

A08/S/a

**2013/14 NHS STANDARD CONTRACT
FOR INTESTINAL FAILURE (ADULT)**

PARTICULARS, SCHEDULE 2- THE SERVICES, A- SERVICE SPECIFICATIONS

Service Specification No.	A08/S/a
Service	Intestinal Failure (adult)
Commissioner Lead	
Provider Lead	
Period	12 months
Date of Review	

1. Population Needs

1.1 National/local context and evidence base

Intestinal failure (IF) comprises a group of disorders with many different causes, all of which are characterised by an inability to maintain adequate nutrition via the intestines. It results from obstruction, abnormal motility, major surgical resection, congenital defect or disease-associated loss of absorption. It is characterised not only by the inability to maintain protein-energy, but also often in difficulties in maintaining water, electrolyte or micronutrient balance, particularly when there has been a major loss of length of the small bowel. If it persists for more than a few days it demands treatment with the intravenous delivery of nutrients and water (parenteral nutrition or PN)

Services for Adults with Intestinal Failure (including those requiring Home Parenteral Nutrition (HPN)) were the subject of a national review undertaken in 2007 which resulted in the publication of 'A Strategic Framework for Intestinal Failure and Home Parenteral Nutrition Services for Adults in England' in 2008. This Strategic Framework was adopted by the National Specialised Commissioning Group as a national commissioning policy. The service specification outlined here reflects the position outlined in the Strategic Framework as amended by the Intestinal Failure Implementation Programme through detailed clinical engagement in the design of the service.

The prevalence of Type III Intestinal Failure (IF) is thought to be approximately 15 patients per million, based on the experience of the Scottish

Managed Clinical Network for Home Parenteral Nutrition (HPN). Incidence of new patients with Type III Intestinal Failure is 2 patients per million per annum.

In England, we estimate that there are between 1,500 and 2,000 inpatient spells per year for patients with Type II IF. These are a complex cohort of patients characterised by significant length of stay and requiring broad multi-disciplinary input into management and care.

For further information, please refer to the document A Strategic Framework for Adult Intestinal Failure and Home Parenteral Nutrition Services in England (2008).

2. Scope

2.1 Aims and objectives of service

This service aims to provide optimal treatment and care for patients with IF (defined as patients who, for a period of 28 days or longer, are unable to maintain nutritional and/or fluid balance via their intestines and who require intravenous nutritional support). It is recognised that surgical procedures are a major cause of intestinal failure.

Specifically this will include:

- Optimal management (either medical; surgical; or both) of Type II IF with a view to effective resolution of this condition.
- Optimal management of (chronic) Type III IF with a view to achieving high quality of life; prolonged life; and where possible reducing dependence on intravenous nutritional support.
- Assessment of suitable Type III IF patients for curative surgery (and where appropriate, undertake such surgery) including onward referral for Small Bowel Transplantation or Autologous Gut-Lengthening Surgery.

2.2 Service description/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 via the intestines. It results from obstruction, abnormal motility, major surgical resection, congenital defect or disease-associated loss of absorption. It is characterised not only by the inability to maintain protein-energy, but also often in difficulties in maintaining water, electrolyte or micronutrient balance, particularly when there has been a major loss of length of the small bowel. If it persists for more than a few days it demands treatment with the intravenous delivery of nutrients and water (parenteral nutrition, PN)

IF can be categorised into three types:

Type 1:	This type of IF is short-term, self-limiting and often peri-operative in nature. Type I IF is common and these patients are managed
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	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:	This occurs in metabolically unstable patients in hospital and requires prolonged parenteral nutrition over periods of weeks or months. It is often associated with sepsis, and may be associated with renal impairment. These patients often need the facilities of an Intensive Care or High Dependency Unit for some or much of their stay in hospital. This type of IF is more rare and needs to be managed by a multi-professional specialist intestinal failure team. Poor management of Type 2 IF increases mortality and is expected to increase the likelihood of later development of type 3 Intestinal failure
Type 3:	This is a chronic condition requiring long term parenteral feeding. The patient is characteristically metabolically stable but cannot maintain his or her nutrition adequately by absorbing food or nutrients via the intestinal tract. These are, in the main, the group of patients for which HPN or Electrolytes (HPE) indicated.

Note: Sometimes metabolically stable patients such as those with severe intestinal dysmotility, abdominal cancer undergoing chemotherapy, chronic high volume intestinal fistulae and patients with abdominal complications of peritoneal dialysis may need prolonged in-hospital parenteral nutrition. These might be considered as having a variant of type 2 intestinal failure. Some patients with type 3 IF require brief spells in hospital in order to deal with catheter complications or problems related to their underlying disease.

This service specification covers all aspects of care for Types II and III 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 management of patients with Type II IF
- Provision of Specialised IF surgery (as outlined in Annex B)
- Follow-up outpatient attendance(s) post discharge of a Type II IF patient
- In-patient management of patients with Type III IF (management of catheter complications or treatment of underlying disease)
- Ongoing out-patient management of Type III 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 (the transplant episode is outside the scope of this specification).

For patients with the characteristics outlined in Annex A1.

It is a contractual obligation for all designated specialised units to return data on all patients with Type II and III IF to the British Artificial Nutrition Survey. It is also a contractual obligation of all designated providers to participate in the National IF Audit

Programme (undertaken by/at the behest of the National Clinical Network).

All designated specialised units will be expected to provide training to the multi professional staff that rotate through them. A trainee will need to demonstrate that they have been employed to work for a significant period on a unit designated for the clinical role he or she wishes to practice independently. It is expected that the relevant Royal Colleges and specialist societies will wish to have a role in such training.

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 inward referrals from secondary care clinicians. Patients with prolonged IF will generally be under the care of either a gastroenterologist; a colorectal surgeon; an intensivist, or an Oncologist.

Any patient who meets the criteria in annex A1 should be discussed with a designated IF centre as soon as possible, and by 21 days of 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. Patients who have been fed parenterally for 28 days will have their care transferred to a designated centre.

However, there may be a number of situations where it is not in the patients' best interests to be transferred. These are 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 complex burns; spinal cord injury; pseudomyxoma peritonei; complex pancreas; upper GI/bariatric surgery – *note this is not an exhaustive list*) or in cases where their condition has stabilised AND arrangements for discharge from local service are already well advanced. This hospital must have the necessary nutritional support team to be able to maintain safe parenteral nutrition at an agreed national level.

A discussion between the patient's current hospital and a specialised IF provider should still occur, and a care plan taking account of their nutritional needs be agreed. There needs to be evidence of a formal liaison between the current hospital and the IF provider, if this occurs more than just occasionally.

The service will also accept referrals from other designated providers of Specialised IF services, particularly when either the referring service is not accredited to undertake the clinical role that the patient requires; or when the patient's condition has stabilised and ongoing care could effectively be undertaken at a designated centre closer to the patient's home (e.g. the initiation/maintenance of HPN).

Discharge criteria and planning

Patients having fully completed their treatment for Type II IF, and who do not progress to Type III IF, will be followed-up as outpatients for 90 days post-discharge and then referred back to local services. The patient's GP and referring unit will be provided with a discharge summary when the patient leaves hospital and after review at 90 days. Some patients e.g. those with short bowel syndrome; abdominal fistula patients not on PN, will require longer term follow up.

Patients with Type III IF that has been resolved, and who have been weaned off parenteral nutrition, will be followed-up as outpatients for one year following weaning. At this stage they will be discharged from the service back to local services and a final discharge summary will be sent to their GP and referring unit.

Patients with Type III IF, that has been resolved either as a result of intestinal transplantation or as a result of Autologous Gut Lengthening Surgery, will be followed up by the service for life.

2.3 Population covered

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 II or Type III IF. This will include (potential or existing) HPN patients, patients undergoing prolonged PN (especially if complications are a problem), & patients requiring specialised IF surgery (as outlined in Annex B) or candidates for intestinal transplantation.

2.4 Any acceptance and exclusion criteria

Acceptance criteria

The service will accept inward referrals from secondary care clinicians. Patients with prolonged IF will generally be under the care of either a gastroenterologist; colorectal surgeon; intensivist; or an oncologist.

The service will also accept referrals from other providers of specialised IF services, particularly when the referring service is not accredited to undertake the clinical role that the patient requires; or when the patient's condition has stabilised and

ongoing care could effectively be undertaken at a designated provider closer to the patient's home.

Referrals to the service will be to the service overall, not to a named consultant. The requirement for timely access to the service and the necessity of a multi-disciplinary approach dictates that the multi-disciplinary team (MDT) should collectively manage inward referrals.

Exclusions

Patients with Type I (short-term) IF are outside the scope of this service specification and remain the responsibility of the patient's responsible Clinical Commissioning Group (CCG).

2.5 Interdependencies with other services

Co-located services

Services that need to be provided on the same site as the specialised service:

- Luminal gastroenterology
- Adult Intensive Care
- Interventional Radiology
- Interventional central venous catheter access
- Enterostomal care

Interdependent services

The following are services that are 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:

- Renal dialysis
- Hepatology
- Plastic surgery
- Gynaecological surgery
- Urological surgery
- Vascular surgery
- Upper GI surgery
- Hepatobiliary surgery
- Clinical psychology/psychiatry
- Microbiology

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 II

- patients)
- Colorectal surgery at DGH level (identification of Type II patients)
- Homecare suppliers of HPN products

3. Applicable Service Standards

3.1 Applicable national standards e.g. NICE, Royal College

Standards for care roles are described in Annexes A1/2

The surgical management of patients with acute intestinal failure, Association of Surgeons of Great Britain and Ireland (ASGBI).

4. Key Service Outcomes

In-patient mortality of Type II IF patients in line with best UK and international experience.

Central venous catheter sepsis rates of Type III IF patients in line with best UK and international experience.

Proportion of Type III IF patients developing irreversible liver disease in line with best UK and international experience.

Re-fistulation rates following intestinal failure surgery in line with best UK & international experience.

Performance Indicator	Indicator	Threshold	Method of Measurement	Consequence of Breach
Type II Intestinal Failure				
Inpatient Central Line Sepsis	Number of Healthcare associated infections Intravenous catheter infections No of days of parenteral feeding	[TBC]	As per National Clinical Network guidelines	Commissioning for Quality and Innovation (CQUIN) payment withheld
Post Surgical Survival	No of deaths within 30 days of surgery	[TBC]	[TBC]	Initially, discussion between

	Total number of surgical cases undertaken			commissioner and provider; possibly followed by external peer-review.
Type III Intestinal Failure				
HPN patient Central Line Sepsis	Number of admissions as a result of Central Line infections	[TBC]	Retrospective analysis over financial year	[TBC]
Annual review of continued need for HPN and number of feed days required	Total number of patients on HPN All patients to undergo an assessment at least annually as to their continued need for HPN	100% compliance	Casenote Audit	CQUIN payment withheld

5. Location of Provider Premises

Provision of care outlined under this service specification will be provided through a national clinical care network arrangement. The appropriate setting of care for a patient will be determined by their presenting need and the clinical role required to meet that need (as outlined in Annex A1). It is envisaged that at different points in a patient's pathway, they would be managed in the setting that best meets their presenting needs. As such, care pathways may span a number of designated providers. In order to facilitate this, it is mandatory that designated providers actively participate in the national clinical care network and participate in the full network MDT.

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

Whilst there are 29 clinical roles that would be classified as specialised (2.1 to 4.3) it is envisaged that centres would either undertake (i) a significant sub-set of these roles; (ii) the majority of these roles; or (iii) all of these roles.

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.

IF Type	General description	Specific Description	Treatment	Unit specifications (see Annex A2)
Type 1 IF (Non Specialised – CCG Commissioned)	Short term IF	1.1 Short term ileus.	Optimal nutritional management	A1,A2,(A3 optional)
Type 2 IF Specialised	PN with complications or PN whose duration is causing concern	2.1 Patients requiring continued PN who have had more than two central feeding catheter infections	Optimal IF management	A1-3, B1-7,
		2.2 Patients with an uncontrolled high output stoma despite standard management*	Optimal IF management	A1-3, B1-7
		2.3 Patients with catheter- related central venous thromboses leading to problems of access for IVN** administration	Optimal IF management & appropriate vascular intervention	A1-3, B1-7, C1.4,

		(e.g. direct IVC## or atrial catheters, venous recannalisation or vascular reconstruction)		
		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 laparostomy)	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 unit	A1-3, B1-67 C1.1-1.3, 1.7,C2,3,4
		2.8 Dehisced abdominal wound	Optimal IF management	A1-3, B1-7, C1.1-1.3,

		or laparostomy needing reconstruction of both GI tract & abdominal wall	with specialist stoma care, interventional radiology (as appropriate) in a specialist surgical IF unit	C2,3,4
		2.9 High output enterocutaneous fistula(s) (>500ml/day) despite standard management#	Optimal IF management	A1-3, B1-7, C1.1-1.3, C2,3,4
		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, C2,3,4
		2.11 Recurrent intestinal fistulation after failed surgical treatment of Type 2 IF in a specialist centre (referral between centres)	Optimal IF management with specialist stoma care, interventional radiology (as appropriate) in a specialist surgical IF unit	A1-3, B1-7, C1.1-1.3, C2,3,4
		2.12 IF Surgery in a patient with radiation enteritis or an inherited defect of connective tissue (eg Ehlers Danlos, Marfans, PXE)	IF surgery in a specialist surgical IF unit	A1-3, B1-7, C1.1-1.3, C2,3,4
		2.13 Persistent IF with significant co-morbidity (heart, renal & liver failure) requiring tailored IVN	Optimal IF management	A1-3, B1-7, C1.1-1.3,1.5, C2,3,4
	Patients requiring Intestinal reconstruction	2.14 With or without abdominal wall reconstruction	IF surgery in a specialist surgical IF unit	A1-3, B1-7, C1.1-1.3, C2,3,4

		2.15 Surgery for severe intestinal dysmotility	IF surgery in a specialist surgical IF unit	A1-3, B1-7, C1.1-1.4, C2,3
		2.16 Intestinal lengthening (tapering, lengthening, STEP & Bianchi/LILT procedures)	IF surgery in a nationally commissioned surgical IF unit (Salford Royal Hospital)	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 specialist surgical IF unit	A1-3, B1-67 C1.1-1.3, C2,3,4,
		2.18 Potentially hostile abdomen requiring further expert surgical appraisal or considered possibly not suitable for further surgery	Optimal IF management in a specialist surgical IF unit	A1-3, B1-7, C1.1-1.3, C2,3,4
		2.19 IF due to sclerosing peritonitis needing specialist enterolysis	IF surgery in a nationally commissioned surgical IF unit (Manchester Royal Infirmary)	A1-3, B1-7, C1.1-1.4, C2,3,4,7
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, B2-67 D1,2
		3.2 Patients with intestinal resection leaving <100cm small bowel without colonic continuity, or with	Optimal IF management	A1-3, B1-7 C1.1 -1.3, D1,2

		<50cm small bowel if there is established continuity with the colon.		
		3.4 Patients with severe intestinal dysmotility with malnutrition who cannot meet their nutritional requirements enterally	Optimal IF management	A1-3, B1-7 D1,2.
		3.5 Severe intestinal dysmotility requiring specialist psychological support	Optimal IF management & specialist psychiatric input	A1-3, B1-7 C1.6, D1,2
	MDT outpatient management	3.6 Established HPN	Optimal IF management	A1-3, B2-7 D1,2
	Non-elective readmission	3.7 Established HPN	Optimal IF management	A1-3, B1-7, D1,2
Intestinal transplant		4.1 Transplant assessment	Transplant assessment	A1-3, B1-67 C1,2,3,5
		4.2a Transplantation & perioperative care	Intestinal transplantation -	Transplant unit
		4.2b Transplantation & perioperative care	Multiveisceral transplantation	Transplant unit
		4.3 Out-patient post-transplantation follow up	Optimal post-transplant care	A1-3, B1-7, C1,2,3,5

Notes

*Standard management - Fluid restriction & electrolyte mix Antimotility agents (loperamide up to 8mg QDS, codeine phosphate up to 60mg QDS) Antisecretory agents (PPI [omeprazole 40mg BD], octreotide)

#Complex fistulation - >1 enterocutaneous fistula, fistulation involving other organ systems e.g. upper or lower GI tract, genito-urinary or biliary tracts (update with the surgical definition)

** IVN - Intravenous nutrition

IVC - Inferior vena cava

ANNEX A2 – UNIT SPECIFICATION FOR EACH CLINICAL ROLE

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 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 or expertise 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)
		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
C2	Good access to and working relations with on-site HDU & ICU		
C3	Critical mass of type 2 IF patients		
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 enterolysis for sclerosing peritonitis*		
D1	Dedicated multi-professional IF outpatient clinics		
D2	HPN experience and on-going critical mass		

*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 14 days) prior to abdominal operations.

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 where planned operative intervention would deliberately result in a period of intestinal failure (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)

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

Interim for adoption from 01/10/13