2) or, where agreed, transfer of the patient's IF care, until they can be transferred back to the referring Integrated IF or Home PN 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 (Annex A4).

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).
- Parenteral nutrition Type 1 (short-term) IF (14 days or less) remains the responsibility of the patient's responsible Clinical Commissioning Group (CCG).
- Operations/treatments not directly related to IF (see Annex A2)
- 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 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 out with 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.

Information Reporting

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

- All centres will return data on all patients with type 2 and 3 IF to the national IF Registry in line with the NHS Standard Contract.
- 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 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 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
- Pharmacy aseptic services
- Renal dialysis
- Hepatology
- Plastic surgery
- Gynaecological surgery
- Urological surgery
- Vascular surgery
- Upper GI surgery
- Hepatobiliary surgery
- Clinical psychology/psychiatry
- Microbiology
- Biochemistry

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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
- Bowel Transplant Services

3. Population Covered and Population Needs

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 A2) or candidates for intestinal transplantation or Autologous Gastrointestinal Reconstruction.

Population Needs

It has been estimated that 10 procedures per million are required to treat severe IF requiring major surgical procedures 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% currently 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, 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, 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.

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 the defined reporting mechanisms.

Number	Indicator	Data Source	Outcome Framework Domain	CQC Key question

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Clinical Outcomes				
101	% of patients waiting >14 days for transfer to medical/surgical IF unit after acceptance	Provider / IF Registry	1, 2, 4	safe, effective, caring, responsive
102	% of patients that have refistulation at 90 days (Type 2 IF)	Provider / IF Registry	1, 2, 4	effective
103	90 day postop mortality (Type 2 IF)	Provider / IF Registry	1, 2	effective
104	In-patient mortality (Type 2 IF)	Provider / IF Registry	1, 2	effective
105	In-patient CVC infection rates (Type 2)	Provider / IF Registry	3, 4, 5	safe, effective
106	1 year survival rate on HPN (Type 3 IF)	Provider / IF Registry	1, 2	effective
107	5 year survival rate on HPN (Type 3 IF)	Provider / IF Registry	1, 2	effective
108	Outpatient CVC infection rate (Type 3 IF)	Provider / IF Registry	3, 4, 5	safe, effective
Patient Experience				
201	Patient information	Self-declaration	5	Effective, caring, responsive
202	Patient experience	Self-declaration	2, 4, 5	Safe, effective, caring, responsive
Structure and Process				
301	There is a lead clinician for the IF service.	Self declaration	1, 2, 3, 4, 5	well-led
302	All patients meeting the IF criteria outlined within the service specification, are discussed with the IF centre.	Self declaration	1, 2, 3, 4, 5	effective, responsive
303	There are discharge arrangements to local services for type 2 IF patients	Self declaration	3, 4	Safe, effective, caring, responsive

304	All HPN patients undergo an assessment at least annually to review their continued need for HPN.	Self declaration	1, 2, 3	Safe, effective, caring, responsive
305	There are outpatient follow-up arrangements for type 3 patients	Self declaration	1 , 2, 3	Safe, effective, caring, responsive
306	The designated IF unit has services co-located on site as per the service specification.	Self declaration	5	Safe
307	Clinical guidelines are in place as per section 5 of the service specification.	Self-declaration	1, 2, 3, 4, 5	Safe
308	There are patient pathways in place	Self-declaration	1, 2, 3, 4	Safe, effective, caring, responsive
309	The IF service submits data to the IF registry.	Self declaration	1, 2, 3, 4	Safe
310	The IF service participates in the national audit programme	Self declaration	1, 2, 3, 4	Safe, effective

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

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 SIF 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 SIF 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 SIF 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 SIF 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 SIF 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 SIF.

6. Commissioned Providers

To be completed when procurement intervention has been finalised.

7. Abbreviations and Acronyms

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

AuGIR Autologous Gastrointestinal Reconstruction

CVC Central Venous Catheter

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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

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ANNEX A1 – DESCRIPTION OF CLINICAL CARE ROLES RELATING TO SPECIALISED SEVERE 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 SIF 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 SIF 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 SIF management	A1-3, B1-7,
		2.2 Patients with an uncontrolled high output stoma despite standard management*	Optimal SIF management	A1-3, B1-7
		2.3 Patients with catheter-related central venous thromboses leading to problems	Optimal SIF management & appropriate	A1-3, B1-7, C1.4,

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
		of access for PN** administration (e.g. direct IVC## or atrial catheters, venous recanalisation or vascular reconstruction)	vascular intervention	
		2.4 Medical management patients with persistent or deteriorating metabolic complications (significant liver or renal dysfunction, recurrent acidosis, poorly controlled diabetes)	Optimal SIF 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 SIF 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 SIF management with specialist stoma care, interventional radiology (as appropriate) in an Integrated SIF Centre	A1-3, B1-7 C1.1-1.3, 1.7, C2-4

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
		2.8 Dehisced abdominal wound or open abdomen needing reconstruction of both GI tract & abdominal wall	Optimal SIF management with specialist stoma care, interventional radiology (as appropriate) in an Integrated SIF 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 SIF management	A1-3, B1-7, C1.1-1.3, C2-4
		2.10 Need for distal limb enteroclysis or fistuloclysis	Optimal SIF 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 SIF in an Integrated SIF Centre (to include discussion and/or referral to National Reference Centres)	Optimal SIF management with specialist stoma care, interventional radiology (as appropriate) in an Integrated SIF Centre	A1-3, B1-7, C1.1-1.3, C2-4
		2.12 SIF Surgery in a patient with radiation enteritis or an inherited defect of connective tissue (eg Elhers Danlos, Marfans, PXE)	SIF surgery in an Integrated SIF Centre	A1-3, B1-7 C1.1-1.3, C2-4
		2.13 Persistent SIF with significant co-morbidity (heart, renal & liver failure) requiring tailored PN	Optimal SIF management	A1-3, B1-7, C1.1- 1.3,1.5, C2-4

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
	Patients requiring intestinal reconstruction	2.14 With or without abdominal wall reconstruction	SIF surgery in an Integrated IF Centre	A1-3, B1-7, C1.1-1.3, C2-5
		2.15 Surgery for severe intestinal dysmotility	SIF surgery in a Integrated IF Centre	A1-3, B1-7, C1.1-1.4, C2,3
		2.16 Intestinal lengthening - AuGIR(tapering, lengthening, STEP & Bianchi/LILT procedures)	SIF surgery in a nationally commissioned Highly Specialised Centre (currently only Salford Royal NHS Foundation Trust)	A1-3, B1-7, C1.1-1.4, C2,3, 4,5,6
	Surgical re-appraisal	2.17 Severe intra-abdominal adhesions requiring further expert surgical appraisal or considered possibly not suitable for further surgery	Optimal SIF management in a Integrated IF Centre	A1-3, B1-67 C1.1-1.3, C2-5
		2.18 Potentially hostile abdomen requiring further expert surgical appraisal or considered possibly not suitable for further surgery	Optimal SIF management in a Integrated SIF Centre	A1-3, B1-7, C1.1-1.3, C2-5
		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 &	3.1 Patients on long term parenteral nutrition who could be	Optimal SIF management	A1-3, B2-7, D1-5

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
	training of new HPN patient	considered for continued home care		
		3.2 Patients with significant intestinal resection leaving a short bowel with or without colonic continuity, and thereby loss of nutritional/fluid autonomy	Optimal SIF 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 SIF 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 SIF management	A1-3, B1-7 D1-5.
		3.5 Severe intestinal dysmotility requiring specialist psychological support	Optimal SIF management & specialist psychiatric input	A1-3, B1-7 C1.6, D1-5
		3.6 Patients with advanced malignancy with loss of intestinal function	Optimal SIF 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	3.7 Patients with central venous catheter blood stream infection	Optimal SIF management & appropriate vascular intervention	A1-3, B1-7, D1-5

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
	awaiting surgery ***	3.8 Patients with catheter-related central venous thromboses	Optimal SIF management & appropriate vascular intervention	A1-3, B1-7, C1.4, D1-5
		3.9 Patients with other catheter-related complications	Optimal SIF 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 SIF 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 SIF 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 SIF management & appropriate vascular intervention	A1-3, B1-7, D1-5
		3.13 Changing or replacing venous access	Optimal SIF management	A1-3, B1-7, C1.4, D1-5
	MDT and outpatient management	3.14 Established HPN	Optimal SIF management	A1-3, B2-7 D1-5

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IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
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 SIF management	A1-3, B1-7
Intestinal transplant		5.1 Transplant assessment	Transplant assessment	A1-3, B1-67 C1,2,3,4,5,6,7
		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, C1,2,3,4,5

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 SIF management	A1-3, B1-7, D1-5

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
		3.2 Patients with significant intestinal resection leaving a short bowel with or without colonic continuity, and thereby loss of nutritional/fluid autonomy	Optimal SIF 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 SIF 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 SIF management	A1-3, B1-7 D1-5.
		3.5 Severe intestinal dysmotility requiring specialist psychological support	Optimal SIF management & specialist psychiatric input	A1-3, B1-7 C1.6, D1-5
		3.6 Patients with advanced malignancy with loss of intestinal function	Optimal SIF 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 SIF management & appropriate vascular intervention	A1-3, B1-7, D1-5
		3.8 Patients with catheter- related central venous thromboses	Optimal SIF management & appropriate	A1-3, B1-7, C1.4, D1-5

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
			vascular intervention	
		3.9 Patients with other catheter-related complications	Optimal SIF 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 SIF 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 SIF 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 SIF management	A1-3, B1-7, D1-5
		3.13 Changing or replacing venous access	Optimal SIF management & appropriate vascular intervention	A1-3, B1-7, C1.4, D1-5
	MDT and outpatient management	3.14 Established HPN	Optimal SIF management	A1-3, B2-7 D1-5
Potential type 3 IF patient	Patients whose clinical and nutritional care requires	4.1 Up to 28 days of in-patient assessment, by which time a decision on IF status is made	Optimal SIF management	A1-3, B2-7 D1-5

IF Type	General description	Specific Description	Treatment	Centre specifications (see Annex A2)
	evaluation by a specialist IF service prior to determining IF status			

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

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ANNEX A2 – INTEGRATED and HPN 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 SIF 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

Code	Description	Sub-code	Subcode description
		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 and Royal College of Surgeons of England/DoH "The higher risk surgical patient 2011 ", 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	To demonstrate ability to meet a critical mass of type 2 SIF patients, with at least 20 IF operations carried out per year as the optimal model for SIF Integrated Centres within 3 years of selection.		

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Code	Description	Sub-code	Subcode description
C4	To demonstrate ability to meet a critical mass of type 2 SIF patients, with at least 10 IF operations carried out per year per centre for clinical safety within 2 years of selection		
C5	Surgical expertise in abdominal wall reconstruction and fistula repair		
C6	Experience in intestinal transplant selection & assessment		
C7	Experience in intestinal lengthening procedures (AuGIR)*		
C8	Experience in surgical enteroclysis for sclerosing peritonitis*		
D1	Dedicated multi-professional SIF outpatient clinics at least every fortnight with capacity for responsive and timely urgent appointments		
D2	To demonstrate HPN experience and on-going critical mass of at least 50 active patients, of which at least 10 are on HPN for >5 years to support an optimal service model within 3 years of selection.		
D3	To demonstrate HPN experience and on-going critical mass of at least 30 active patients, of which at least 10 are on HPN for >5 years to meet reasonable access requirements within 2 years of selection.		
D4	Clear processes for patient help and advice by appropriately trained and experienced staff 24 hours a day, 7 days a week		
D5	Clear processes for emergency admission to an appropriate ward 24 hours a day, 7 days a week		
D6	Access to a pharmacy aseptic suite that is able to compound bespoke parenteral nutrition for patients		

*AuGIR – Autologous intestinal reconstruction

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

To qualify as within the definition as a 'specialised *procedure for the management of Severe 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)[+]

4. Abdominal surgery **in a commissioned SIF 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 severe 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

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ANNEX A4 – TRANSITIONAL ARRANGEMENTS: DESCRIPTION OF NATIONAL REFERENCE CENTRES DURING NETWORK TRANSITION.

- Commissioners will facilitate the provision of training and support during this 3 year transitional period by recognising the two commissioned “National Reference Centres” for these purposes within the national arrangements.

- It is recognised that some SIF patients are particularly complex, and even experienced teams in Integrated IF Centres may require clinical advice and surgical assistance from colleagues, especially during the period of transition, from the current arrangements to a nationally commissioned network. Examples of such situations could 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.